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Cover Page Footnote

This article is based in part on a manuscript developed in 1995 with support from the Administration on Developmental Disabilities, Administration on Children and Families, U.S. Department of Health and Human Services (M. G. Fifield & Fifield, 1995). The contents of this report do not necessarily reflect the position or policy of the Administration on Developmental Disabilities and no official endorsement should be inferred. Correspondence concerning this article should be addressed to Bryce Fifield, Center for Persons with Disabilities, 6800 Old Main Hill, Utah State University, Logan, UT 84322-6800. Email: Bryce.fifield@usu.edu

The Origins of University Centers on Developmental Disabilities: Early Expectations and Legislation[1]

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Plain Language Summary

This article describes the origins of disability-related programs at U.S. universities. The idea for these programs came from a committee set up by President John F. Kennedy in 1962. This committee included stakeholders who wanted to improve the lives of people with disabilities. This article includes an overview of the recommendations by this expert committee. The committee suggested developing disability-related programs at universities. These programs would help people with disabilities through research, service, and training. This article describes key decisions that shaped the identity of these programs. These university programs were originally known as University-Affiliated Programs (UAP). They were later renamed University Centers for Excellence on Developmental Disabilities (UCEDD).

Current Context to Understand the Past

This article is the first of a two-part publication describing the origins, evolution, and programmatic expectations of University Centers on Developmental Disabilities (UCEDDs). Originally conceived as University-Affiliated Facilities (UAF), these programs were to bring the expertise of the academic community to focus on the needs of people with disabilities and address recommendations made in the original Report of the President's Panel on Mental Retardation (1962). There are currently 67 UCEDDs and 52 Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs in the U.S. and its Territories. These programs are made up of a variety of academic institutions, organized in a wide range of administrative structures, and entertaining a broad spectrum of disciplines. UCEDDs engage in many different service, teaching, research, technical assistance, advocacy, and policy activities. They are part of an evolving, but loosely connected, web of public, private, and government agencies serving the disability community. The UCEDD network has evolved over its 55-year history along with this web of disability stakeholders; sometimes by design, sometimes by

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neglect, sometimes out of necessity, and sometimes in desperation.

Capturing this diversity and describing the key junctures that have influenced the evolution of UCEDDs is challenging. It is difficult to present a linear historical discussion of events that are intertwined, often parallel, and frequently cyclical. Furthermore, because of the historical complexity and constant changing relationships between those who have big stakes in the UCEDD network, it is often difficult to attribute key decisions to particular individuals or events.

UCEDDs evolve. Part of that evolution is reflected in the various names of these programs. Originally described as University-Affiliated Facilities (UAFs), they became University-Affiliated Programs (UAPs), later to become University Centers of Excellence in Developmental Disabilities Education, Research and Services (UCEDDERS), and, most recently, University Centers of Excellence in Developmental Disabilities (UCEDDs). Their organizational structure morphs in response to academic and instructional pressures. The focus of their work changes with the availability of funding and the expertise of faculty and staff. The language they use to describe their work and impact on the disability community drifts with the language used in legislation and resulting regulations. At their core, UCEDDs are unique members of the disability community. Located at universities, teaching hospitals, or institutions of higher learning, they are frequently misunderstood by siblings in the disability community. Having a foot in the community for service and technical assistance, they are often viewed askance by their academic siblings in the academe.

UAFs for individuals with developmental disabilities were first authorized in Title I, Part B of Public Law 88-164. This Act was signed into law October 31, 1963, by President John F. Kennedy, just 22 days before he was assassinated. The signing of Public Law 88-164, along with Public Law 88-156 seven days earlier, represented the initial legislation intended to implement the recommendations of the President's Panel on Mental Retardation.[2]

Mental retardation had been recognized as a public health issue 7 years earlier when the Department of Health, Education, and Welfare (HEW) established the Department Committee on Mental Retardation —later known as the Secretary's Committee on Mental Retardation. This committee was given the authority to expand Maternal and Child Health services authorized by Title V of the Social Security Act to address the needs of persons with mental retardation and their families (Office of Mental Retardation Coordination, 1972).

The findings, recommendations, and resulting implementation legislation attributed to the President's Panel on Mental Retardation built upon the work of the Secretary's Committee on Mental Retardation, programs promoted by the Children's Bureau through Title V of the Social

[2] The term “Mental Retardation” is used in this article because that was the historical term used in the official legislation, correspondence, professional, and advocacy literature of the time. Over time, this term took on derogatory connotations, fell out of favor with the consumer community, and has been replaced with the more generic term of “developmental disability.”

Security Act, as well as the Technical Advisory Committee established in 1959 (Hormuth, 1981). It was against this background of committee assignments and expanded national and local programming that the Panel's Report to the President was prepared and submitted.[3]

A Call to Action

President Kennedy's Panel on Mental Retardation was appointed in October of 1961 and consisted of 27 distinguished physicians, scientists, educators, lawyers, and family members. The Panel was organized into six task forces: (1) prevention (clinical and institutional), (2) education and habilitation, (3) law and public awareness, (4) biological research, (5) behavioral and social research, and (6) coordination. Following a year of work, the Panel published its findings and recommendations in the *Report to the President: A Proposed Program for National Action to Combat Mental Retardation* (President's Panel on Mental Retardation, 1962). The report identified the status ("State of the Nation Data") and need for expanded services to individuals with mental retardation. More than 95 recommendations for action were made in various sections of the report. Major system-wide needs included the following.

- *Training.* The critical shortage of trained personnel was identified repeatedly, and more than 21 recommendations focused on action needed to address such shortages.

- *Research and Statistical Data*. The report emphasized the need for additional research and statistical information on the incidence, causes, and related data concerning mental retardation. It called for institutions of higher education to undertake research linked with clinical service programs.

- *Role of Government Organizations*. Several recommendations addressed the role and responsibility of federal government agencies in supporting basic research, providing scholarships for training, and encouraging clinical research.

- *Facilities*. The shortage of buildings and other facilities in which to conduct research and provide service and training programs for individuals with mental retardation was addressed by recommendations in several sections of the Report.

- Coordination Between Governmental Agencies. The Report documented the independence and lack of cooperation between governmental agencies and called for increased cooperation between and among agencies at both the state and federal level.

When published, the Panel's Report was among the most comprehensive, multi-faceted, and well-researched documents in the disability field. It called for a comprehensive approach on

[3] Between 1960 and 1994, many changes occurred in the organizational structure and the names of federal agencies administering disability programs. Often, the same unit had several different names within the span of a few years. In addition, the names of disability interest groups changed to reflect more current service philosophies.

many fronts including: federal, state, local, interagency, and interdisciplinary. Each section provided both specific and general recommendations followed by a statement of where the responsibility for action lies (President's Panel on Mental Retardation, 1962).

President Kennedy had a personal commitment to improving the lives of people with mental retardation and was not reluctant to ask Congress for the funding necessary to implement the vision of the Report. Even before the Report was made public, efforts to implement the recommendations had begun (R. L. Cooke, personal communication, June 22, 1994). By the time the Panel's Report was published in 1962, President Kennedy was pressing Congress and his administration for legislative action.

Dr. Robert L. Cooke, a member of the President's Panel and advisor to the Kennedy family, reported that by the spring of 1963 a series of draft bills had been prepared by HEW to be used as the basis for President Kennedy's forthcoming message to Congress. During the preparation of these bills, decisions that would impact the disability field in various ways were made. It was determined that the President's message to Congress would combine legislation on mental health and mental retardation into a single package. However, in combining these two programs, mental health interests seemed to overshadow the concerns for mental retardation. To balance this, a fresh angle or idea was needed for mental retardation. At the request of Eunice Kennedy Shriver, President Kennedy's sister, Dr. Cooke described the need for facilities at medical centers, similar to mental health facilities, combining interdisciplinary training, service, and clinical research. The few paragraphs drafted by Dr. Cooke that developed this concept into a proposal was later included in the President's message on mental retardation, and subsequently, into the Mental Retardation Facilities Construction Bill (R. L. Cooke, personal communication, June 22, 1994).

The UAF provision "…called for the establishment of University-Affiliated Facilities to be constructed on a somewhat regional basis in association with major medical centers so that practical, clinical training in comprehensive diagnosis, care, and treatment of individuals with mental retardation would be available to all graduates of schools of medicine, nursing, social work, and the like. These facilities were to make possible an interdisciplinary approach to the training of physicians, nurses, therapists, and many types of educators and psychologists with opportunities for clinical exposure comparable to that existing in many major medical centers in the field of mental health" (R. L. Cooke, personal communication, June 22, 1994).

The proposal combined several recommendations from the Panel's Report to the President into a single initiative: "The construction of academic facilities for higher education..., the critical shortage of trained personnel..., research and training in service settings..., interdisciplinary training, interagency support and comprehensive diagnostic and evaluation services" (President's Panel on Mental Retardation, 1962, pp. 70, 82).

The proposed UAFs could also address other initiatives outlined in the Panel's Report, such as: continuum of care, community-centered services, employment, parent training, strengthening of families, prevention, etc. The ability to respond to these new initiatives was especially important because it addressed the needs expressed by parents of children with

mental retardation. As secondary consumers of disability services, they had expressed a need for practical solutions that focused on immediate needs and would result in immediate changes.

The support of higher education was stimulated by the possibility of federal funds for campus facilities to conduct research, provide training, and clinical services. By linking training and service programs in higher education institutions with service-delivery systems, many of the needs of state service agencies could also be addressed.

As the UAF concept was further developed, much discussion was generated around the most appropriate setting and program structure for UAFs. Dr. Elizabeth Boggs, also a member of the President's Panel, stressed the need for a strong community-based program with linkage to universities. Dr. Tarjan, who was the Vice Chairman of the President's Panel, emphasized the need for a university-based unit that reached out to the community and linked the resources of the university with the disability community (V. Keeran, personal communication, July, 1994). The name selected for the program reflected both of these concepts, and UAFs emerged as a program to provide interdisciplinary training, service, and clinical research centers to implement many of the major recommendations of the Panel's Report. Many of these provisions were included in the Developmental Disabilities Act (DD Act) of 1970, The Rehabilitation Act of 1973, the Education for All Handicapped Children Act of 1974, and the Technology-related Assistance Act (1988). Further, the core concepts outlined in the Panel's Report also influenced the language used in Americans with Disabilities Act (ADA), and subsequent reauthorizations of disability programs (M. B. Fifield & Fifield, 1994).

Enthusiasm for the proposed UAF program was not universal. Some administrators in HEW recognized that their limited resources would be needed if this new initiative was to be implemented. This would place other priorities on hold. The funding for construction of UAFs came from monies budgeted to community centers rather than research centers. The Division of Hospital and Medical Facilities of the Public Health Service was given the construction authority, and the legislative authority was patterned after the Hill Burton Act (Secretary's Committee on Mental Retardation, 1966).

On several occasions, provisions to earmark funds for the staffing and operation of UAFs were proposed to the Secretary's Committee on Mental Retardation similar to those provided to mental retardation research centers. Such proposals were not accepted. Some said the authority already existed and, thus, was not needed. Others felt that additional time was needed to develop a "sound and well-thought-out proposal for initial staffing grants" (R. L. Cooke, personal communication, June 22, 1994).

Because the President's Panel had recommended cooperation from a variety of government agencies in supporting UAFs, it seemed that providing operational funds for UAF staffing was to be a shared responsibility and, thus, did not need to be provided explicitly. However, what seemed to be overlooked was that HEW offices, bureaus, and programs were already short on resources and were in the habit of competing for new resources, not cooperating. Funding to staff to operate UAFs would have to be taken from existing priorities in a variety of different agencies.

Mental Retardation: An Early Program Priority

The 1960 Amendments to Title V of the Social Security Act pertaining to Maternal and Child Health and Crippled Children's Programs included special project grants that went directly to public and nonprofit institutions of higher learning for regional and national projects. The Children's Bureau in HEW administered these special projects and had established a number of comprehensive diagnostic centers (Hormuth, 1981). In its assessment of resources, the President's Panel reported 77 special child development clinics supported by Title V funding, serving more than 20,000 children and families. Some of these clinics were in university settings. Still others provided limited training and multidiscipline service programs (R. L. Cooke, personal communication, June 22, 1994; Hormuth, 1964). These Children's Bureau clinical training and demonstration projects provided ongoing program support, but they did not provide for critically needed space, particularly in universities. Because the UAF application was to construct facilities, less attention in the application was given to the program to be housed in such facilities. Initially, it was assumed that the program (Children's Bureau Projects) would exist before the construction was completed. After 1968, UAF construction applications were approved for universities that presented acceptable plans to develop and organize training and service programs.

Although the need for on-campus facilities was common to all UAF applicants, the programs these facilities were to house differed depending upon the Children's Bureau support already obtained and other program support planned. Each university application incorporated different projects under the proposed structure of the UAF. The first UAF applications came from universities receiving Children's Bureau support. However, at the time, it was unusual for any university to have a training or service program emphasizing mental retardation. It was the Mental Retardation Research Centers (MRRC) and UAF Program that made such research and training respectable academic activities. Thus, it was not until a UAF program became operational that a significant number of universities across the nation became active in mental retardation and developmental disabilities research.

The application used to request UAF construction funding was an adaptation of the hospital construction application used in the Hill-Burton program. The application emphasized documentation of the need for services, compliance with building codes, and relationships between other health services (Utah State University, 1966). The criteria for approval included, among other things, the amount of matching money and projections of financial self-sufficiency (Mayeda, 1970). However, there was little effort on the part of the agency reviewing construction applications to monitor these plans or to determine how realistic they were because the application was viewed as more an application for construction than a program.

Dr. Cooke reported that the minutes of the meetings of the committee reviewing UAF applications suggested sharp differences in the opinions of members regarding the expectations of UAFs. Medical representatives emphasized the health orientation of the legislation; whereas, the behaviorists and educational specialists felt that to be interdisciplinary, UAFs must include behavior and education specialties (R. L. Cooke, personal communication, June 22, 1994). Consequently, some facilities were approved to provide programs with strong clinical and

medical orientations, while others focused on behavior and learning (Boggs, 1971) Efforts to bring participating organizations together to agree on a common mission and to address the need for core support and staffing were of limited success.

University-Affiliated Facilities Program Support

To find operational and training funds for UAFs, the Secretary of HEW established an ad hoc liaison committee with representation from the Office of Education, National Institutes of Health, Children's Bureau, Vocational Rehabilitation, and National Institute of Mental Health, as well as representation from the mental retardation field. R. L. Cooke (personal communication, June 22, 1994) pointed out that it was the committee's purpose to obtain program and staffing funds from each agency on a voluntary basis.

Unfortunately, the only agency that responded with operational and training support for UAFs was the Division of Health Services in the Children's Bureau under Dr. Arthur Lesser. The 1965 Amendments to the Social Security Act authorized the Children's Bureau to support training first under Section 519 of Title V of the Social Security Act. A year later, Section 511 of Title V extended the provision to provide interdisciplinary training in multi-agency settings (Division of Developmental Disabilities [DDD], 1972).

Public Law 88-164 provided not only construction authorization, but Title III of the Act authorized the Bureau of Education of the Handicapped (BEH) to provide funding to train special education teachers. Because this training authority and the UAF Construction Authority were in the same legislation, it would be expected that training funds from the BEH would have been made readily available. However, this was not the case. The BEH determined that the only eligible recipients for special education training funds were colleges of education. Because the first UAFs were established as components of medical schools, the BEH considered them medical rather than university units; thus, they were not eligible for such training support. In response to inquiries about BEH resistance to support UAFs, Dr. Gallagher, Director of the BEH, contrasted the medical orientation of UAFs to that of education and argued that UAFs were not appropriate settings in which to train special education teachers. In 1968 BEH submitted plans to provide funding for five selected UAFs to establish a program which would support a coordinator as a member of the interdisciplinary teams (Baxter, 1969, Memorandum to Kendrick Lee, Jr., Budget Examiner, Bureau of the Budget, Department of Health, Education, and Welfare). By 1970, BEH had funded six of the UAFs and offered to extend it to all 19 if additional funding was provided. In fact, the BEH provided funding ($390,747) for a special education coordinator in 16 of the first UAFs. The special education coordinator's role was not to train special education teachers; rather, it was to acquaint the trainees of other disciplines with the field of special education. By 1972, the BEH was providing $493,000 for special education coordinators in 18 programs (Braddock, 1972, p. 22). After 1976, and the passage of the Education for All Handicapped Children Act (94-142), special education funding to UAFs was discontinued.

Diverging Expectations

In 1966 several mental retardation authorities, including the Hospital Improvement Program (HIP), were consolidated into the newly elevated Division of Mental Retardation (DMR) under the direction of Dr. Robert Jazlow. It was staff from the DMR who established the guidelines for UAF construction (DMR, 1964). However, the Children's Bureau published its own guidelines for staffing and training programs (Children's Bureau, 1965). The eligibility criteria and expectations for UAFs proposed by DMR and the Children's Bureau were quite different.

The Children's Bureau, which included both Crippled Children's Services (CCS) and Maternal and Child Health (MCH), was transferred to Social and Rehabilitation Services (SRS) in 1967. Two years later, MCH and CCS were moved into the Health Services and Mental Health Administration (HSMHA) of the Public Health Service (PHS). The MCH expectations for UAFs reflected its health mission (i.e., nursing, nutrition, occupational and physical therapy, speech pathology, social work, as well as audiology, health administration, psychology, pediatric dentistry, and where BEH support was lacking, special education). In contrast, the criteria established by the DMR reflected the social and vocational priorities of the Rehabilitation Service Administration (RSA).

Furthermore, construction applications submitted to DMR were derived from several different planning programs that had different expectations. Between 1963 and 1969, the Joseph P. Kennedy, Jr., Foundation, along with the Mental Retardation Branch of the Public Health Service, provided planning grants to assist in developing interdisciplinary programs. Mayeda (1970) reports that approximately 30 universities received such grants and used them to plan and prepare their applications for UAF construction funds. During this same period, other universities received special planning grants from the public health service and/or clinical service grants from the Children's Bureau. These grants were also used as the basis to plan and apply for UAF construction funds. Other universities applied directly for construction funds without any federal or foundation planning money.

The construction application was different than the MCH program support application (Federal Register, 1964). Consequently, some universities applied for only UAF construction funds, others applied only for MCH program training monies, and others applied for both construction and training funds. All of the above were happening simultaneously and amounted to diverse channels by which UAF applications were submitted. Different components were included in the applications, and components being approved as UAFs independent of decisions on other components (Mayeda, 1970).

The federal designation of UAF was based on the construction authority from the DMR. However, programs that did not receive construction funds but did receive Children's Bureau training grants were also considered UAFs. As a consequence, some UAFs were facilities without programs, others were programs without facilities, and still others had both construction and program support (Mayeda, 1970).

The multi-dimensional approach to establishing UAFs continued even after the construction funding was discontinued in 1970. UAF centers were established by the DDD, while other programs approved by MCH, which administered UAF Section 511 training funds after it had been moved from the Children's Bureau, also considered themselves UAFs. Furthermore, there was limited communication between the DDD and MCH. Programs often considered themselves UAFs and became members of the Association of University-Affiliated Facilities when they were conducting UAF-like programs funded by special MCH training projects or DDD projects of national significance. Such programs were frequently used as a basis for pursuing UAF, MCH, and/or DDD funding.

The first-generation UAFs (1963-1974) emphasized clinical services, diagnosis and treatment programs, interdisciplinary leadership training of personnel, and the concentration of expertise in a single location. The second generation UAFs (1975-86) emphasized community-based services and developmental concepts. Serving the full life span of persons with developmental disabilities was to be considered along with environmental concerns. Third-generation UAF expectations (1987-1994) focused on consumer empowerment, independence, and inclusion.

Accumulating Expectations

It should be noted that the expectations of first-generation UAFs were not superseded by second-generation expectations. Second-generation expectations were generally added to previous expectations. Thus, as expectations changed, they were not replaced but became cumulative. For example, first-generation UAFs, were expected to provide diagnosis, treatment, and clinical services (Federal Register, 1964). However, once such programs were established, it was difficult to shift resources to respond to other expectations. Facilities were designed and built, programs were created, and staff were recruited and selected (often with tenure) in response to the initial expectations. Further, once such commitments were made on the part of a UAF, other university, community, and state expectations of the UAF began to take shape. As a consequence, first- and second-generation UAFs seldom dropped or discarded ongoing training or service programs. Rather, they added new services and program elements in response to the emerging national expectations of later generations.

This process of accumulating expectations has increased the diversity within the UAF network. As a consequence, many UAFs have evolved as umbrella-type organizations under which different programs reflected different models, techniques, and philosophies of service depending on their funding source (M. G. Fifield, 1991). For example, many first-generation UAFs started by providing clinical diagnosis and treatment services required by MCH training grants, which have been continued. Later, they added demonstration classrooms, specialized services, treatment, education, training and care, as well as, preschool, early intervention, and aging programs (Federal Register, 1964). To this, they then initiated programs that focused on community-based services and home programs. Technical assistance and outreach training were then added to keep pace with later expectations and state-of-the-art practices.

First Generation University-Affiliated Facilities

In February of 1965, the John F. Kennedy Institute at Johns Hopkins University became the first institution to be awarded a construction grant—5 months after the first announcement of the program in the Federal Register. By January 1967, the DMR had approved and funded 14 additional UAFs to be constructed in 18 locations, obligating $30.3 million. By 1967, there were 43 applications for planning programs, and more than 100 universities had expressed an interest. By late 1967, two UAFs were operational: Boston Children's Hospital directed by Dr. Alan Crocker and Johns Hopkins, The Kennedy Institute, directed by Dr. Robert Cooke. Three additional projects had been approved but not funded. The administration proposed a 5-year extension, projecting $10 million in fiscal year 1968 and $20 million in each of the successive 4 years, for an accumulation of 23 additional new facilities. However, by December of 1967, the fiscal climate had changed and the total increase was $9.1 million. These were the last dollars actually appropriated for construction of new UAFs.

By 1969, the Federal Government had spent $41,836,000 for the construction of 19 UAFs. Approximately 49% of the costs of the facilities had come from federal sources. The remaining construction costs came from the universities in which the UAFs were located, from state agencies, and from local contributors. In fiscal year 1969, the investment of the Federal Government in training and core support was $9,105,000. Ninety percent of this came from Children's Bureau/MCH and totaled slightly less than half of the amount estimated to be required to maintain the facilities at full training capacity (Mayeda, 1970).

First-Generation Expectations

The 1965 decision of the Children's Bureau to provide training support to UAFs was pivotal in establishing initial expectations. Because no other federal agency provided staffing, training, or other program support until 1969, it was the policies and priorities of the Children's Bureau, (later MCH in HSMHA) that controlled the activities of most UAFs. Consequently, UAF training was focused on children. Health services were emphasized, and only those UAFs located in medical schools were eligible for MCH Section 511 funds. Non-MCH funded UAFs found what support they could from their host universities or from small training grants. In addition, non-MCH funded UAFs pursued direct service and research contracts, piggybacking the training they provided from such activities.

Early Oversite Review of the University-Affiliated Facility Program

The absence of coordination between federal agencies in promoting UAFs and the variation in the amount and type of support received had not gone unnoticed. Concerns about coordination and the types of support received from federal programs stimulated efforts to describe and evaluate the network and to generate recommendations for its improvement (Babington, 1969). One of the first investigations of this nature was requested in July of 1969 by Wallace Babington, Executive Director of the Secretary's Committee on Mental Retardation. In

response, W. F. Baxter, Staff Assistant to the Secretary's Committee on Mental Retardation, prepared a report and summarized the inconsistencies:

> The Division of Mental Retardation administers the UAF Construction Program, but has practically no funds available to support those programs after the construction phase. Although there is multiple funding within the department for operating expenses, most of the available monies come from the Children's Bureau. Funds from the Children's Bureau are limited to services and training in the health field and, therefore, are not available to University-Affiliated Facilities with a behavioral orientation. Additionally, these funds are limited and do not meet the needs of eligible universities.

The report (Baxter, 1969, Interdepartmental Assessment of the UAF Program, memorandum to the Budget Examiner, Bureau of the Budget, Department of Health, Education, and Welfare) further pointed out that UAFs had not been able to establish special education and vocational rehabilitation components as originally recommended because they were not able to obtain support from the relevant federal agencies. Perhaps the most significant recommendation of Baxter's report was to earmark funds so that support for UAFs would not have to be taken from an agency's existing priorities.

While Mr. Baxter's report was being prepared, a contract was issued by the Social and Rehabilitation Services of HEW to EDUCOM to visit each of the UAFs in the network and provide a complete report on "all phases of the...program" (Baruch, 1969). During the next few months, Mr. Tadashi Mayeda, as project director, visited 19 sites and collected and analyzed an extensive amount of data. Mayeda identified the 16 original objectives for UAFs from P.L. 88 164. He catalogued the emerging requirements of UAFs and related these to the President's Panel and the various groups implementing the recommendations of the Panel. He described the diversity of the UAFs, noting that each started from a unique position and then moved on to other activities as opportunities were available. While noting that MCH support was addressing the need for mental retardation specialists in the health field, he pointed out that the comprehensive training mission of UAFs was virtually neglected.

> No UAF had seriously addressed the task of upgrading the professionals, currently or about to be employed, in mental retardation residential institutions, foster homes, day care centers, community diagnostic and evaluation clinics, sheltered workshops, or any other institution or program specializing in mental retardation problems. (Mayeda, 1970, p. 9)

Mayeda was asked to gather data to determine the role of the facility in responding to the UAF objectives in P.L.88 164. In particular, he was asked to respond to two questions: "Is a facility required to implement the concept of the program?"; and "If required, are more facilities needed?" He answered the first question with a resounding YES!

> The facilities produce a capstone effect on separate and isolated programs beneficially bringing them together into one setting for their benefit and, most importantly, for the benefits of the individual seeking services. (Mayeda, 1970, p. 30)

In answer to the second question, Mayeda pointed out that by 1969, the first generation UAFs had progressed beyond the first phase of development, and that new and expanded plans should be formulated for Phase II. He also pointed out that new construction should be part of the second phase (Mayeda, 1970).

The Mayeda report, aside from bringing together important descriptive information about the development of UAFs, is particularly interesting because of the issues addressed and the methodology used. He analyzed cost of tenancy estimates, tenant capacity, and descriptive information on resident and training populations. These ratios were selected to reflect the prevailing expectations of UAFs as health-related programs and cost-effectiveness indices appropriate to teaching hospitals (i.e., bed counts, residence-to-staff ratios, percent of maximum utilization of facilities, etc.).

Mayeda estimated that in 1969, UAFs were operating at approximately 20% of their training capacity due to the unavailability of training support. He reported that all UAFs were experimenting with new methods of care, focusing on the total environment and bringing in the resources of the community. He calculated ratios between construction costs, floor space, and both client and trainee residence. In addition, he calculated ratios between client waiting periods, caseload data, and the distribution of staff and labor costs.

Mayeda concluded that the full training capacity of the UAFs could be reached by fiscal year 1974. However, to reach full training capacity, he recommended an investment of at least $6.7 million per annum over a 5-year period awarded at the rate of $300,000 per institution on a cost-sharing basis. He recommended an extra $100,000 be awarded for each satellite unit (Eugene, Oregon; Bloomington, Indiana; Lawrence and Parsons, Kansas). He further recommended that new construction be based on regional requirements and provided a rationale for changing the staffing and training grants. In the appendix of his report, he provided examples of management plans, instruments for the evaluation of UAFs, and annual report requirements.

Of particular importance to the future development of UAFs was Mayeda's assessment of UAFs not located in medical centers, specifically the multi-location UAFs, which were considered satellites affiliated with colleges of education. These units, he reported, were excluded from training and operating monies and seemed to be “...awkward appendages to the central unit not capable of providing a complete range of interdisciplinary training...but in a unique position as stations for traveling clinics or service clinics away from the central unit” (Mayeda, 1970).

This evaluation clearly reflected the health and medical emphasis of the first generation UAFs. Programs that were designed around an educational or behavioral model that provided inservice training and technical assistance were noted as “gross departures from operating norms” (Mayeda, 1970).

However, despite its sophistication and comprehensive methodology, Mayeda's report had little impact, and his recommendations received little attention from the UAF network or the

funding agencies (i.e., MCH and DDD). Mayeda described UAFs as they were in 1969, and his recommendations were based on early expectations of UAFs. Even before his study was started, professionals and constituency organizations were at work on new legislative provisions for future amendments of P.L. 88-164 that would significantly change the expectations of UAFs in the years to come (Boggs, 1971).

Between 1966 and 1969, many of the recommendations of the President's Panel on Mental Retardation were being implemented. However, despite efforts of the National Association of Retarded Children, other constituency and professional organizations' progress on improving services to individuals with mental retardation was minimal. Some of the key congressional supporters were no longer in positions to direct the needed legislation, and by 1969 the Johnson Era, along with the Great Society, was replaced by a much more conservative Nixon White House. This, along with several reorganizations within HEW, resulted in many new players and decision makers.

In early 1969, a coalition of various mental retardation constituencies formed to promote legislation and expansion of the programs and services introduced during the Kennedy era. This coalition included the American Association of Mental Deficiency (AAMD), National Association of Coordinators of State Programs for the Mentally Retarded (NACSPMR), Council for Exceptional Children (CEC), National Association of Retarded Citizens (NARC), and United Cerebral Palsy Association (UCPA). Dr. Boggs reported that the coalition initially had misgivings about including the UAFs. The UAFs were seen as political liabilities because the new administration had not sought any further funding for them and because some state mental retardation coordinators saw the UAFs as unwilling to reflect state needs in their goals. It was later decided to include support for UAFs in legislation, but to separate it into a different title (Boggs, 1976, personal communication).

Early in 1969, the Senate Committee on Labor and Public Health, chaired by Senator Yarborough, introduced amendments to P.L. 88-164. Senator Edward Kennedy asked to be the prime sponsor of the legislation, citing the family history of association with the cause of mental retardation and with P.L. 88-164 in particular. On August 13, 1969, Senators Kennedy and Yarborough introduced S.2846, referred to as the Disability Services Act. Dr. Robert E. Cooke's input into the UAF title of the bill was solicited by Senator Kennedy. Dr. Cooke used videotapes of two children seen at the John F. Kennedy Institute, the first UAF to become operational. The two children, whose progress was shown, were present at the hearing with their families and provided an impressive demonstration of the benefits of services they had received (Boggs, 1971).

Both House and Senate bills included provisions to continue the UAF construction authority at $20 million per year. In addition, the Senate bill authorized $5 million and the House bill $8.5 million for UAF operational support. In conference, it was the language of the House Bill that was accepted, after which it was submitted to the President for signature.

There were presidential advisors urging President Nixon to veto the bill, but with the support and urging of Dr. Edward Newman, Director of the Rehabilitation Service Administration,

and H.E.W. Secretary Elliot Richardson, the President signed the bill on October 30, 1970, and P.L.91-517, the Developmental Disabilities Service and Facilities Construction Act of 1970, became law (Boggs, 1971). However, the appropriation of federal funding to implement the new provisions was a separate struggle that required an additional year and resulted in far lower funding than had been originally authorized.

Early in January 1971, Assistant Secretary Hitt of HEW established a special interagency committee to review the regulations and guidelines for P.L. 91-517, the DD Act. This committee was to serve as a coordinating broker and to provide input to other agencies on the implementation of the DD Act. Five months later, Assistant Secretary Egeberg, HEW Assistant Secretary for Scientific Affairs, established an ad hoc committee on funding of University-Affiliated Facilities. This committee included membership from all of the relevant agencies. The minutes of committee meetings, planning papers, and interoffice memos suggest a lack of agreement and the inability to provide meaningful coordination of the DD Act on funding of UAFs. Of particular concern was a limited involvement of special education in DD Act planning for UAFs.

President Nixon signed the appropriation bill on August 12, 1971, which provided $4.25 million for the operation of UAFs, just half of the amount authorized, and no money was appropriated for new construction. The same appropriation bill included a significant increase in Section 511 for training in MCH-funded UAFs.

Developmental Disabilities Act Support and Expectations

1. Of the $4.25 million appropriated for UAFs, approximately $600,000 was distributed to nine additional UAFs at about $75,000 each. These funds were used as planning and startup costs. However, no additional funding was provided to the new UAFs for the next 4 years.

2. Less than $3 million was distributed to UAFs approved earlier with ongoing programs, including those with construction facilities.

3. Funds provided by the DD Act were to be used for administrative and operating costs only (DDD, 1972).

4. In an effort to decentralize the administration, the DDD passed much of the grant approval authority on to the 10 HEW regional offices.

5. The DD Act funding focused on a large number of social and organizational expectations, which changed with each administration and reauthorization.

Maternal and Child Health Support and Expectations

1. MCH fiscal support for UAF training was significantly greater than support provided through the DD Act.
2. During this same period, MCH also made the decision to allow UAFs to retain clinical income

rather than returning it as an offset to their grant. As a result, revenues available for MCH funding for UAF program support increased significantly (R. L. Cooke, personal communication, June 22, 1994).

3. MCH support was provided to only 19 UAFs for clearly stated, stable program objectives, which were administered at the Washington level.

The differences between MCH support and expectations with those of DDD had a significant impact on how UAFs would evolve, eventually leading to two diverging emphasis areas: policy/ systems change, and professional training.

University-Affiliated Facilities for the Developmentally Disabled

The impact of the DD Act (P.L. 91 517) was, however, much more than fiscal resources or how the program was administered. The coalition building that preceded its final approval and the statement of philosophy and purpose were to have major impact in the years to come. Each section from the stated congressional findings and purposes to the definitions and provisions themselves, later had an important impact on future expectations of and activities in UAFs.

The DD Act instigated many important changes that were adopted and later included in other legislation (M. B. Fifield & Fifield, 1994). The term "mental retardation" was dropped in favor of developmental disabilities. This change in language was insisted on by UAF directors who pointed out that mental retardation was too narrow and could not be diagnostically differentiated from other similar disabilities (Boggs, 1971). Representative Rogers modified the definition to include sensory disorders and chronic disease, and Senator Kennedy accepted—tying it to neurological handicapping conditions related to mental retardation.

The term "developmental disabilities" not only broadened the service population, but it also implied a different service philosophy. Rather than approaching a developmental disability as a disease to be cured or cared for, it was viewed more as a delay in development—a delay that could be ameliorated by educational intervention, instruction, stimulation, and expanded opportunities for inclusion (M. B. Fifield & Fifield, 1994).

The 1970 legislation provided a federal/state formula grant to assist states in developing and implementing a comprehensive state plan. The law also provided for the comingling of funds from other federal programs to facilitate the development of comprehensive services for people with disabilities.

The DD Act identified the purpose of UAFs and changed the term "clinical training" to "interdisciplinary training" to emphasize the cross-disciplinary nature of UAFs. It changed the name of the administrating agency from the Division of Mental Retardation to the Division of Developmental Disabilities (DDD) and placed it under the Rehabilitation Service Administration.

In the fall of 1972, the DDD provided its first description of the mission, purpose, and objectives of UAFs (DDD, 1972).

> The mission of the University-Affiliated Centers is to lead the field of service to the developmentally disabled of all ages by (1) training administrative, professional, technical, direct care and other personnel needed to provide the whole range of services for the developmentally disabled; (2) demonstrating exemplary services; (3) carrying out research incidental to those activities; and (4) assisting communities, states, an regions to reach their objectives. (p. 2)

UAFs should

> ...exemplify the principles and practices which will lead to increasing effective programs for prevention, treatment, and habilitation including active participation in planning activities. The usual resources of the college or university provides the basic elements required by this multi-faceted program, but the center should not limit its activities and concerns to the academic setting only. It must involve itself in all appropriate ways with the special needs and resources of the community and region within which it operates. (DDD, 1972, p. 2)

This document further defined a UAF as a center housed in an identifiable building or suitable portion thereof, which encompasses the following program elements:

- The responsibility for overall administration resides within the university;
- The university demonstrates a significant long-term commitment to interdisciplinary training and developmental disabilities;
- An organizational entity within the administrative structure that has as its primary function the responsibility for interdisciplinary training;
- Individuals responsible for the program have regular faculty appointments;
- Training programs are interdisciplinary and encompass a broad and comprehensive range of disciplines;
- The program is designed to be relevant to the manpower needs of the geographic area served;
- The program is integrally related to exemplary service functions; and
- The program demonstrates a capacity to utilize the resources of the university to develop new approaches (DDD, 1972).

Notwithstanding the UAF language in the DD Act, and the mission and purpose of UAFs as stated by DDD, the importance of the expectations listed above was not implemented until after 1975 following the first amendments. Several reasons can be identified for this delay. First, the core funding authorized by the new DD Act was used to help provide administrative support to assist in the administration and supervision of other services which the UAF provided (DDD, 1972). Because approximately 90% of all fiscal support provided to UAFs came from MCH training (Mayeda, 1970), DD core support was viewed as administrative support for MCH training.

Second, the decisions of the Director of Social and Rehabilitation Services (SRS; the agency

to which DDD reported) to use much of the $4.25 million appropriated to plan and start new UAFs rather than provide UAF program support, established a precedent that continues in the new millennium. Politically appointed commissioners, directors, and sometimes associate secretaries made decisions about the allocation of congressionally appropriated funds that had significant impact on the evolution and expectations for UAFs. Beginning in 1972, most additional funding provided for UAFs would be used to start new programs rather than to expand and improve the support for those currently in the network. Furthermore, new initiatives and expectations would accompany each legislative reauthorization, and there would be many changes in administrative personnel.

In 1972, DDD awarded grants to 30 UAF programs. Planning and start-up grants were awarded to nine universities ranging between $35,000 and $75,000 each. Core grants were awarded to 20 UAFs, ranging between $79,293 and $417,696 (Braddock, 1972). All of the UAFs that had constructed facilities participated in this allocation. New UAFs receiving DD core support included some that originally applied in the late 1960s for construction and/or pending MCH training support. Although UAF construction funding was authorized in the new DD Act, funding for construction of new UAFs was not appropriated, and the UAF construction program was phased out. In later reauthorizations, construction was dropped from the legislation. Other federal support provided in fiscal year 1972 included $12,988,000 through MCH, Section 511 Training Support, for 18 programs ranging between $112,000 and $1,612,000 per UAF. That same year, BEH provided $493,000 to 18 programs with grants ranging between $25,000 and $30,000 (Braddock, 1972).

Core funding provided by the DD Act changed the relationships between UAFs that had two or more facilities in the same state. MCH training support was not shared with their satellite facility except as an outreach site. Thus, the facilities on other campuses were on their own to find funding and other program support. Consequently, some satellite facilities negotiated separately for DD core support. Oregon established two separate UAFs, as did Indiana. Tuscaloosa was dropped from the network, as recommended by Mayeda. The Georgia and Kansas UAFs elected to stay together as a single administrative unit and make their case for additional DD core funding. Between 1972 and 1975, when the first reauthorization of the DD Act was passed, the DDD added an additional nine programs to the UAF network—only two of which received MCH support.

When the DD Act was first authorized in 1970, it was for 3 years. Thus, it was to expire or be reauthorized in 1973. Congress, facing the need to reauthorize 13 major federal programs, which included the DD program, elected to give all of these programs a 1-year extension under an amendment to the Public Health Service Act, without any changes in language or appropriation.

Summary

The decade between 1960 and 1970 saw the genesis of what would eventually become a nationwide network of University Centers on Developmental Disabilities (UCEDDs). These

evolved rapidly from what were essentially UAFs for mental retardation to two distinct program foci—one on hospital-like clinical programs and the second focused on umbrella organizations focusing on a panoply of treatment, service, education, and intervention programs. Legislation and funding authorizations rapidly moved from construction of brick-and- mortar buildings to funding operational programs, but struggled to craft language broad enough to describe everything that these programs should be doing. Originally conceived as an academic/community combination that could address recommendations made in the President's Report, these programs immediately faced the challenge of finding funding for such innovations. Thus, these University-Affiliated Facilities (UAFs) became University-Affiliated Programs (UAPs) and their combined work scope was covered with a host of federal grants, a few state contracts, and local services. The range of activities was largely dependent on the salesmanship and success of individual program faculty and staff at finding a market for the things they could do with (and for) the disability community.

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