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The Origins of University Centers on Developmental Disabilities: Second Generation Expectations and Growth

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Abstract

Part two of a two-part publication tracing the evolution of University Centers for Excellence in Developmental Disabilities. Originally University Affiliated Facilities evolved into University Affiliated Programs on disabilities. Early expectations outlined by President Kennedy's Committee on Mental Retardation grew as funding for disability services and programs became available. Key legislation, program developments and organizational decisions are described for the time frame of 1970 through 2000.

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. 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 in Developmental Disabilities (UCEDD).

This is the second of a two-part publication describing the origins, evolution, and growth of programmatic expectations of University Centers for Excellence in Developmental Disabilities (UCEDDs). These programs were originally conceived as University-Affiliated Facilities (UAFs) and were intended to focus the expertise of the academic community on the needs of people with disabilities and address recommendations made in the Report of the President's Panel on Mental Retardation[1] (1962). The network of university programs has grown to include 67 UCEDDs and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs in the U.S. and its Territories. UCEDDs and LENDs are different programs with differing funding streams and purposes. However, both are located at Universities or Medical Schools/Teaching Hospitals. Together, they comprise the UCEDD Network, despite their differing funding authority.

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[1] The term "Mental Retardation" is used because that was the terminology of the time and was used in the official legislation, correspondence, and advocacy literature. Over time, this term has taken on pejorative connotations and has been replaced with the more generic term of "developmental disability."

These programs are hosted in a variety of academic institutions, organized with a wide variety of administrative structures, and serving a wide spectrum of disabilities. Over its 55-year history, the UCEDD network has evolved along with a web of disability stakeholders, sometimes by design, sometimes by neglect, sometimes out of necessity, and sometimes in desperation. Describing this diversity and the key events that have influenced this evolution is challenging. It is difficult to present a linear description of events that are intertwined, often parallel, and frequently cyclical. It is often impossible to attribute key decisions to particular individuals or events.

As described in Part 1 of this publication (M. B. Fifield & Fifield, 2020), UCEDDs evolve. They have been known as University-Affiliated Facilities (UAFs), later University-Affiliated Programs (UAPs), in the legislation as University Centers for Excellence in Developmental Disabilities education, Research and Services (UCEDDERS), and most recently rebranded as University Centers for Excellence in Developmental Disabilities (UCEDDs). UCEDDs have grown up with other parts of the disability community including, protection and advocacy organizations, state councils on developmental disabilities, service provider networks in the public and private sectors, advocacy groups, federal and state oversite agencies, legislation providing services, treatment, and benefits for people with disabilities, and the consumer network of people with disabilities and their families. This publication describes the evolution of the UAF/UAP/UCEDDRS/UCEDD network during the 1980s and 1990s.

Second Generation University Affiliated Facilities (UAFs)

The Developmental Disabilities Act, authorized in 1970 and funded in 1972, introduced many substantive changes in the expectations of UAFs. However, it was not until the passage of other major disability legislation in rehabilitation and education, and after the first reauthorization of the Developmental Disabilities Act in 1975, that the second-generation expectations for UAFs began to solidify. P.L. 94-103, The Developmentally Disabled Assistance and Bill of Rights Act, not only extended but made several revisions to the DD program. The 1975 amendments authorized the three major components of the DD system: (a) state Developmental Disabilities Planning Councils (DDPCs); (b) Protection and Advocacy (P&A) agencies; and (c) University-Affiliated Facilities (UAFs). The new amendments also expanded the definition of developmental disabilities to include autism and learning disabilities. States were required to spend at least 30% of their formula grants on de-institutionalization.

Of particular importance to the UAF network was Section 145(e) of the 1975 Amendments, which authorized special project grants and earmarked no less than 25% of each year's appropriation for "projects of national significance." This provision provided approximately $12 million for projects of national and regional significance by which many of the recommendations of the President's Panel could be implemented.

Projects of national significance were awarded for up to 3 years through an open competition. UAFs were expected to compete with all other eligible applicants. However, this source of support was particularly important to UAFs for it provided the first funding within the

DD program from which UAFs could seek support for the program elements they were mandated to provide (i.e., exemplary services, interdisciplinary training, technical assistance, and dissemination). Section 145(e) was important to the UAF network by providing additional fiscal support to launch projects addressing issues of the day and state-of-the-art techniques.

In 1978, the DD Act was again reauthorized by the Comprehensive Rehabilitation Service Administration Construction Act (PL 95-602). These amendments mandated a functional rather than a categorical definition for developmental disabilities, which again changed the size and nature of the population the DD program was to serve. By 1978, core funding provided through the DD Act was described as *seed money* to help UAFs pursue other sources of support to provide the programs expected of UAFs.

Following the 1978 amendments, the Developmental Disabilities Division (DDD), the federal agency charged with managing the UAF program, undertook new initiatives and encouraged UAFs to apply for funding to address aging, technology, dual diagnosis, urban and rural area/poverty projects, minorities, advocacy, case management, early intervention, and transition into employment. UAFs were also expected to use core support to seek other sources of funding (i.e., Office of Special Education, Rehabilitation Services, state funding, and Title XX) to provide mandated program components.

In contrast, funding provided to UAFs from Maternal and Child Health (MCH) was for the training of health professionals. This support was available only to UAFs located in medical centers and was independent of developmental disabilities core support. MCH training funds were not considered leveraged support, nor were these funds to be used to obtain other funding.

From a fiscal standpoint, the most significant legislation that emerged during the 1970s was not the DD Act, but the 1973 Vocational Rehabilitation Act (P.L. 93-112) and the landmark Education for All Handicapped Children Act (P.L. 94-142), which was signed into law in 1975. The Rehabilitation Act contained Section 504, which prohibited discrimination because of disability in federally assisted programs and became the foundation upon which future disability rights legislation would be based. P.L. 94-142 held that all children, regardless of disability, had the potential to learn and had a right to a free and appropriate public education in the least-restrictive environment and provided a structure for funding services to school-aged children.

The Vocational Rehabilitation Act and Education for all Handicapped Children's Act significantly influenced UAFs because they included programs for training, program development, model services, technical assistance, and research. These Acts were seen by most UAFs as sources of federal funding that could help them address DD-mandated program components. Farlee et al. (1976) pointed out that UAFs were among the most aggressive applicants to submit proposals to the Bureau of Education of the Handicapped (BEH) and the Rehabilitation Service Administration (RSA), even though UAFs faced complications in securing such support.

Co-mingling of funds from other federal programs was encouraged by the Developmental Disabilities Act. However, other federal agencies operated under regulations that did not

encourage leveraging or co-mingling of federal support. Requests for proposals (RFPs) from BEH and RSA focused on specific objectives and applications did not extend beyond the purpose of their authorizing legislation to address interdisciplinary training or other DDD initiatives. These placed applications submitted by UAFs in an awkward type of competition. Furthermore, personnel in the BEH continued to view UAFs as medically oriented programs (Dr. Jasper Harvey, personal communication, 1976). To circumvent this bias, UAFs often submitted their grants to BEH through their university departments of special education or state agencies. Special Education and Rehabilitation review panels often did not know when they were reviewing applications from UAFs, a situation which many UAF directors felt improved their chances of approval.

Most funding from education and rehabilitation was provided through time-limited, competitive proposals. To survive on such funding, the proposals submitted by UAFs had to receive high-ranking scores and they had to compete every 3 years. Not all UAFs or satellite UAFs were able to sustain a successful grant writing effort in such a competitive environment. During the late 1970s and 1980s, at least 18 programs that had been recognized as UAFs withdrew from the national network.

UAF Satellites

The UAF provisions of the 1975 DD Amendments included language permitting existing UAFs to expand programs by establishing satellite centers. Satellites were seen as a way of expanding UAF services at reduced cost and providing better control of the numbers and status of the UAFs entering the network (M. G. Fifield, 1976), although a lively debate emerged in defining whether a UAF satellite was a clinical extension of the host UAF in the same state or a free-standing center in another state (M. G. Fifield, Moss, & Landeen 1976). The DDD only approved the four UAF satellites located in states other than the host UAF as free-standing centers. For the next decade, when funding was available, the satellite provision was interpreted as the preferred way of bringing new programs into the network.

The feasibility study for a UAF initially required the host UAF to conduct the study in conjunction with the DDPC of the receiving state. In practice, most of the feasibility studies were done by an interested group of faculty members from a university wishing to establish their own UAF. From the early 1980s on, the role of the host UAF became less and less significant, and the commitment and support from the DDPC increased in importance.

Since satellite programs quickly responded to the needs of their state and to available federal initiatives, they basically became new UAFs (Davidson & Fifield, 1988). When it was determined a satellite could meet the requirements of a full UAF, DDD encouraged them to apply. This increased core funding by approximately $50,000. The difference between the expectations of a full UAF and a satellite UAF was not particularly clear, but the interdisciplinary training program component was the most difficult expectation for new programs. Most UAFs could find funding for outreach training and technical assistance through subcontracts with state agencies; however, establishing an interdisciplinary training program with core courses on campus without

MCH support or a large continuing service base was very difficult for most satellite programs. Consequently, many UAF satellites remained satellites for many years.

Impacting Generic Service Systems

The Developmental Disabilities Act was not meant to replace the support provided to individuals with disabilities from other human service programs. The Act focused on provisions that created changes, filled gaps, coordinated, and in other ways changed the generic service system so they could better accommodate the needs of individuals with developmental disabilities (Boggs, 1971). Common to each component of the DD system (DDPC, P&A, and UAFs) was the expectation that they would impact other service systems by:

1. The developmental disabilities state planning councils through state planning, awareness activities, and stimulation grants.
2. The protection and advocacy agencies through legal recourse and advocacy activities.
3. The UAFs through training, technical assistance, exemplary services, and dissemination.

Other techniques used to ensure greater impact included a required state fiscal match, and in the case of UAFs, the expectation of leveraging resources.

Local Match

The amount and nature of the required local match was an important issue negotiated during the hearings in 1969 and 1970 (Boggs, 1971). During the UAF construction phase, a local match was not only required, but the amount of local match was one criterion for approval. Mayeda (1970) reported that approximately 49% of the costs for the construction phase was provided locally. P.L. 91-517 required a 25% match on all programs. This requirement was maintained in subsequent reauthorizations and was also required of recipients of grants offered by state developmental disabilities planning councils. The local match requirement was patterned after the vocational rehabilitation legislation and was intended to facilitate a federal/ state partnership in carrying out the purpose of the legislation (Boggs, 1971).

Leveraging DD Resources

Leveraging was not expected from other programs authorized by the Developmental Disabilities Act. However, leveraging resources was clearly implied in the guidelines for UAF core funding and the funding level in the first appropriation that became available in 1972. Throughout the 1970s, staff members of DDD and UAFs nurtured hopes that additional developmental disabilities program monies would be appropriated. Such was not to be the case. Thus, the core grant for administration and operation was increasingly viewed as seed money to be used to obtain funding from other sources to provide the interdisciplinary training, exemplary services, and other mandated program components. Since it was also expected that UAFs would use their resources primarily to meet the needs of individuals with developmental disabilities,

the impact of DD core funding could be increased several times in a UAF that aggressively sought and obtained other sources of support. This leveraging concept was consistent with the recommendations of the President's Panel on Mental Retardation, which had recommended that funding should be provided from several sources.

The UAFs that received MCH training support had an ongoing source of program support. However, it was not always easy for them to use their support to meet the expectations of both MCH and the DDD. MCH expectations remained focused on training for health personnel, clinical services, and leadership; whereas the ADD initiatives shifted with changing priorities of successive administrations. Applications for ADD funding submitted by MCH-funded UAFs were often criticized because they continued to provide the clinical programs that MCH required.

Difficulty Generated by Leveraging

Successful leveraging of additional resources is dependent upon what other sources of support are available, the eligibility of the UAF to compete for such sources, as well as the success of the UAF in writing winning grant proposals. In addition to these conditions, leveraging also has other problems. With each new funding source, additional expectations were generated. Satisfying the many stakeholders in a UAF with funding from many sources was a difficult requirement. This was made even more difficult by the need for annual DD core applications and quarterly reports of DD-required activities. A frequent complaint of the UAF directors was that DD core support, which often represented a small portion (as little as 5 to 20% of the UAFs operating budget), exerted an inordinate influence over the total program (Farlee et al., 1976).

Leveraging also generated problems in reporting results and accomplishments. Some UAF sources of support objected to the UAF reporting their funding as leveraged. Furthermore, leveraging resources were often administered differently or reported through multiple channels within the university making them difficult to track, compare, or acknowledge. Leveraging sometimes created a no-win situation. For example, if the UAF was successful at obtaining non-DD support that served a much broader population, such as grants from Education or Rehabilitation, they were open to criticism from the DD community for focusing too much effort on other individuals with disabilities and not doing enough for those with developmental disabilities.

In 1978, President Carter reorganized the Department of Health, Education, and Welfare, elevating the Department of Education to a cabinet level and creating the Department of Health and Human Services (HHS). The Office of Special Education and Rehabilitative Services (OSERS) was established within the Department of Education. In this reorganization, Social and Rehabilitation Services was replaced by the Office of Human Development Services (OHDS) within the Department of Health and Human Services, and the Rehabilitation Program moved to OSERS. DDD stayed in HHS reporting to OHDS. Later, the Division name was changed to the Developmental Disabilities Office (DDO) and still later to the Administration on Developmental Disabilities (ADD).

Federal Evaluation Studies of the UAF Network

As the UAF network grew, concerns for evidence of their effectiveness, accountability, and impact were raised. Between 1969 and 1983, seven separate studies were undertaken to determine the effectiveness and impact of the UAF network. Table 1 provides data on each of these studies, the initiating agency, who conducted the study, major findings, and recommendations.

Table 1

Evaluation Studies of UAPs

Date	Initiated by	Conducted by	Major findings	Major recommendations
1969	Select Committee on Mental Retardation	Assistant Secretary of HEW	• Federal support principally from • Children's Bureau • Services limited to the health field • Not all UAPs qualify for training monies	• Earmark funds from appropriate federal agencies for training and core support
1970	SRS	Mayeda	• UAPs operating at 20% capacity due to lack of federal funding • The experimenting with new programs • 90% of funding from MCH	• Facility is needed • Needs to be a new phase • 300 per year per UAP for core program support • Regional programs
1976	HEW	George Tarjan, Chairperson, Long-range Planning Task Force	• UAPs have implemented each of the original program concepts (i.e., IDT, continuum of care, change agents) • Established standard of excellence • Suggested performance criteria	• Greater precision in defining UAP mission • Establish a national network with both core and program support from federal sources • Change the name • Establish topical or regional centers • Strengthen relationships with state programs • Accreditation
1978-80	P.L. 95-602 UAF Standards	David Phoenix, PI, Systems Research and Development Corporation	• Draft of standards prepared	• Field testing for implementation
1978-79	Senate Sub-Committee on the Handicapped	Controller General	• Funding from numerous sources, no fixed pattern • Vague mission	• Establish a national policy • Establish measurement criteria • Develop unified UAF guidelines
1980	ADD	Henney, PI E.M.C., Inc.	• UAFs are an important part of the national program	• Develop program criteria
1983	ADD	Elizabeth Boggs, Chair, UAF Ad Hoc Workshop on University Affiliated Facilities	• Diversification • Funding from various sources	• Improve standards of quality, site reviews and panels • Cooperation at the federal level • New initiatives

The first study was conducted by the Select Committee on Mental Retardation to identify the barriers and problems UAFs were experiencing in becoming operational. The second study was undertaken under a special contract with Tadashi Mayeda to evaluate the network and make recommendations concerning further expansion. The major findings of these studies are summarized in Table 1.

The third effort to evaluate the federal investment in the UAF network was initiated by the Secretary of HEW in 1975, who awarded a contract to The American Association of University Affiliated Programs (AAUAP)[3] for a comprehensive evaluation of the UAF Program. This contract consisted of two parts: (1) the collection of descriptive data on UAFs (Farlee et al., 1976), and (2) an analysis and report from the *Long-Range Planning Task Force* convened for the purpose of reassessing the original UAF concept and making recommendations for the future (Tarjan & and the UAF Long-Range Planning Task Force, 1976). The Long-Range Planning Task Force was chaired by Dr. George Tarjan, who was the Vice-Chair of the 1962 President's Panel on Mental Retardation and actively participated in developing the concept of UAFs. The Task Force also included Dr. Elizabeth Boggs and Dr. Robert E. Cooke, who participated on the President's Panel, as well as directors of consumer and professional disability organizations, directors of UAFs, and other leaders in the disability field. After analyzing the data prepared by Farlee and reviewing other data, the Task Force concluded:

> *...experience with the UAF Program in the period following the implementation of P.L. 88-164 has validated each of the original program concepts stated by the 1962 panel: training in models exemplifying a continuum of care, interdisciplinary training, UAFs as change agents, and incremental implementation, testing the UAF concept. (p. 4)*

The final section of the Task Force report provided recommendations for funding agencies, Congress, AAUAP, and individual UAFs. Of particular importance were recommendations concerning restructuring government participation in the program around the concept of core support and lead agency responsibility.

> *The task force finds no realistic alternative to multiple federal funding of the UAFs in view of the wide range of needs of developmentally disabled persons, the interdisciplinary approach required by the range of needs, and the categorical nature of most federal programs. Indeed, these considerations provide justification for a more vigorous effort to expand the base of the UAF program support rather than one to consolidate all funding in one agency. (p. 32)*

The recommendations of the Task Force's Report were clear, precise, and specific. They were referred to repeatedly by AAUAP, in negotiating with MCH, DDD, and in testifying before Congress. However, there was no systematic effort from the administration or Congress to implement the recommendations, even though some were adopted either in legislation or administrative procedures and initiatives several years later.

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[3] In 1973 the name of the organization was changed from AUAF to AAUAP with new bylaws and incorporated in the State of Delaware.

Two years after the Long-Range Planning Task Force had completed its study, Senator Randolph, Chairman of the Senate Subcommittee on the Handicapped, requested the Controller General to conduct a comprehensive evaluation of the total developmental disabilities program including the UAFs. Following a year of field work in which an extensive study was made of a sample of seven UAFs, the report was published February 20, 1980. The UAF section of this report pointed out that from the beginning, the UAFs were funded from numerous sources with no fixed pattern, with vague mission statements, and varying guidelines.

> This has placed facilities in a precarious "can't win" situation...trying to serve too many organizations. (p. 95)

The report recognized the complexity of UAFs, the lack of measurement criteria, and pointed out that HEW had not issued guidelines for UAF programs, developed specific regulations to make them accountable, or established national policies or strategies for them. The recommendations provided by the Controller General (1980) were consistent with the three previous UAF evaluations.

In addition to the evaluation of the total DD program requested of the Controller General, the 1978 DD Amendments directed the Secretary to develop and promulgate program standards to evaluate UAFs. To address this requirement, ADD awarded a contract to develop such standards to Systems Research and Development Corporation. Systems Research utilized the AAUAP membership criteria as its foundation and undertook the initial work of convening panels, designing criteria of compliance, and procedures for collecting evaluation data. However, this contract was terminated as concerns about the growth of the federal budget superseded interest in standards, and efforts were directed to curtail the growth and expansion of UAFs (Frances Lynch, personal communication, 1981).

As part of an ADD technical assistance contract, Henney (1981) analyzed the data UAFs submitted quarterly in progress reports and prepared a report on his findings. This study reported very little that was not contained in earlier UAF evaluation studies. However, it did identify the evaluation points that were later placed in the UAF database and appeared in future UAF program criteria.

The Doldrums

In 1981, President Reagan followed up on his campaign promise by introducing a program for economic recovery focused on cutting federal spending. Much of this was included in the Omnibus Budget Reconciliation Act (OBRA) of 1981. This legislation resulted in budget cuts in many domestic programs and several large, multipurpose block grants, which changed priorities and the role of federal agencies in addressing the needs of persons with disabilities (Braddock, 1986). Special centers that required continuous federal core funding were identified as prime targets for discontinuation, and efforts to curtail the growth and expansion of UAFs received special attention.

In the early 1980s, plans to cut back the UAF Program and/or eliminate the national

network entirely were under consideration (Senator Orrin Hatch and Assistant Secretary Hardy, personal correspondence, 1981). During these austere times, UAFs had few strong advocates. The State Developmental Disabilities Planning Councils, Protection and Advocacy Agencies, and professional organizations were busy protecting themselves and could not afford to defend a competing program. Constituency groups, which had provided strong support for UAFs in the 1960s, were likewise concerned with continuing support for de-institutionalization, educational provisions, and a more equal distribution of federal income maintenance support. The perceptions these groups had of UAFs was that they were medically oriented programs operating in academic institutions and pursuing research and services that were difficult to relate to the needs of consumers of disability services or the agencies responsible for serving them on a day-by-day basis (Bob Gettings, Edward Sontage, and Fred Weintrop, personal communication, 1982). One federal administrator described the UAF program as seen by its critics as follows:

> *UAFs are like dinosaurs, with large medical appendages not addressing the real needs of the developmentally disabled. If allowed to multiply they could consume much of the federal budget. Yet, if they are killed, they would cause a terrible stink. The hope is, that by feeding them a few bales of hay periodically they would get hungry and go away. (Doris Harr, personal correspondence, March 1978)*

In 1982, Dr. Jean Elder the newly appointed Commissioner of the Administration on Developmental Disabilities, asked the Assistant Secretary, Dorcus Hardy, to delay plans to reduce or eliminate the UAF Program until she had studied the situation. During the summer of 1982, Commissioner Elder appointed the Ad Hoc Workgroup on the UAF Program to make recommendations concerning the role and future of UAFs. Dr. Elizabeth Boggs, an original member of President Kennedy's Panel on Mental Retardation, chaired the workgroup that included consumers and service providers.

The Ad Hoc Workgroup reviewed the history and the mission of UAFs. They studied the funding pattern, evidence of productivity, and federal expectations. In 1983 they issued their report containing many recommendations, which included further improvement of standards, quality assurance, and expanding relationships with state and local service systems. The report again called for cooperation at the federal level. Recommendations to the ADD for managing UAFs included:

1. Three-year core grant cycles,
2. Discretionary funds for new initiatives,
3. Priorities for establishing new programs

Most of the recommendations of the Ad Hoc Workgroup on UAFs had been addressed in some form by previous studies. What appeared to be different about Dr. Boggs' report (Boggs, 1983), was that it was commissioned by the ADD, and the recommendations focused on things for which the ADD was responsible and capable of doing without waiting for consensus from other federal agencies or an executive decision from the Secretary. As a result, many of the recommendations of the Ad Hoc Workgroup were implemented in-house by the ADD.

The New Wave

The findings and recommendations of the Ad Hoc Workshop for UAFs convinced Commissioner Elder that the UAF program could *lead the field of service to the developmentally disabled* (DDD, 1972, p. 2) by providing leadership for the changes and new initiatives the administration wished to pursue.

First, the application review process for UAFs was strengthened by including a rigorous peer-review process. UAF applications that did not meet expectations were placed on a partial funding cycle. A site visit was scheduled, sponsored by the ADD, with team members made up from colleagues of other UAFs, state and federal program administrators, administrators of constituency organizations, and an ADD staff member. The procedures to be followed in conducting site visits were adapted from those established by the AAUAP in its consideration of membership. The ADD site visit provided a direct onsite evaluation of compliance with ADD expectations and included technical assistance and recommendations for program improvement. Problems were noted and corrective action plans were required. UAFs not able to comply with expectations were placed on probation, and when appropriate changes were not evidenced, funding was terminated, and the program moved to another university (Davidson & Fifield, 1992).

Second, responding to the recommendation that the ADD should be more proactive, three new UAF initiatives were pursued: employment, adult services, and services to minority populations. However, rather than simply assigning UAFs to undertake these initiatives with or without start-up funding, the ADD administrative staff were assigned an active role working directly with the UAFs. Commissioner Elder undertook an aggressive campaign to relate these initiatives to constituency groups and to bring the DD system together to plan, report, and support one another in addressing these new initiatives. By 1985, Dr. Elder had demonstrated that UAFs could serve as the vehicle by which the initiatives of the administration and the needs of persons with disabilities could effectively be addressed, and there was no longer talk of reducing or eliminating the UAF program.

Out of the Doldrums

The language of the 1984 amendments to the Developmental Disabilities Act (P.L. 98-527) addressed several of the recommendations of the *UAF ad hoc workshop*. Overall, the new amendments brought the DD network closer together. UAF directors were placed on state developmental disabilities planning councils and new provisions were added, reflecting increased responsiveness to consumer and constituency groups. The 1984 amendments identified desired consumer outcomes such as independence, productivity, and community integration. In response, an aggressive effort was undertaken by UAFs to develop criteria by which consumer outcomes could be identified and reported (Guralnik, 1991). The minimum core grant to UAFs was increased to $150,000, and new appropriation language included authorization for additional satellite UAFs.

Changes were also taking place within the AAUAP. For years, the AAUAP had focused much of its effort on helping individual UAFs to survive. Annual meetings usually centered on discussions of appropriations legislation and other potential sources of program support.

Responding to the Boggs report (1983), the AAUAP committed itself to becoming increasingly proactive. An electronic mail and message system was established within the network, and efforts to expand relationships with consumers and other professional organizations were undertaken. In 1985, a series of position papers were developed addressing concepts of interdisciplinary training, special purpose UAFs, early intervention services, relationships with MCH, and services to adults with disabilities. These became topics of discussion and were later used in drafting legislative provisions.

When Dr. Bill Jones accepted the Executive Director position of the AAUAP, these efforts were moved into high gear. Close relationships were forged with other professional and consumer organizations. The association established the Consumer Organization Liaison Committee as a standing committee with membership from the leadership of the Washington-based consumer organizations. The issues and concerns of consumer organizations became AAUAP initiatives. Some of these included expanding training in epilepsy, early intervention, and expanding activities to address direct consumer outcomes. All of AAUAP's position papers, initiatives, and planning documents were systematically reviewed and commented on by the Consumer Organization Liaison Committee members. These efforts helped forge common objectives and a united legislative agenda. This further strengthened the role of the AAUAP and the Consortium for Citizens with Developmental Disabilities (CCDD).

Since the beginning of national constituency disability organizations (National Association for Retarded Children in 1950, United Cerebral Palsy Association in 1948), some form of a legislative liaison, coalition, or consortium has brought these groups together to promote desired legislation. UAP leadership and staff have joined in this effort since the middle 1960s. The first Executive Director of the AAUAP (then AUAF) was Cynthia Sturdevant, who had been very active with the NARC. Subsequent AAUAP executive directors continued this effort—some more vigorously than others. Over time, the CCDD (now the Consortium for Citizens with Disabilities, CCD) has played substantial roles in helping to shape legislation and national policy affecting the disability community. The CCD includes representation from over 120 professional and consumer organizations whose common concern is legislation provisions that improve the lives of people with disabilities. Senate and House committee members look to the CCD to promote consensus among its members regarding new legislative language and provisions. Although not always possible, there is little doubt that the greater the consensus between the CCD members, the higher the probability of favorable legislative outcomes. Dr. Jones not only made this a priority but also took on a leadership role in researching provisions, developing position papers, and arbitrating differences among the membership.

During the 1980s, the leadership and faculty of UAFs began taking an increased role in responding to and shaping disability legislation at the national level. Many programs were developing areas of expertise related to employment, rehabilitation, education, and early

intervention. Much of the research data about employment models for people with disabilities that would eventually find its way into the professional literature was developed in employment projects located in UAFs. Thus, the directors of these projects were called upon to provide testimony and to join with constituency groups in promoting supported employment in the Rehabilitation Act (Kiernan, 1986).

Similarly, by 1986 sixteen UAFs had ongoing early intervention initiatives and provided data needed to support proposed legislation in this area. Several UAF directors and faculty members were asked to provide descriptive data and report on model early intervention programs. Two years later, when hearings on the Technology-Related Assistance Act for Individuals with Disabilities were held, UAF faculty with pilot projects in technology were again called upon for testimony (M. G. Fifield, 1988.

The 1986 legislative session was particularly successful in addressing new initiatives for people with disabilities. Under the leadership of Senator Lowell Weiker, Chairman of the Subcommittee on the Handicapped, and Senator Hatch, Chairman of the Senate Committee on Labor and Human Resources, supported employment provisions were added to the 1986 Amendments to the Rehabilitation Act, and early intervention provisions for infants and toddlers became Part H of the Education for All Handicapped Children's Act. As these provisions were crafted and negotiated, representatives from UAFs played prominent roles.

Emerging Expectations of Second Generation UAFs

The expectations of the second generation of UAFs that emerged in the late 1970s and mid-1980s occurred during a period when major transformations were occurring nationally and in the developmental disability field. The five UAFs that entered the network between 1975 and 1978 were very much like the first generation UAFs. After 1978, five UAF satellites entered the network, and three UAFs were established at a different university after another UAF program in the same state had been discontinued. In addition, four programs were considered part of the UAF network, but were not fully recognized either by the ADD or MCH: New Mexico, Mississippi, Ohio University, and Winthrop College in South Carolina.

Some of the most significant expectations of second generation UAFs were those placed on their host universities. During the 1960s and early 1970s, the advantages of a UAF to a university were apparent. These advantages included the possibility of a facility in which to conduct clinical research, preservice, interdisciplinary training, and leadership—all activities highly valued and consistent with the expectations of universities. Throughout most of the 1970s, UAF faculties and host-university administrators remained hopeful that additional construction funds would be appropriated. When the construction authorization was repealed in the 1978 Reauthorization, the hope for construction faded.

Between 1976 and 1987, the expectations for the sponsoring universities for UAFs became increasingly explicit. These expectations included academic appointments for the Director and key staff, space to house an expanding program, leveraging of outside resources,

and the anticipation that in the future the UAF would be asking for and receiving state-appropriated funding.

Such commitments were not easily negotiated with university administrators; consequently, it was increasingly difficult to convince university administrators that they should sponsor a UAF. In some cases, it was these very expectations that caused some UAFs to drop from the system (Ken Dumars, personal communication, 1985). Other UAFs sometimes went through considerable restructuring in an effort to find a good fit within their host universities.

Other expectations for UAFs that emerged during the second generation included those concerned with developing and maintaining close relationships with the state Developmental Disabilities Planning Council and the state service agencies; working on systems change; and conducting outreach training, technical assistance, and service programs in community settings.

The activities to address these expectations are not closely associated with the traditional roles of university faculty. Clearly, the second generation UAF faculties, staffs, and directors were expected to spend a significant amount of time off-campus working with agencies and individuals in community settings.

Second-generation UAFs tended to represent either the center-based clinical model or the community-based model, which focused less on direct services to clients. Many of the new UAFs that began operating in the 1980s were structured so that the bulk of their activities were embedded in the community rather than in a clinic or hospital setting. The differences between these models seemed to be widening, driven to a large extent by the sources of their support. In May of 1976, there were 39 recognized UAFs; 21 reported they had MCH training support. The Department of Education, through the Bureau of Education of the Handicapped, provided the second largest source of support for UAF programs (Farlee et al., 1976). The largest single source of support for UAFs, however, remained from MCH but was available to only 22 programs (Farlee et al., 1976).

Fiscal data, which includes sources and the amount of funding obtained and how such funds were spent, is among the most important program information available. Each UAF collects and maintains such data. However, collecting comparable and defendable data across the UAF network, or fiscal support and expenditures, is complicated by reasons of leveraging and organizational structure in individual UAFs. Leveraging creates many reporting problems, not only because of the variety of sources of support but also how partial support is separated out, how such funding is managed, and what portion of it is used for UAF activities. Furthermore, each university has its own way of determining cost centers and attributing sources of income. Major components counted as part of the UAF may also be counted as components of other university units. The relationship between such units and the UAF varies between universities. For example, some MCH training grants are clearly administered by the UAF. At other universities, the MCH training grant is administered by a unit only loosely connected to the UAF.

At times, major components like research and training centers, health or education institutes, engineering centers, or special training programs were developed by the UAF but later

reassigned or gradually taken over by another university administrative unit. Furthermore, it is not uncommon for a university to assign a special institute, research, or technical assistance program like a center for the gifted, substance abuse, or aging to be administered by the UAF rather than to establish another administrative unit. The activities and the fiscal data on such as reported depends largely on each UAF's definition and criteria. Consequently, fiscal data, at best, are estimates. Two of the seven UAF evaluation studies systematically collected and reported UAF fiscal data. Other UAF evaluation studies collected information on selected sources of support. However, it was not until 1987 that an ongoing systematic effort was undertaken to collect and report UAF fiscal data.

By the middle 1980s, the MCH training expectation no longer dominated most of the UAF training activities. Other funding sources had been found to support interdisciplinary training, and other strategies to address the training requirement had been devised, including greatly expanded outreach training. Rather than MCH and non-MCH UAFs, there were UAFs with MCH programs and UAFs that did not have MCH funding but may have had other program support from the Office of Special Education, Rehabilitation Service Administration, National Institute on Disability and Rehabilitation Research, or state sources.

The 1987 DD Act Amendments

Even before the 1987 legislative session began, the leadership of the AAUAP and consumer organizations were working together to develop new provisions. Table 2 identifies the most significant changes in the UAP[4] program contained in the 1987 DD Act reauthorization.

Perhaps as important as the changes themselves, was the support for the provisions provided by disability consumer organizations, particularly members of CCDD. This reflected a change in the way UAPs were perceived by consumer organizations and the role they would be expected to play in the future. Core support for UAPs was increased, new UAPs in unserved states were made a priority, and the training initiatives provided the first ongoing DD program support.

One of the most significant changes was in the name of the program. The program name had been a frustration almost from the start. The term *facility* had always been misleading and required lengthy explanations. Changing the official name to *University Affiliated Program* (UAP) helped, but, of course, did not fully solve the communication problems. With such significant provisions in the new amendments, the conditions were in place for a new generation of UAPs.

Third Generation UAPs

Consumer-outcome expectations for UAPs emerged in the 1980s starting with the 1984 Amendments to the DD Act. However, it was not until the 1987 Amendments became law that

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[4] Throughout the remainder of this paper, University Affiliated Programs (UAP) will be used both in the present and past tense.

Table 2

Changes in the UAF Provisions of the 1987 Amendments of the Developmental Disabilities Act

Provision or language	Significance
Name change	University Affiliated Facilities were no longer facilities, but Programs (UAPs).
New UAPs were a priority	Both authorization and appropriation legislation provided for new UAPs in unserved states. This provision was strongly supported by the National Association of Developmental Disabilities Councils (NADDC).
Training initiatives: • Staff training to service aging developmentally disabled individuals • Staff training for direct service providers • Staff training for early intervention services	The most important new UAP provision was the training initiatives. This was the first time that DD funding was provided to UAPs to meet their training expectations.
Increase in core support	This was a small increase but reflected renewed confidence in the need for and the relevance of UAPs.
Ongoing support for the UAP database	This provision permitted an ongoing collection of comparative data reflecting the national impact of the UAP network and the development of a national profile of productivity.

these additional expectations began to be addressed by programs through their core grants and additional funding sources. Consumer-outcome expectations, quality and impact indicators, provisions that increased consumer involvement and participation, and opportunities for state councils and UAPs to work together received considerable attention.

Expanded Relationships Between DDPCs and UAPs

Section 122 of the 1987 Amendments to the Developmental Disabilities Act called for a comprehensive review and analysis of the effectiveness and consumer satisfaction of developmental disabilities services provided or paid for by federal funds. Under this section, each state council was required to undertake and submit to the governor and state legislature a written report of such a study. Furthermore, the ADD was required to compile the state data and submit a composite report to Congress. This requirement was referred to as the 1990 Report and involved an extensive national evaluation study requiring the collection of descriptive and consumer satisfaction data (Jaskulski et al., 1990).

At the national level, the research, design, and data analysis for the 1990 report was subcontracted to the UAP faculty at Temple University. Many state councils asked their UAPs to help them meet the requirement of the 1990 Report. In many states, the Council subcontracted

the study to the UAP. In other states, the UAP was given the responsibility to prepare their state report or undertake major components of the work involved. In most states, this was a very positive and supportive initiative and represented an expanded relationship between the state planning council and the UAP.

UAP Program Standards

Early drafts of the 1970 DD Act and the 1975 Amendments called for UAP standards and/or accreditation. However, when the laws were signed, standards were included in overall evaluation efforts with the entire DD program, which was contracted to the EMC Institute, Inc., in Philadelphia under the direction of Dr. Irwin Schpok.

By 1976, chaffing under criticism that UAPs had no common level of quality, the AAUAP undertook the task to develop association membership standards. Dr. Herb Cohen, Director of the Rose Kennedy Center, chaired this committee and utilized the criteria first published by DDD in 1972 (DDD, 1972). The membership standards derived from this effort identified three membership levels—full, associate, and affiliate. The standards included an application that required documentation of compliance and made provisions for verification during site visits.

Included in the 1979 Amendments to the Developmental Disabilities Act, Section 122(a) directed the Secretary to establish by regulations UAP standards that reflected the special needs of persons of various ages with developmental disabilities. In addition, the Secretary was directed to include performance standards related to each of the mandated UAP activities.

To develop program standards for UAPs, the DDD contracted with Systems Research and Development Corporation located at Research Triangle in North Carolina to develop program criteria for UAPs. This effort was led by Mr. David Phoenix, who started with the membership standards developed by the AAUAP and the suggested *guidelines for measuring program acceptability* included in the Long-Range Planning Task Force for UAFs Report. Systems Research Corporation proposed program criteria, submitted them to consensus panels, and made them ready for field testing in 1979.

It was difficult to determine how serious Congress was about UAP program standards, even though they were mandated in the authorization legislation. The Appropriations Committee did not provide sufficient funding to develop the standards, let alone to implement and monitor them. Also, the only funding provided UAPs by the Developmental Disabilities Act was the discretionary funds to be used for administration and core support. The funding UAPs obtained to provide mandated interdisciplinary training, exemplary service, dissemination, and technical assistance programs did not come from ADD, but from other federal and/or state funding agencies. In effect, the authorizing language directed the Secretary to develop performance standards that would tell UAPs how they could use the funding they had obtained from grants and contracts awarded from other agencies.

With the passage of the Omnibus Budget Reconciliation Act of 1981, which combined the reauthorization of several disability programs and proposed further reductions in funding, work

on the development of UAP performance standards was tabled. Between 1981 and 1984 little was done to further develop UAP standards or program criteria.

The 1984 DD Amendments (P.L.98-527) again required the Secretary to develop and promulgate UAP standards. However, as recommended by Dr. Boggs, rather than subcontracting this task, as was done earlier, it was assigned to Marjorie Kirtland, then Deputy Director of ADD. Following 1.5 years of work, on November 20, 1987, the first program standards for UAPs were published in the *Federal Register* (1987).

Although program standards were now established, as prescribed by law, provisions to implement, monitor, and determine compliance were not in place. Furthermore, the published standards were based on the second generation UAP expectations contained in the 1984 and earlier reauthorization amendments. By the time they appeared in the *Federal Register*, the 1987 DD Amendments were already enacted in P.L. 100-146 and included many changes in the expectations of UAPs, which were not part of the standards.

A system to implement UAP standards was proposed during the AAUAP annual meeting in October 1987 by Ray Sanchez, Director of ADD's Division of Program Planning and Development. The proposed system was called the Quality Enhancement System (QES) and was endorsed by UAP directors and the ADD. The QES included a new application process, review panels, and site visits. Over the next few years, cooperation between the ADD and members of the AAUAP developed five documents designed to sequentially implement the QES (Davidson & Fifield, 1992).

1. Guidelines for the Development and Maintenance of Quality University Affiliated Programs (Davidson & Fifield, 1988).
2. Handbook for Conducting University Affiliated Programs Site Reviews and Self-Assessments (M. G. Fifield, Davidson, Garner, & Stark, 1989).
3. Technical Manual on University Affiliated Program Core Functions (Golden, 1990).
4. Revisions of the UAP Continuing and Competitive Core Grant Application.
5. National Information Reporting System for University Affiliated Programs (Pappas, 1990).

Accompanying the National Information Reporting System for UAPs was the *UAP Data Collection, Reporting, and Utilization Manual* (Pappas, 1990). This manual culminated almost 15 years of work in developing and implementing a network-wide data reporting system (Guthrie, 1976; Pappas, 1990). This effort started in 1976 with Don Guthrie of the Neuro-Psychiatric Institute at UCLA. From that time forward, a variety of efforts to collect and report data about UAP activities were launched. Sometimes these efforts were supported with funds from MCH and sometimes with funds from the ADD. Both agencies expressed a need for information about UAP activities, but the agencies differed in the types of data they wanted, the definitions and collection methods that needed to be developed, and the formats for reporting the data. Consequently, each effort to gather data about individual UAP activities across the network became increasingly complex and controversial.

It was not until the DD Amendments of 1987 that a consistent approach to data collection and reporting was put into place. This system was designed primarily around ADD data needs. Like other data collection efforts, it was criticized and challenged from the start, because common definitions and data collection mechanisms were difficult to agree upon, and self-report measures were used. It was viewed primarily as descriptive and always putting the program in the most favorable light.

Systems Change

The data UAPs collected as part of the national information reporting system was to be submitted by each UAP to the ADD and to MCH (Training and Client Services) in an annual report. In addition, the report called for information that documented activities and yearly accomplishments in addressing consumer outcomes, meeting the needs of minorities and underserved populations, leveraging, and systems change. Although leveraging non-ADD resources and systems change have always been an ADD expectation of UAPs, this was the first-time accomplishments in these areas were to be reported. These data points articulated the programmatic expectations of the ADD.

The AAUAP undertook the task of analyzing the data reported and combining and grouping it to reflect the impact that the UAP network had nationally. Because of the nature of the data reported and the diversity within the UAP network, the report was primarily descriptive and explained the scope of the UAP network rather than specific accomplishments. Systems change became the heading for activities designed to impact and improve the developmental disabilities service delivery system. Initially, UAP systems change activities focused on core functions; however, following the 1984 DD Amendments, UAP faculty were expected to advocate and promote the purposes and the values expressed in the Developmental Disabilities Act and its amendments.

Among the changes brought about by the 1987 Amendments was renewed interest in establishing a UAP in every state. Between 1987 and 1994, each annual appropriation included additional funding to support new UAPs or satellite UAPs. States could apply either for a satellite or a full UAP, based on what they felt would be their best presentation to the review panel. Twenty new UAPs were admitted to the network between 1987 and 1994—five were satellites, and 15 were full UAPs. By 1993, seven satellite programs had become full status UAPs.

Competition between universities in unserved states for their UAP was often fierce. This in-state competition was handled by the ADD by providing either a consortium or multi-campus UAP or having each interested university submit a competitive proposal and selecting the proposal that they felt was the strongest.

Consortium or Multi-Campus UAPs

Between 1972 and 1984, multi-campus UAPs were not encouraged by the ADD. The history of multi-campus centers was not encouraging because competition between universities

had been much more common than cooperation and few multi-campus UAPs had survived. Out of the six multi-campus, first-generation UAPs, Kansas was the sole survivor. The others either separated into independent UAPs or one was dropped as another unit took the leadership. However, after the 1987 Amendments, intra-state university competition for the designated UAP resulted in divided loyalties. To resolve this problem, a consortium or multi-campus program was an obvious compromise, and several were submitted and approved, including Arkansas, Texas, New Mexico, and New Hampshire.

The satellite and host UAP models were another version of a multi-campus unit. This model had not been any more successful than the multi-campus UAPs in the same state. Satellites that were successful separated as soon as possible from their host and became full UAPs.

Competitive UAP Proposals

When universities within the same state were unable to work out a consortium or a multi-campus program, in-state university competition was handled by the ADD encouraging each university to submit its own application and let the ADD review panel identify the winning proposal. Competing universities in Texas, North Dakota, and Oklahoma were submitted and awarded following this procedure. A selection was made in Texas and a year later in North Dakota. A year later, Oklahoma submitted an acceptable consortium-type application.

Specialized services are still being offered and the health components of UAPs have remained. The 1993 UAP survey also asked directors to identify the legislation that has exerted the greatest impact on their programs. The programmatic impact of legislation has depended primarily on the funding it provides any specific UAP, and the cumulative effects of important legislation are reflected in the difference between legislation reported as important by first generation UAPs and third generation UAPs.

The programmatic implications of new federal initiatives and interests are also determined by the longevity of the elected or appointed decision maker. Federal administrators often want to leave their stamp of influence on the programs they direct. Initiatives generated by such well-intentioned directors are frequently changed with the next appointee. The frequency with which this has occurred in ADD has caused some UAP directors to become wary about taking on new initiatives until it is clear whether the new initiative is to be a long-term emphasis or a flash in the pan.

At this point in time, third-generation expectations are coalescing around expanded consumer empowerment and involvement in UAP planning and operations, responsiveness to state needs, and an expanded community rather than university focus. Technical assistance and outreach training is replacing the expectation of core interdisciplinary preservice training. Third generation UAPs seem to be state focused rather than a national or regional resource program as envisioned in the 1970s (Tarjan & the UAF Long-Range Planning Task Force, 1976).

Overarching Themes in the Evolution of UAPs

In examining the historical, descriptive, and survey data drawn together for this study, several overarching themes emerge. Three themes in particular have had significant impact on the evolution of the UAP network: the diversity and changing nature of the expectations of UAPs, the imperative to respond to consumer needs, and the role of values in developing programs.

Diversity

In 1962, the Panel's Report to the President pointed out that mental retardation was a complex problem requiring bold, creative approaches on many fronts. The UAP implementation legislation reflected such creativity and diversity, by design and sometimes by neglect.

University-Based

Inherent in our nation's university system are expectations of academic freedom, critique and challenge by colleagues, and technology transfer. Traditionally, it has been the nation's universities that have conducted the research leading to new scientific discoveries and to the development of new social theory and policy. It is the expertise found among university faculty that our society looks to for new initiatives, studies in organization systems, and fact finding. Perhaps the most unique feature of our nation's universities is their diversity. They are organized differently, funded from multiple sources, and bring together scholarship and scientific expertise from diverse fields.

By locating the proposed developmental disabilities programs in universities, the UAPs evolved in many different directions determined by their location, the strengths and interests of the host university faculty, as well as the mission and goals of the university. Different UAPs reported to different administrative units and were composed of different program components. Each of these influences affected the evolution of UAP programs in different ways and added variety, comprehensiveness, and multiple perspectives to the disability field.

Expectations of Administrative and Supervisory Agencies

UAPs have been established by more than one federal agency. The first centers were established through a construction program for service and training clinics that already existed supported by Children's Bureau. The Division of Mental Retardation, which first administered UAPs, was renamed several times. In addition, it has been placed under several different federal administrative organization structures and has had a large number of directors, commissioners, or appointees acting in that capacity. As often happens, the agendas and interests of the second administrative echelon's directors, commissioners, or associate directors has also influenced the expectations of UAPs.

Over the past 30 years, the agency administering the UAP shifted from an agency focusing on health to Social and Rehabilitation Services (SRS), then to the Office of Human Development

Services (OHDS), and more recently to the Administration on Children and Families (ACF). Even when specific directives were not passed down to the ADD, UAPs were encouraged to apply for discretionary funding to the secondary echelon agencies, and UAPs have undertaken projects in Aging, Head Start, Foster Care, Special Needs Adoptions, Family Support, and Employment.

In addition, the interests of an appropriately placed legislator sometimes established or added significantly to the program support of selected UAPs. Even though such legislative favoritism was viewed as *pork*, UAPs so favored had to compete for renewal, and many developed exemplary programs.

Influence of Diverse Funding Sources

The studies undertaken to evaluate UAPs, summarized in Table 1, repeatedly called for a common mission and a common source of funding. The fact that these recommendations were not implemented, although troubling at the time, has become a major source of diversity. Individual programs interpreted the UAP mission in line with their own strengths and sought support from different sources. Each agency from which a UAP was successful in obtaining funding had its own set of expectations and objectives.

Because of their need to rely on many sources of funding, legislation other than the DD Act has influenced the evolution of priorities, expertise, and capacity of UAPs. Not only does the impact of funding from other non-DD Act legislation for each UAP generation differ, but certain UAPs have pursued funding, programs, and opportunities made available under certain legislation at the expense of other opportunities. For example, health legislation has had a greater impact on first generation UAPs than on second generation programs. For other programs, the influence of rehabilitation and education legislation is greater than the health legislation, and even greater in many instances than the DD Act itself.

Discretionary Funding with Short-Term Competitive Grants

Most UAPs have obtained the majority of their fiscal support through competitive grants awarded generally for a 2- to 5-year period. In many cases, UAPs have competed with each other for these grants. Thus, there were winners and losers and programs and services offered by UAPs reflect this success/failure ratio.

Programs funded under time-limited federal grants have a side benefit in that they require successful applicants to be current with the literature and best practices. Success in obtaining competitive grants requires the applicant to demonstrate the very characteristics UAPs were expected to exemplify. The fact that so many UAPs have survived and even thrived, reflects not only resourcefulness, but the merits of each individual program.

Consumer Participation

The disability field has been responding to consumer pressures since the early 1960s.

Even before then, it was the National Association for Retarded Children (NARC) that carried the momentum for services and programs and the legislation that has supported them. President Kennedy, himself, was a consumer. One of the important precedents set by the President's Panel in 1962 was that of strong consumer participation. Later consumer members of the President's Committee on Mental Retardation and members of consumer organizations played an important role in the implementation legislation. Boggs (1976) reported that the leadership of the President's Committee shifted from professionals to consumers during the early 1970s. The Developmental Disabilities Act of 1970 expanded the role of consumer participation and state planning councils with consumer membership. Each subsequent reauthorization of the Developmental Disabilities Act has increased and strengthened consumer participation.

All UAPs were required to establish an advisory or policy committee. Until the late 1980s, most had a single advisory or policy council with representation from consumers. During the last half of the 1980s, representatives from consumer organizations and members of the DDPCs were encouraged as consumer representatives. More recently, the ADD has encouraged UAPs to place primary consumers on their boards and councils. Expanding and effectively empower consumer participation in the leadership and management of UAPs continues to be a growing trend over the last decade.

The Americans with Disabilities Act (ADA)

Public Law 101-336 was signed by President Bush on July 26, 1990. The ADA, which extends federal civil rights protections to all Americans with disabilities, has been described as the most significant disability legislation of the decade and it has added a great deal of strength to the consumer-empowerment movement. Although this legislation impacts **all** individuals with all types of disabilities, not just those with developmental disabilities, and as such, was much more general than the Developmental Disabilities Act, UAPs as a part of the disability field, were expected to both comply and facilitate university and state compliance of the ADA and to work with public and private organizations on compliance issues (Seelman, 1993). The ADA initially provided opportunities for UAPs to seek funding to provide technical assistance, develop training materials, conduct seminars, and for UAP staff to take training themselves in the implementation of ADA provisions.

One of the outcomes of the ADA has been a significant increase in the interaction between UAP faculty and staff and representatives of disability organizations, particularly those concerned about individuals with mobility impairments and individuals with vision and hearing loss.

Such groups have not traditionally been a service population of UAPs. People from these organizations and consumers with such disabilities have been added to many UAP policy and advisory boards and to specific projects. This not only increases consumer representation but expands UAP efforts to better address the needs of these disability groups.

1990 Amendments to the Developmental Disabilities Act

P.L. 101-494 was signed into law 1 month after President Bush signed the ADA. These amendments used the same language as the ADA and reflected increased sensitivity to disability rights, values, and consumer empowerment. Consumer outcome measures (i.e., independence, productivity, and integration) were defined and the core functions of UAPs were grouped under three headings: (a) interdisciplinary training (although not defined, it was to provide training for parents, professionals, paraprofessionals, students, and volunteers); (b) demonstration of exemplary services and technical assistance; and (c) dissemination of findings.

The language of the 1990 DD Amendments reflected some subtle, yet meaningful, changes in the expectations of UAPs. Preservice training, model service programs, research, and leadership activities typically associated with universities were de-emphasized. The expectations emphasized included community-based training, optional services, technical assistance, and dissemination. The 1990 Amendments also provided three new training initiatives: (a) positive behavior management programs, (b) assistive technology, and (c) training needs determined by the UAP in consultation with the state planning council. The criteria for approving UAP applications for both training and core funding included competency- and value-based training and peer reviews, including site visits.

In 1992, ADD included consumers as members of the panels that reviewed UAP core and training grants. The comments of panel members on evaluation forms reflected their concern for language that was politically current; indicated value-based programming; and showed principles, priorities, and implementation of ADA and consumer empowerment. In July 1992, a special institute was sponsored by the ADD to train a group of consumers to serve as members of UAP site visit teams. From that time forward, a trained consumer has been included as a member of each UAP site visit.

Values-Based Programming

National policy reflected in federal legislation is not always based on objective data (Seekins & Fawcett, 1986). Congressional hearings are often staged, with witnesses carefully selected and coached to provide testimony supporting the values and provisions congressional leadership have already determined to promote in legislation (Weatherford, 1985).

In the disability field, reaction to intolerable conditions in large congregate state institutions triggered the de-institutionalization movement (P.L. 91-517). Renewed concern for human dignity was translated into the *Bill of Rights* provisions of the Developmental Disabilities Act and the Protection and Advocacy Program (P.L. 94-103). In more recent reauthorizations, service philosophies, including family support, community-based services, and consumer outcomes became legislative language and new program initiatives.

Over the past five decades, many such value-based provisions have been added to various reauthorizations of disability legislation (i.e., free and appropriate education, least-restrictive environment, consumer responsive, reasonable accommodation, essential job elements, and

presumed eligibility). The 1994 Amendments to the DD Act (P.L. 103-230) added a list of eight value or policy principles under Part A, General Provisions, Section 101, Findings, Purpose, and Policy. These policy principles address the values and beliefs concerning the capability and participation of individuals with disabilities and family members, respect for individual and cultural differences, the benefits of services and supports provided in an individual manner, and the advantages of integration and participation.

To many in the disability field, the term "inclusion" has evolved to reflect the combination of desired outcomes from support and service programs. Perhaps at the broadest level, inclusion emphasizes the need to change the environment and remove societal barriers to better accommodate the person with disabilities rather than changing the individual. More recently, independence and productivity, integration, least-restrictive placement, and other similar values have been encompassed under the term "inclusion." However, defining, measuring, and balancing inclusion with other values has been more difficult.

Early in the 1990s, professional organizations and consumer groups rallied around the concept of inclusion. The CEC called for a policy on inclusive schools in community settings. Special debates and consensus panels were convened to develop such a policy. By the middle of 1993, inclusion seemed to be the clarion call within the disability field. UAPs in Maine and Massachusetts had changed their name to reflect their commitment to community inclusion. The AAUAP established a special committee on inclusion and undertook efforts to assess and encourage commitment to inclusion within the network. However, different individuals and groups in the disability field defined the term "inclusion" and applied it quite differently. On a continuum, this could range from a conservative interpretation that considers it one of many options, to a very liberal definition in which inclusion is a right, and the choice of something less than full inclusion is not acceptable (Burke & Grannon, 1994).

1994 Amendments to the Developmental Disabilities Act

By 1993, as the hearings started on the reauthorization of the Developmental Disabilities Act, opposition to the deinstitutionalization provisions were expressed by the Voice of the Retarded (VOR), a national organization representing many parents and family members with loved ones living in institutionalized settings. In effect, institutionalization is the opposite of inclusion, and VOR was concerned that inclusion was being interpreted to supersede choice, options, and family support rather than describing the environment in which supports were to be offered. VOR, along with representatives from the deaf community and several organizations representing learning disabilities, expressed concern that many considered inclusion as the ultimate value. They pointed out that inclusion was a placement, not a program decision. Its emphasis could lead to placement without support and could be trading effective treatment for such placement.

This opposition delayed congressional agreement on the language and the provisions of the 1994 Amendments to the DD Act for over 6 months. When the 1994 Amendments were passed by both houses and signed by President Clinton on April 7, 1994 (P.L. 103-230), the

resulting language did little more than try to accommodate both extremes, and in doing so, called attention to the fact that how inclusion was defined and implemented would be a major policy debate in future reauthorization legislation.

As the new millennium began, the UAP network was well established. Individual programs were established in every state and territory of the nation. Programs were located in a wide range of research universities, teaching colleges, medical schools, and teaching hospitals. Some UAPs were multi-campus consortia operations, while some operated outside of formal academic structures. Funding for the network continued to come from the MCH programs to operate clinical LEND programs and from the ADD for broader community-based programs. The national association of UAPs underwent significant restructuring and was rebranded as the Association of University Centers on Disabilities (AUCD), which pursued a broad range of disability initiatives, not just serving the interests of the constituent programs.

In 1976, the UAF Long-Range Planning Task Force concluded that the original UAF concept was sound and that it was in meeting a significant social need (Tarjan & the UAF Long-Range Planning Task Force, 1976). The original concepts have matured over the past 6 decades. In response and along with the evolution of the disability community, UAFs have evolved into programs and more recently into University Centers on Disabilities (UCEDs). Their funding and activities are highly diverse and collectively impact the lives of millions of people with disabilities and their individual social and community networks. In many planned, unplanned, and unexpected ways, the current network of programs is successfully addressing the needs of the disability field as originally outlined by the President's 1962 panel.

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