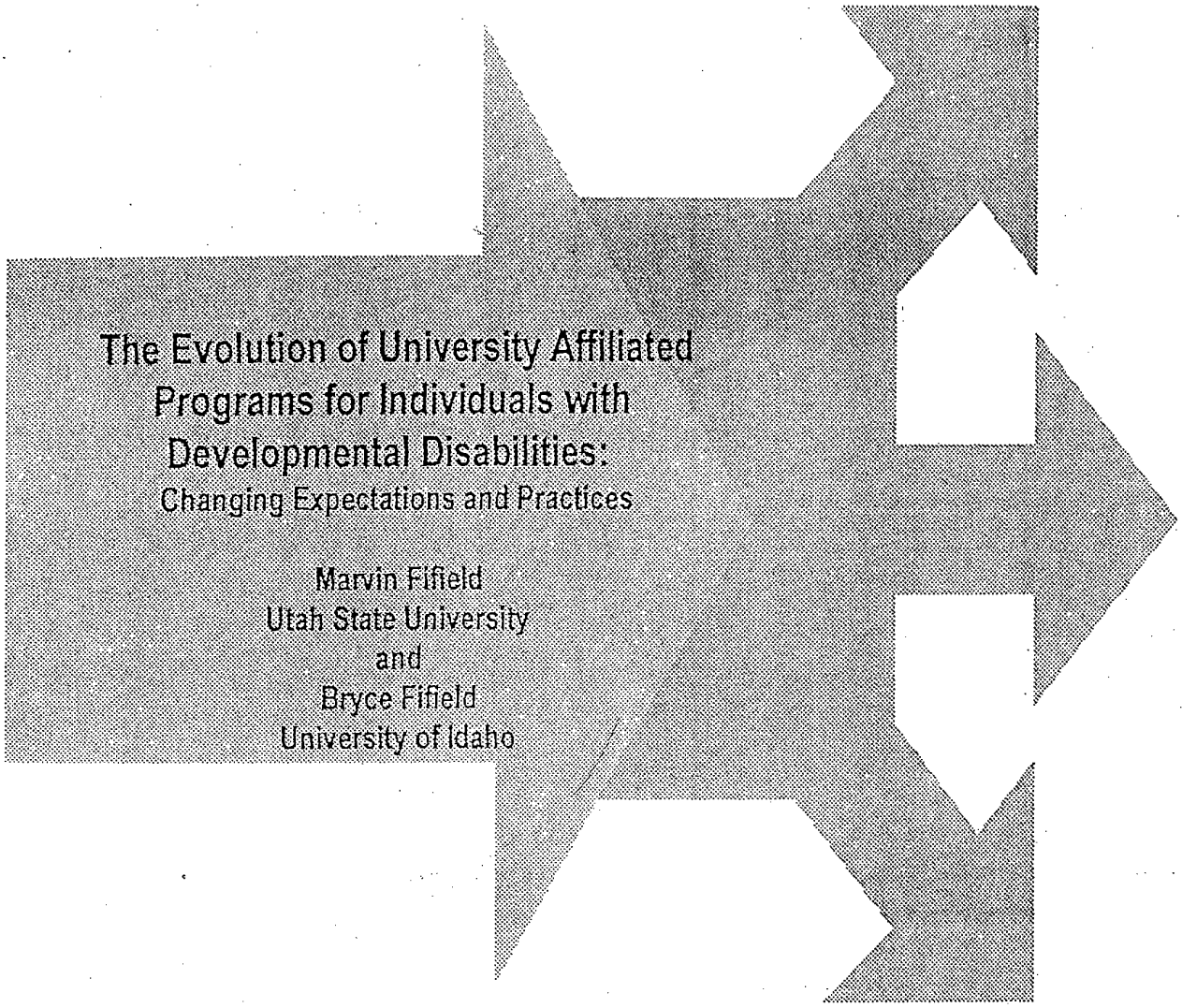

The Evolution of University Affiliated Programs for Individuals with Developmental Disabilities:

Changing Expectations and Practices

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TABLE OF CONTENTS

Acknowledgements

The national network of university affiliated programs is a complex system of professionals in many disciplines, academic institutions, service agencies, special interest groups, consumer organizations, and special projects. This system has evolved over the past 30 years, sometimes according to design and sometimes by neglect.

Capturing this diversity and describing the key junctures that have influenced this evolution has been 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 UAP system, it is often difficult to attribute key decisions to particular individuals or events.

The preparation of this document extended over four years and required bringing together material and information from a variety of sources. Much of the material reviewed and cited came from personal files of the professional people who participated in this process over the past 30 years. Some of these were directors of UAPs; others were directors of federal funding agencies. Other contributors were members of planning and policy committees that shaped or influenced decisions that impacted the UAP network.

Dr. Robert Cooke not only conceptualized the university affiliated program and promoted it through the early formative years, but then became the director of the first UAP responsible for implementing and developing the program. Dr. Cooke reviewed the manuscript for the document and provided valuable suggestions, input, and corrections. Dr. Elizabeth Boggs provided an immense amount of the historical data and information. This included both documents which she has published and drafts, notes, and other materials she is currently preparing. Rudolph Hormuth was the point person in the Children's Bureau and later in the Bureau of Maternal and Child Health. Rudy had an integral and vital role in the development of the UAP network, obtaining support, and directing MCH training activities. Rudy's personal file of memorandums, concept papers, agendas, policy and drafts of policy papers, were provided to the authors. In addition, Rudy and Jim Papai reviewed drafts of the manuscript and provided corrections and suggestions for improving its accuracy. Vic Kiernan was the Administrator of the UCLA/UAP and often the point person representing the association of UAP directors. Vic reviewed the manuscript and provided historical information on the events and people involved between 1965 and 1978. Vivian Hilton was the "UAF" Program Administrator between 1965 and 1972 in the Division of Developmental Disabilities. His input, encouragement, and suggestions were particularly helpful. Other people who reviewed and provided input and suggestions include Dr. Jack Rubenstein, Dr. Alan Crocker, Katy Beh Neas, and Bill Jones. The authors wish to express their appreciation for the material and information provided by those identified above and to the many other people who reviewed and provided suggestions and information used in the completion of this report.

The Evolution of University Affiliated Programs for Individuals with Developmental Disabilities Changing Expectations and Practices

This report is a historical overview of the evolution of the network of University Affiliated Programs for Individuals with Developmental Disabilities (UAPs). Originally University Affiliated Facilities were proposed as an entity by which many of the recommendations of President Kennedy's Panel on Mental Retardation could be implemented. Over the past 30 years, as a result of legislation and emerging best practices, the network has evolved considerably from a group of facilities (UAFs) to University Affiliated Programs (UAPs). Information about the development of UAPs and the implementation of new initiatives was obtained from a questionnaire completed by UAP directors, through telephone interviews with people who have played substantive roles in the development of the UAP network, and through a review of legislation, government documents, and correspondence. These data are reported and related to the legislative initiatives that have affected the UAPs over the past 30 years.

Background

University Affiliated Programs (UAPs) 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 signed seven days earlier, represented the initial legislation intended to implement the recommendations of the President's Panel on Mental Retardation.

Mental retardation had been recognized as a public health issue seven 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 (Appendix E provides a table listing the early mental retardation activities of HEW) (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 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.[1]

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 consumers. The Panel was organized into six task forces: (a) Prevention (Clinical and Institutional), (b) Education and Habilitation, (c) Law and Public Awareness, (d) Biological Research, (e) Behavioral and Social Research, and (f) 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

[1] *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. Also, the names of disability interest groups changed to reflect more current service philosophies. Even more confusing is the practice of reducing names of agencies and organizations to initials or acronyms. To help the reader through this confusion, acronyms, their meanings, and when changes were made, are provided in Appendix A.*

research and provide service and training programs for individuals 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.

The Panel's Report to the President was among the most comprehensive, multi-faceted, and well researched documents in the disability field. It called for a comprehensive approach on 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, p. 17).

Unlike many other Presidential initiatives and national studies, 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 formulate legislation to implement the recommendations had begun (Cooke, no date).

Implementation Legislation and Proposed University Affiliated Facility Program

Legislation to implement the recommendations of the Report of the President's Panel on Mental Retardation was a high priority because President Kennedy had made it a theme of his special Report to Congress a year earlier in October of 1961. 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 new idea or concept was needed in 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 developing 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 (Boggs, 1976, personal correspondence; R. E. Cooke, M.D., June 22, 1994).

A University Affiliated Facility 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 (Cooke, 1962, p. 2).

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 University Affiliated Facilities (UAF)[2] many of the recommendations contained in the Panel's Report to the President could be addressed. The support of higher education was stimulated by the possibility of federal funds for campus facilities to conduct research and 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 be addressed. The proposed UAFs could also be a vehicle for developing, testing and demonstrating many of the new

2 *The program used the name University Affiliated Facility (UAF) until 1987. The 1987 amendments to the Developmental Disabilities Act changed the name to University Affiliated Program (UAP).*

initiatives referred to throughout the Panel's Report: 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 expressed a need for practical solutions that focused on immediate needs and would result in immediate changes.

As the UAF concept was further developed, much discussion was generated around the most appropriate setting, linkage, and program structure for UAFs. Dr. Boggs, also a member of the President's Panel, stressed the need for a strong community-based program with linkage to universities (Boggs, 1976). 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 (Vic Keeran, July 18, 1994, personal communication). 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 some of the major recommendations of the Panel's Report. A summary of the recommendations provided by the President's Panel which have become initiatives and/or expectations of UAFs or Mental Retardation Research Centers (MRRC's) over the years are listed in Table 1. Many of the provisions listed in Table 1 were later included in the Developmental Disabilities Act of 1970, the Rehabilitation Act of 1973, and the Education for All Handicapped Children Act of 1974 (Fifield & Fifield, 1994). (See Table 1, pp. 6-7.).

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 Services was given the construction authority, and the legislative authority was patterned after the Hill Burton Act (Boggs, 1976; 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

Table I

Selected Recommendations of the President's Panel on Mental Retardation Which Became Special Initiatives and/or Expectations of UAPs and Research Centers

Major Recommendations

Combat mental retardation on a broad front, using creativity and originality (p. 9).
Highest priority to construction of academic facilities for research and training (p. 29).
Focus on Planning and Implementation (p. 74).
Hill-Burton Funding Support (p. 141).
Federal Grants in aid and contracts (p. 174, 190).

Recommendations Which Became Expectations of University Affiliated Programs				Recommendations That Became Expectations of Research Centers	Special Initiatives Recommended
Training	Services	Applied Research and Dissemination	Technical Assistance and Consultation		
Increase the supply of scientific manpower and training specialist (p. 22, 39).	Provide early educational diagnosis and evaluation for learning problems (p. 109).	Better dissemination and application of findings of research (p. 21).	Coordination of research, training and services (p. 172).	Basic research on the cause and prevention of mental retardation (p. 14).	Maximize capacity to achieve independence in the mainstream (p. 13).
Shortage of personnel in all areas and need for volunteers (p. 70).	Exemplary programs demonstrating new concepts of services (p. 176).	Effective "communication from one discipline to another" (p. 21).	Improve exchange of scientific data and information (p. 35-36).	Federal leadership in research (p. 21).	Strengthen the bridge between formal schooling and employment (p. 64).
Steady influx of trained personnel and new knowledge gained from research (p. 172).	Demonstration or pilot programs (p. 141, 186).	Prompt application of laboratory findings in clinical practices (p. 28).	Communications coordination and authority (p. 16-17).	Develop research centers on mental retardation in universities and institutions (p. 24).	Importance of the family in planning (p. 75).
Compelling urgency to train additional teaching and research manpower (p. 113).	Development of interdisciplinary demonstration programs (p. 189).	Information about MR services available and dissemination (p. 189-190).	Application of practices and knowledge already developed through research (p. 168).	Office of Education augment exceptional child research (p. 34).	Families should be supported and sustained (p. 88).
Interdisciplinary training (p. 83).	Comprehensive programs with continuum of care (p. 73, 83).	Universities to establish clinical research programs through teaching hospitals (p. 25).	Expanded efforts to communicate knowledge (p. 34).	Universities offer opportunities for research training in more than one discipline (p. 45).	Case management (p. 87).
High priority training more college level instructors (p. 114).	Community-centered services (p. 15).	Specialized conferences on mental retardation (p. 36).		National Institutes on learning (p. 31-33, 183).	Expand the development of community resources (p. 96).
Develop leadership in administration and supervision of services (p. 107).	Universities and departments of health collaborate on regional genetics services (p. 57).	Information and public awareness (p. 15, 157-160).		Research in the behavioral science to address therapeutic and rehabilitation possibilities (p. 24).	Joint work experience job training in sheltered and activity center workshops (p. 123).
Preparation of leaders and potential leaders (p. 176).	Concentrate on high risk groups (p. 50, 79).	Interagency research and development activities (p. 184).		Research on the learning process and educative techniques (p. 31).	Employment assistance for gainful employment (p. 129, 187).

Recommendations Which Became Expectations of University Affiliated Programs				Recommendations That Became Expectations of Research Centers	Special Initiatives Recommended
Training	Services	Applied Research and Dissemination	Technical Assistance and Consultation		
Train seed personnel (p. 176).	Expand daycare (p. 69).	Goal of education research is to find and develop each individual's potential (p. 100).		Federal government to collect and analyze prevalence data (p. 29).	Options to institutionalization (p. 134).
University interdisciplinary training with service agencies (p. 187).	Screening tests for early detection in well-baby clinics (p. 77).	Early detection of school learning difficulties (p. 109).			Residential care should be therapeutic in character (p. 133).
Provide scholarships and fellowships (p. 43).	Expert comprehensive diagnosis and evaluation services and planning (p. 82).	Test research hypothesis in service settings (p. 173).			Flexible admission and release points (p. 133).
Post-doctorate fellows and career professorships (p. 41).	Interdisciplinary or multi-disciplinary team clinics (p. 83).	Determine aspects of medical care that can be provided by non-medical personnel (p. 42).			Return persons to their own community (p. 136).
Graduate fellowships by Office of Education (p. 44).	Fixed point of referral and information for consultive services (p. 92).				Full human rights, legal rights and privileges for the retarded (p. 150).
Preservice and inservice training summer workshops (p. 41).	Develop specialized classroom services for total age range (p. 108).				Establish protective services in each state (p. 150).
Teaching grants and traineeships (p. 126).	Development of regional genetics counseling service programs (p. 57).				Citizen's advocacy groups (p. 185).
A major increase in the number of rehabilitation personnel (p. 120).	Provisions for emotional support and infant stimulation (p. 66).				Comprehensive planning and coordination at the regional, state and local level (p. 139, 186).
Training of attendants and aids for residential services (p. 136).	Urgent need to expand preschool programs (p. 105).				Designation of major responsibilities to "lead agency" (p. 189).
Parent training and education (p. 95).	Develop an instructional materials center (p. 107).				Every human being has potential for useful activity (Developmental Principal) (p. 100).

In addition to the recommendations provided in the proposed report to the President, each task force published a separate report that provided further elaboration on the recommendations in the report along with many additional findings and recommendations.

Secretary's Committee on Mental Retardation similar to those provided to mental retardation research centers (Boggs, 1976; Lesser, Hundley, and Doyle, 1965). 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* (Cooke, 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 in the initial initiative. 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 and operate UAFs would have to be taken from existing priorities in a variety of different agencies (Lesser et al., 1965).

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 which went directly to public and non-profit 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). The President's Panel in its assessment of resources 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 (Boggs, 1976). Still others provided limited training and multidiscipline service programs (Boggs, 1976; Cooke, 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. Since 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. Table 2 contains information on construction applications from universities with Children's Bureau support.

Table 2
UAF Construction Applications from Universities with Children's Bureau Support*

Universities	Support from Existing or Expanded Programs Incorporated in the UAF Structure		
	Clinical Service & Training Programs	Bio-Chemical and Cytogenetics Laboratory Programs	Dental & Clinical Psychology Training Programs
Johns Hopkins University	X		
University of Colorado	X	X	
University of Alabama	X	X	X
Indiana University	X		
University of Miami	X	X	
University Kansas	X		
University of Tennessee	X		X
University of No. Carolina	X		
University of Oregon (Oregon Health Science University)	X	X	
University of Washington	X	X	
Ohio State University	X		X
University of Wisconsin		X	
University of Cincinnati	X	X	X

* adapted from Baxter (1969)

Although all of the first UAF applications came from universities receiving Children's Bureau support, it was unusual for any university to have a training or service program emphasizing mental retardation. It was the 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 for 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 (Cooke, 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 (Cooke, no date).

UAF 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. Cooke (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 P.L. 89-97. A year later, Section 511 of Title V of P. L. 90-248 extended the provision to provide interdisciplinary training in multi-agency settings (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, and thus, 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 (Baxter, 1969). 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). 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, but 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, this practice was discontinued.

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 (Boggs, 1976). It was staff from the Division of Mental Retardation who established the guidelines for UAF construction (Grants for Construction of University Affiliated Facilities for the Mentally Retarded, Title I, Part B, P.L. 88-164, no date). However, the Children's Bureau published its own guidelines for staffing and training programs (Guidelines for Staffing and Training Program Grants, University Affiliated Facilities for the Mentally Retarded and Multiply Handicapped 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 back into the Health Service and Mental Health Administration (HSMHA) of the Public Health Service (PHS). The MCH expectations for UAFs reflected the health mission of HSMHA, i.e., nursing, nutrition, occupational and physical therapy, speech pathology, social work, as well as medical disciplines. In contrast, the criteria established by the Division of Mental Retardation 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 which 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, September 5, 1964). Consequently, some universities applied for only UAF construction funds;

others applied only for MCH program training monies. Still others applied for both construction and training funds. Some construction applications were approved with MCH training money; others were not. 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 Division of Mental Retardation. 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. University Affiliated Facilities centers were established by the Division of Developmental Disabilities (DDD)[3], 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.

Appendix B provides a table listing all of the UAFs that reported that they are currently or were part of the national UAF network and the date they received support from the Developmental Disabilities Act and/or MCH. The authors have separated UAFs into three separate generations. The date the UAF reported they entered the

[3] *The Developmental Disabilities Service and Facilities Construction Act of 1970 (P.L. 91-517) changed the name of the administrating agency from the Division of mental Retardation to the Division of Developmental Disabilities. In most subsequent legislation, mental retardation was replaced with developmental disabilities. The programs funded by the Children's Bureau and Maternal and Child Health continued, However, to use the term mental retardation for several more years. Recently the term "Children with Special Health Care Needs" has replaced Crippled Children's Services and is used to include mental retardation.*

national network, as well as the cluster of expectations outlined by the language and provisions of authorizing legislation, determined the generation into which they were placed. Although there is overlap, each generation is separated from others depending upon the funding that did or did not accompany such legislation, and the changes that have evolved in service philosophy, definitions, and best practices.

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, September 5, 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 (Fifield, 1990). 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 which focused on community-based services and home programs. Then, technical assistance and outreach training were added to keep pace with later expectations and state-of-the-art practices.

The First Generation UAFs

In February of 1965 the John F. Kennedy Institute at Johns Hopkins University became the first institution to be awarded a construction grant, five months after the first announcement of the program in the Federal Register. By January 1967, the Division of Mental Retardation had approved and funded 14 additional UAFs to be constructed in 18 locations, obligating $30.3 million. Dr. Boggs (1967) reported that 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 five-year extension projecting $10 million in fiscal year 1968 and $20 million in each of the successive four 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. As Dr. Boggs (1976) points out, these were the last dollars actually appropriated for construction of new UAFs.

Table 3 identifies the first 19 UAFs, where they were located, and other significant characteristics.

As noted in Table 3, five of the funded UAFs had more than one facility. Generally, they had their primary program in a medical center and their satellite program in a non-medical center, usually a College of Education (Mayeda, 1970). However, there were three exceptions to this pattern. Utah State University was a single facility funded in a College of Education. In Kansas, the main facility was in Lawrence, co-located with a MRRC, a medical program in Kansas City, and a

Table 3
First UAFs Funded, Location, and Significant Characteristics

Location	Located in Medical Center	Located in Private University	Located in Public University or Institute	Co-located with Mental Retardation Research Center	UAF with 2 or More Facilities on Different Campuses
University of Alabama Birmingham and Tuscaloosa, AL	X		X X		X
University of California Los Angeles, CA	X		X	X	
University of Colorado Denver, CO	X		X	X	
University of Miami Miami, FL	X	X			
Georgia Department of Public Health Atlanta, GA University of Georgia, Athens, GA	X				X
Indiana University Indianapolis and Bloomington, IN	X		 X X		X
University of Kansas Lawrence Kansas City, KS Parsons, KS	 X		 X X X	 X	X
John F. Kennedy Institute John Hopkins University University of MD	X	X			
Children's Hospital Boston, MD	X	X		X	
Fernald State School Waltham, MA			X	X	
New York Medical College New York, NY	X	X			
University of No. Carolina Chapel Hill, NC	X		X	X	
University of Oregon Portland, OR Eugene, OR	 X		 X X		X
Ohio State University Columbus, OH	X		X		

EVOLUTION OF UAPs

Location	Located in Medical Center	Located in Private University	Located in Public University or Institute	Co-located with Mental Retardation Research Center	UAF with 2 or More Facilities on Different Campuses
University of Tennessee Memphis, TN	X		X		
Utah State University Logan, UT			X		
University of Washington Seattle, WA	X		X	X	
Georgetown University Washington, DC	X	X			
University of Wisconsin Madison, WI	X		X	X	

(adapted from Mayeda 1970)

satellite program at Parsons State School in Parsons, Kansas. In Georgia, the primary facility was located at the Georgia Department of Public Health in Atlanta, and an additional facility was located at the University of Georgia in Athens (Mayeda, 1970).

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 totalled 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, and later MCH in HSMHA that controlled the activities of most UAFs. As a consequence, 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 UAF 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 (W. K. Babington, Chairman of the Secretary's Committee on Mental Retardation, 1968)). One of the first investigations of this nature was requested in July of 1969 by Wallace Babington, Executive Director to the Secretary's Committee on Mental Retardation. In response, W. F. Baxter, Staff Assistant to the Secretary's Committee on Mental Retardation, had a report and support document prepared, summarizing many of the emerging inconsistencies. As Baxter (1969) stated:

> *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* (Baxter, 1969).

The report further pointed out that UAPs 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 (Baxter, 1969). 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. (Baxter, 1969).

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, August 6, 1969). Table 4 provides a listing of the 19 UAFs recognized by HEW in 1969 and their directors.

During the next few months, Mr. Tadashi Mayeda, as project director, visited 19 sites, and collected and analyzed an extensive amount of data. Mayeda

Table 4
UAFs and Directors Recognized by HEW in 1969

UAP	Director
University of Alabama (Birmingham)	Andrew E. Lorincz, M. D.
University of Alabama (Tuscaloosa)	Albert J. Baumeister, Ph.D.
University of California (Los Angeles)	George Tarjan, M.D.
University of Colorado (Denver)	John H. Meier, Ph.D.
Georgetown University (Washington DC)	Robert J. Clayton, M.D.
University of Miami (Miami)	Frederick Richardson, M.D.
Georgia Dept. of Public Health (Athens)	Andrew L. Shotick, M.D.
Georgia Dept. of Public Health (Atlanta)	James D. Clements, M.D.
Indiana University (Bloomington)	Milton V. Wisland, Ph.D.
Indiana University (Indianapolis)	Morris Green, M.D.
University of Kansas (Lawrence)	Richard L Schiefelbusch, Ph.D.
Johns Hopkins University Children's Rehabilitation Institute (Baltimore)	Robert E. Cooke, M.D.
Children's Hospital Medical Center (Boston)	Allen Crocker, M.D.
Walter E. Fernald State School (Waltham)	Hugo W. Moser, M.D.
New York Medical College (New York City)	Margaret Giannini, M.D.
University of North Carolina (Chapel Hill)	Harrie Chamerlin, M.D.
Ohio State University (Columbus)	William Gibson, M.D.
University of Oregon (Eugene)	Robert H. Mattson, Ed.D.
University of Oregon (Portland)	LeRoy O. Carlson, M.D.
University of Tennessee (Memphis)	Robert G. Jordan, M.D.
Utah State University (Utah)	Marvin G. Fifield, Ed.D.
University of Wisconsin (Madison)	Rick Heber, Ph.D.
University of Washington (Seattle)	Bob Deisher, M.D.

identified the 16 original objectives for UAFs from P.L. 88-164. He catalogued the emerging requirements of UAFs and related these back to the President's Paneland to 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 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., bedcounts, 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 travelling 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 were 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 (Boggs, 1971).

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).

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 (Boggs, 1971). On August 13, 1969, Senator Edward Kennedy and Senator 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).

This, of course, ended only the authorization phase of the new legislation. The appropriation of federal funding to implement the new provisions was a separate struggle which required an additional year and resulted in funding at a level far less than that originally authorized (Boggs, 1971).

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 Developmental Disabilities Act. This committee was to serve as a coordinating broker and to provide input to other agencies on the implementation of the DD Act (Hitt, January 6, 1971). 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 (Egeberg, May 15, 1971). The minutes of committee meetings, planning papers, and interoffice memos suggests 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.

Particular effort was spent considering a consolidated funding system whereby federal agencies could provide appropriate fiscal support which would then be administered by the Division of Consolidated Funding (DHEW, Consolidated Funding Project, OMB #80-DO186HEW608D: Washington D.C.). This effort was not considered feasible due to jurisdictional problems and issues of economy (Hormuth, April 13, 1973).

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 (Boggs, 1971) (See Table 5.) In addition, there were several other differences between MCH support and expectations for UAFs and that provided by the Developmental Disabilities Act.

DD Act Support and Expectations

❶ 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 four years.

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

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

❹ In an effort to de-centralize the administration, the Division of Developmental Disabilities passed much of the grant approval authority on to the 10 HEW regional offices.

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

MCH Support and Expectations

❶ MCH fiscal support for UAF training was significantly greater than the DD Act support as presented below in Table 5.

❷ 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 (Cooke, 1994).

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

Table 5
Fiscal Support of UAFs by Maternal and Child Health, 1967-1975

YEAR	AMOUNT
1967	$3,912,000
1968	6,900,000
1969	8,833,000
1970	8,990,000
1971	11,957,000
1972	14,306,000
1973	14,784,000
1974	15,017,000
1975	16,341,000

The differences between MCH support and expectations with those of DDD had a significant impact on how UAFs would develop, particularly in the future.

UAFs 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 which 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 Developmental Disabilities Act instigated many important changes which were adopted and later included in other legislation (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 overcome or circumvented by educational intervention, instruction, stimulation, and expanded opportunities for inclusion (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 co-mingling 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 Division of Developmental Disabilities provided its first description of the mission, purpose, and objectives of UAFs (DDD, 1972b).

> *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, and 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.* (p. 2)

This document further defined a University Affiliated Facility 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, 1972b).

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 were 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 Developmental Disabilities Act was used to help provide administrative support to assist in the administration and supervision of other services which the UAF provided (DDD Draft Guidelines, 1972). Since 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.

Secondly, 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 was followed by the DD program administrators. As will be seen, this continued for the next 25 years. 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 reauthorization, and there would be many changes in administrative personnel.

Grants were awarded to successful UAF applicants late in 1972. The amount of each grant was based on a formula that provided a minimum of $75,000 to each existing UAF, plus additional funding based on the size of the individual UAF's

ongoing training and service program (Braddock, 1972; Utah State University, 1972; personal correspondence with Marjorie Kirkland, 1972, Deputy Director, DDD). Because the training and service programs for most UAFs were determined by the size of their MCH grant, those UAFs with the largest MCH grants received the largest amount of DD core support. UAFs could claim and defend training or service programs supported by other federal or state services also received additional funding. The application process required each UAF to describe the size of their program, sources of support, and present their best case for the amount of core support they requested (Utah State University, 1971). Consequently, the ingenuity of the grant writer in claiming state and federal support for the program also had a significant influence on the amount of core funding awarded (Vic Keeran, 1993, personal communication).

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 MCH training support which had been pending. Although UAF construction funding was authorized in the new Developmental Disabilities 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 Developmental Disabilities Act changed the relationship 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 Developmental Disabilities Act was passed, the Division of Developmental Disabilities added an additional nine programs to the UAF network, only two of which received MCH support (See Appendix B).

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

Second Generation 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. PL 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, and the new amendments also required that states include de-institutionalization plans in their DD state plan.

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 three 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 to 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 not only for the additional amount of fiscal support provided, but also because the projects undertaken by UAFs addressed cutting-edge issues of the day and state-of-the-art techniques.

Appendix C lists the UAFs that received funding under projects of national and regional significance, the initiative they addressed, the starting and ending dates of such projects, the contact person, and the annual level of support . . (McLaughlin, 1987). Appendix J presents the results of a survey of UAP directors conducted in 1993 which collected data about the individual program's response to these and other initiatives, when they were undertaken, and those that were continued. As indicated in Appendix J, once UAFs started initiatives, they generally found some way to continue them. When such programs were no longer supported from DDD, other funding sources were generally found.

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. Special Projects of National and Regional Significance under the Developmental Disabilities Act were considered the preferred source.

Following the 1978 amendments, the DDD undertook a number of 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 tran-

sition into employment (see Appendix J). 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.

Funding provided to UAFs from Maternal and Child Health 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 leverage other sources.

From a fiscal standpoint, the most significant legislation that emerged during the 1970s was not the DD Act, but the Vocational Rehabilitation Act (P.L. 93-112) in 1973 and the landmark Education for All Handicapped Children Act (P.L. 94-142), which was signed into law in 1975. These two pieces of legislation are considered the most important disability legislation of the decade because they impacted so many individuals, and they provided sizeable fiscal appropriations for their implementation. The Rehabilitation Act contained Section 504 which prohibited discrimination on the basis of a disability in federally assisted programs. Section 504 became the foundation upon which future disability rights legislation would be based. P.L. 94-142 implemented the developmental concept that all children, regardless of their disability, had the potential to learn and had a right to a free and appropriate public education in the least-restrictive environment.

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 which could help them address DD mandated program components. Farlee (1976) pointed out that UAFs were among the most aggressive applicants to submit proposals to BEH and the Rehabilitation Service Administration, even though UAFs faced complications in securing such support.

Co-mingling. 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 that extended beyond the purpose of their authorizing legislation to address interdisciplinary training or other DDD initiatives. This 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.

Unfortunately, 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 survived. Appendix B lists at least 18 programs that at some point were recognized as UAFs but were dropped or 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 (Fifield, 1978), 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 (Fifield and Moss, 1978). The DDD only approved the 4 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 Developmental Disability Planning Council (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 1980's on, the role of the host UAF became less and less significant, and the commitment and support from the DDPC increased in importance.

Satellite UAFs were funded at about 75 percent of full UAFs with the exception of the Navajo satellite, which received funding equal to that of a full UAF and was exempt from the 25 percent local match. Although satellites were not expected to provide the same complement of services as full UAFs, they were expected to address the unique needs of their state or area. No additional funding was provided the host to help the satellite with the exception of the Navajo satellite, for which the Utah UAF received a small amount of money for travel costs for the first three years.

Since satellite programs quickly responded to the needs of their state and to available federal initiatives, they basically became new UAFs (Davidson & Fifield, 1984). 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. The date, level of support, host UAF, and the date satellites became full UAFs is presented in Table 6.

Table 6
Satellites and Level of Support

Date	Satellite	Level of Support	Host UAF	Date Became Full UAF
1978	Diné Center for Human Development	$150,000	Utah State University	Dropped 1989
1978	Vermont	$75,000	Shriver's Center, Massachusetts	1988
1978	Rochester, NY	$75,000	Boston Children's Hospital	
1978	Montana	$75,000	Utah State University	1989
1981	Hawaii	$75,000	Univ. of So. California	Dropped 1984
1985	Connecticut	$75,000	Rose Kennedy Center, N.Y.	1991
1985	Virginia	$75,000	Georgetown, Washington D.C.	1988
1985	Minnesota	$75,000	Iowa	1988
1988	Idaho	$150,000	Eugene, Oregon	1993

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 which 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: (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; and (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 criteria for approval. Mayeda reported that approximately 49% of the costs for the construction phase was provided locally (Mayeda, 1970, p. 3).

Public Law 91-517 required a 25% match on all programs. This requirement was maintained in all future 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 P&A agencies or DDPC's. However, leveraging resources was clearly implied in the guidelines for UAF core funding and the funding level in the first appropriation which became available in 1972. Throughout the 1970s, staff members of DDD and of UAFs nurtured hopes that additional developmental disabilities program monies would be appropriated. Such was not to be the case, however. 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. Maternal and Child Health 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 which MCH required.

Most UAFs sought funding from grants made available through the Rehabilitation Act and the Education for All Handicapped Children Act and/or a variety of other state and federal sources. Farlee (1976) reported that MCH-funded

UAFs were just as aggressive in pursuing such projects as were other UAFs.

Difficulty Generated by Leveraging

Leveraging 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 is 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 5-20% of the UAFs operating budget), exerts an inordinate amount of control over the total program (Farlee, 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 are 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. The Developmental Disabilities Division (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 7 provides data on each of these studies, the initiating agency, who conducted the study, major findings, and recommendations.

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 7.

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)[4] for a comprehensive evaluation of the UAF Program. This contract consisted of two parts: the collection of descriptive data on UAPs (Farlee et al., 1976), and 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 et al., 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 that:

...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,

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

Table 7
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 a 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 a 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, Chairperson 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

interdisciplinary training, UAFs as change agents, and incremental implementation, testing the UAF concept. (Tarjan et al, 1976, 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. (Tarjan, 1976, 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.

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 were consistent with the three previous UAF evaluations (Controller General, February 1980).

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 awarded to Dr. Lee Henney in 1980, he reviewed and 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 most recent comprehensive evaluation of the UAF network was undertaken under the direction of Dr. Elizabeth Boggs, who had participated on the President's Panel in 1962 and on the UAF Long-Range Planning Task Force in 1976. The situation which resulted in this study had particular relevance to the evolution of UAFs and their program expectations.

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, 1986b). 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 bails 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 Workshop on the University Affiliated Facilities (UAF) Program to make recommendations concerning the role and future of UAFs. In addition to Dr. Boggs, who chaired the workshop, three other members also served on the Long-Range Planning Task Force. Other members included representatives from consumers and service providers who used the technical assistance and consultation provided by UAFs, directors of UAFs, and representatives of federal agencies.

The Ad Hoc Workshop on UAFs 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 a large number of 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:

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

Most of the recommendations of the Ad Hoc Workshop on UAFs had been addressed in some form by previous studies (see Table 8). What appeared to be different about Dr. Boggs' report, 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 Workshop for UAFs 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. To implement these recommendations, the ADD made two major changes:

- First, the application review process for UAFs was strengthened by including a rigorous review process by a peer review panel. 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. A draft of site visit guidelines were prepared by Vic Keeran following a university-sponsored site visit to the Alabama UAP in Birmingham. These guidelines were field tested by Dr. Boggs, Vic Keeran, and Dr. Wes Libb in a university-sponsored site visit to the Utah UAP. The ADD site visit provided a direct on-site 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 found 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 and Fifield, 1992). In response to these efforts, ADD funding was terminated at Rutgers University, the University of Michigan, and the University of California at Irvine (see Appendix B).

- Secondly, 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. The data reported in Appendix J shows that between 1981 and 1985, seven UAFs started employment initiatives; seven UAFs had ongoing programs addressing adults with DD; four UAFs had initiatives designed to serve or recruit minority students and to work with historically Black colleges; and finally, one UAF was conducting the first early intervention program. Furthermore, Appendix J shows that by 1991, 52% of the UAFs had employment projects; 83%, adult service projects; 76%, minority recruitment; and 86%, early intervention projects. 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 family 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 measurement 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, 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 (NARC in 1950, UCPA 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 1960's. The first Executive Director of the AAUAP

(then AUAF) was Cynthia Strudevant, who had been very active with the NARC. Subsequent AAUAP executive directors continued this effort, some more vigorously than others. Appendix H provides a list of the Presidents and Executive Directors of AAUAP and the dates which they served. During the last several years, the CCDD (now the Consortium for Citizens with Disabilities, CCD) has had increasing influence in the development of legislation and national policy. 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 a 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.

Like the decade earlier, the legislative provisions that had the most significant fiscal impact for UAFs were those in the Rehabilitation and Education Amendments. Supported employment, first called for in the 1984 amendments to the Developmental Disabilities Act, was strengthened and added to the 1986 amendments of the Rehabilitation Act as Section 705 of Title VII.

As shown in Appendix J, by 1986 5 UAFs, were conducting employment projects and an additional 6 had transition projects. 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. The directors of these projects were thus called upon to provide testimony and to join with constituency groups in promoting supported employment in the Rehabilitation Act (Horner & Bellamy, 1979; Kiernan, 1986).

Similarly, by 1986 16 UAFs had ongoing Early Intervention initiatives and provided data needed to support proposed legislation in this area (see Appendix J). Several UAF directors and faculty members were asked to provide descriptive data and report on model early intervention programs (Healy, 1986; Guralnik, 1986). 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 (Fifield, 1988; Healy, 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 program in the same state had been de-funded for not meeting the expectations of the ADD. The data in Appendix B shows that there were at least 10 UAFs that were dropped during the second generation period. 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 1960's and early 1970's 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, and 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. Table 8 shows some of the organizational changes that have occurred with respect to the placement of UAFs in their host universities. These data were provided by the UAF directors in 1993.

Table 8
Initial and Current Placement of UAP within University Setting

Setting	Initial Placement		Current Placement		%-age Change
	n	%	n	%	
University Medical or Health Center	8	28	9	31	+3
University Research Center or Graduate School	5	17	4	14	-3
College of Medicine	6	21	5	17	-4
College of Education	2	7	3	10	+3
Other College	2	7	4	14	+7
Department of Pediatrics	3	10	3	10	0
Other Department	2	7	1	3	-4
Independent Service Agency	1	3	0	0	-3

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 model of many of the new UAFs which were community-based and focused. 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, 1976). The largest single source of support for UAFs, however, remained from MCH but was available to only 22 programs (Farlee, 1976). The ratio of MCH, ADD, and BEH support had not changed significantly by 1984 (Boggs, 1984). (See Appendix E.)

UAF Fiscal Data

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 be also 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. As a consequence, 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. Table 1 of Appendix E provides the data reported by Dr. Farlee and Dr. Boggs in their UAF evaluation studies. Table 2 of Appendix E summarizes the funding from UAFs as reported as part of the National Information Reporting System. The changes in the numbers of UAFs reporting makes the data difficult to compare. However, major fiscal trends in the amount and sources of UAF support are reflected.

By the middle 1980's, 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 and changes for the 1987 DD Act reauthorization. The 1987 DD Amendments contained several important provisions that had impact on the UAF network. Table 9 identifies four of the most significant

changes in the UAP[5] program contained in the 1987 Amendments.

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.

Table 9
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.

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

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

The expectations of a third generation of UAPs began to emerge in the mid-1980's with the consumer-outcome language of the 1984 Amendments to the DD Act. However, it was not until the 1987 Amendments became law that additional expectations began to be applied across the network. 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, 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 with developmental disabilities of various ages. 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 which 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 one and one-half 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 (Fifield, Davidson, Garner, & Stark, 1989).
3. Technical Manual on University Affiliated Program Core Functions (Golden et al., 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, 1979; 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, 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 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. Due to 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, but 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. Although many examples of leveraging and systems change could be reported, the Agent Orange Initiative perhaps represents one of the most unique and creative initiatives carried out by the ADD.

The Agent Orange Class Assistance Program (AOCAP). Following the end of the hostilities in Vietnam, a group of veterans filed a class action suit against the chemical companies that provided Agent Orange to the military for use in Vietnam. In the settlement of the Agent Orange class action suit, the judge directed that a portion of the settlement money would be spent over approximately 10 years through a special outreach-type program that would have replication properties to other service systems. It was to be used in programs across the United States, focusing on case findings, diagnosis, service coordination, and intervention. In 1988, Dr. Jones, as Executive Director, and Dr. Fifield, past president of the AAUAP met with attorneys from the law firm representing the Vietnam veterans who had been exposed to Agent Orange. In response to this meeting a proposal was prepared and submitted to the law firm, representing the veterans and the Evelyn and Walter Haas,

Jr. Fund from San Francisco, who was at that time handling the settlement.

In July 1990, ADD Commissioner Deborah McFadden arranged a planning meeting with AOCAP leadership. From this meeting a concept paper was prepared by which Request For Proposals (RFP) could be issued to appropriate organizations and training and technical assistance to AOCAP grantees to be provided by AAUAP.

The AOCAP provided a new resource to support UAP activities and an opportunity to impact the Veteran's Administration, an agency which had always been distant and apart from the human service system. The service values of the developmental disability field (family centered, community based, systems change, and consumer empowerment) were reflected in the applications submitted by individual UAPs and the AAUAP and were endorsed by AOCAP. The AOCAP projects and the experience over the next 5 years were an embarrassment to the Veterans Administration (VA), for they illuminated how out of touch the VA had been with the greater part of society. The AOCAP National Symposium *The Legacy of Vietnam Veterans and Their Families: Survivors of War--Catalysts for Change* held in May 1994 and the published proceedings provided an example of leveraged resources and systems change activities at a level not documented before.

Expanding the UAP Network. 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. Between 1987 and 1994, 20 new UAPs were admitted to the network; five were satellites, and 15 as full UAPs. By 1993, seven satellite programs had become full status UAPs (see Appendix B).

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 (see Appendix B).

The satellite and host UAP model was 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. Oklahoma, a year later, submitted an acceptable consortium-type application.

Expectations of Third-Generation UAPs

The third-generation expectations for UAPs were influenced by many changes which emerged in response to shifts in service philosophy, settings, and values during the past two decades (Williams & Knox, 1994). In Appendix I, a schematic time line is presented which identifies the relationship of these changes. The shift in disability service philosophies was evidenced in UAPs through both new projects and modification of ongoing services. To determine the nature and direction of these programmatic changes in UAPs, a questionnaire was sent to all UAP directors asking them to identify the changes that occurred in their programs and the impact of such changes. Changing expectations have had the greatest impact

on first-generation UAPs, and thus, best reflect trends of the future. Table 10 presents a summary of the data provided by first-generation UAP directors on their rating of the major programmatic changes that have occurred in their UAP and the impact of such changes. The major changes reflected in Table 10 include a programmatic shift from child-focused, to community, family, and systems change.

Table 10
First Generation UAPs Reporting A Change in Program Focus

FROM	→	TOWARD	Level of Importance	n	%	Index of Importance
Child Centered Program	→	Program for Youth and Adults	1 2 3	7 4 6	24 14 21	35
Center-based	→	Community-based	1 2 3	6 5 4	21 17 14	32
Services offered in a clinic	→	Services offered in a home or community	1 2 3	4 2 7	14 7 24	23
Direct service orientation	→	Family support and systems change	1 2 3	2 4 8	7 14 28	22
Mental Retardation	→	Other disabilities	1 2 3	4 2 4	14 7 14	20
Individual Intervention	→	Family Intervention	1 2 3	3 3 2	10 10 7	17
Service in an institution	→	Service in the community	1 2 3	2 2 2	7 7 7	12
Health focus	→	Learning and development focus	1 2 3	1 2 1	3 7 3	8
Specialized services	→	Generic services	1 2 3	0 2 2	0 7 7	6

n=28

Level of Importance (Greatest importance = 1 x 3; Moderate importance = 2 x 2; Less importance = 3 x 1.

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. These data are presented in Appendix K. 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. As shown in Table 11, national initiatives or expectations and needs assessment data also exert a great deal of influence on program focus.

Table 11
Factors Which Influenced First Generation UAPs
To Change Program Focus

FACTOR	n	%
New Sources of Funding	23	79
National Initiative or Expectation	22	76
Needs Assessment Data	18	62
New Information & Technology	14	48
State or University Expectation	10	34
Additional Expertise Among Staff	9	31

The programmatic implications of new federal initiatives and interests are also determined by the longevity of the elected or appointed decision maker. Often federal administrators want to leave their stamp of influence on the programs they direct. Initiatives generated by such well intentioned directors are often 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 1970's (Tarjan, 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 organizations 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 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 (see Appendix G). 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 (HRS), 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 8, 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. The extent of the influence of funding obtained from legislation other than the DD Act is shown is Appendix K, Impact of Legislative Provision on UAPs. Not

only does the impact of the 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 and third generation programs. For other programs, the influence of health and education legislation is greater than the rehabilitation 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-Responsiveness

With the current emphasis on consumerism, it is easy to forget that the disability field has been responding to consumer pressures since the early 1960's. Even before then, it was the 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 1970's. 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 1980's, most had a single advisory or policy council with representation from consumers. During the last half of the 1980's, representatives from consumer organizations and members of the DDPC's were encouraged as consumer representatives, and more recently, the ADD has encouraged UAPs to place primary consumers on their boards and councils. Expanding consumer input and participation has been a growing trend over the last decade.

The nature and extent of consumer participation in UAPs today is shown in Table 12 on the following page. These data were obtained from a questionnaire and telephone interview conducted in the summer of 1994 in which 85 percent of the UAPs responded. In addition to the number of UAPs reporting that they provided worksite accommodation, information in alternate formats, and special accommodations, several indicated that these were available and would be provided when called for. These data suggest that UAPs have responded to the consumer empowerment provisions of recent legislation and the encouragement of funding agencies in a variety of ways.

The Technology Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-407) was the first law that mandated a **consumer-responsive** system. Eight UAPs were designated as their state lead agency to implement the provisions of the Tech Act. At least five other UAPs prepared their state application for Title I funding but submitted it through another state agency. These five UAPs and several others have subcontracted major portions of the Tech Act workscope (Hardy, 1994). The provisions of the Tech Act have brought additional attention to the consumer movement, helping to define and operationalize the concepts of **consumer representation**, **consumer participation**, and **consumer driven**. These concepts and definitions have been incorporated into the UAP programs participating in the Assistive Technology Programs, resulting in policy statements, consumer support services, and expanded efforts to involve consumers as shown in Table 12.

Table 12
Involvement of the UAP Network in Consumer Empowerment Activities

	Activity or Initiative	# of UAPs Reporting	%
1.	UAP's reporting a consumer empowerment or responsiveness position statement, policy, or initiative.	41	69
2.	UAP's with an advisory board or council made up of over 50% consumers.	39	66
3.	UAP's reporting a policy or procedure to facilitate recruitment of students and staff with disabilities which are in addition to or above that of the typical Affirmative Action policy of the university.	28	47
4.	UAP's that provide work site accommodations.	41	69
5.	UAP's reporting an assigned staff member responsible to facilitate consumer input participation in planning, implementation, and dissemination.	41	69
6.	UAP's reporting they provide information to consumers in alternate formats.	39	66
7.	UAP's reporting systematic technique for collecting information from consumers on planning new projects, conducting them, evaluating, or determining consumer satisfaction.	45	76
8.	UAP's providing special accommodations such as computers, special telephones, TDD's, transportation, secretarial services, and babysitting to compensate consumers who are involved in the governance of the center.	40	68

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 the 49 million 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 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. A telephone interview conducted during the summer of 1994 (85% of all UAPs participated) shows how programs are responding to ADA expectations as seen in Table 13.

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.

Table 13
The Involvement of the UAP Network
in ADA Implementation Activities

	Activity or Initiative	# of UAP's Reporting	%
1.	UAP's reporting a formal policy statement or philosophy expressing a commitment to ADA.	26	44
2.	UAP's reporting a direct working relationship with the state agency responsible to implement ADA at the state level.	32	54
3.	UAP's reporting they offer special workshops, course work, or outreach training on ADA.	35	59
4.	UAP's reporting that they develop and disseminate ADA resource material including fact sheets, newsletters, and provide information referral on ADA.	36	61
5.	UAP's reporting a regular assigned staff member serving as an ADA consultant or expert.	29	49
6.	UAP's reporting the availability of special equipment and expertise to provide information in alternate formats.	36	61

The 1990 Amendments to the Developmental Disabilities Act. P.L. 101-494 was signed into law one 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, 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. Appendix D presents a side-by-side of selected UAP language of the DD Act Amendments in the 1984, 1987, 1990, and 1994.

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 which was politically current, value-based programming, and the principles, the priorities, and implementation of ADA and consumer empowerment (Analysis of the recommendations of the 1992 UAP Review Panels). 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.

Although several Presidents have encouraged the appointment of people with disabilities as staff and directors of disability agencies, President Clinton moved

far beyond encouragement and made this a priority. Paul Miller, Director of the Office of Presidential Personnel in the White House, reported that as of February 3, 1994, people with disabilities filled 42 key administrative positions in programs and offices designed to meet the needs of people with disabilities. In addition, 11 other people with disabilities served on boards, commissions, and national councils (Report on Disabilities, 1994).

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 two 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 1990's, 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 have 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 different 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).

The 1994 Amendments to the Developmental Disabilities Act. By 1993, as the hearings started on the reauthorization of the Developmental Disabilities Act, opposition to the de-institutionalization 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 six 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.

The Future of UAPs

Over the last two decades, not only have there been changes in the philosophy, values, and best practices, but the popuation needing support and the types of services they need have also changed. Among the more significant of these changes has been the aging of the DD poplation (Shapiro, 1993). Survivors of head and spinal cord injury seek services and inclusion, and the disabling effects of substance abuse, violence, and AIDS are a growing societal concern. The impact of these issues and others not yet recognized, will be significant. Perhaps the need for UAPs today is greater than it was 30 years ago. However, the future of UAPs and the nature of their programming will be determined not only by the need and funding available, but also by how they respond to a variety of issues that are currently being debated.

Some of the issues and decisions discussed earlier in this paper identify trends that will certainly have a major impact. Some of these trends include program diversity, consumer responsiveness, response to the expectations of major UAP stakeholders, and multiple funding sources. In the following section, some of the key issues in the disability field are identified and discussed in terms of how they may impact the future of UAPs individually and as a network.

Developmental Disability Versus Disability. There has been much debate about the advantages and disadvantages of disregarding categories of disabilities and bringing the developmental disability system into the larger disability movement. New provisions and language in legislation strongly suggests that Congress is leaning in that direction. The 1994 Reauthoriation of the Developmental Disabilities Act included an option to drop the age of onset, which would significantly expand the population to be served. The implication of such a move will affect

UAPs in different ways. Some may need to change their focus. Others will be able to absorb such change easily, for they already have many programs that have a generic disability focus.

Inclusion. As previously pointed out, there is currently a growing controversy over the definition of inclusion and how it is to be implemented. Although this debate seems outside of the UAP network, it fractures the disability field, and UAPs are being pulled in different directions. It is difficult to determine what effect this may have. Most likely, inclusion will not remain a conceptual rallying point for long. Many can remember the galvanizing influence of other concepts such as **normalization, deinstitutionalization, mainstreaming,** and **community-based** services. Politically current terminology will most likely give way to yet another clarion call in the years to come.

The Consumer Movement. Consumer empowerment and the rise of consumer responsiveness is based on the premise that increased consumer participation and decision making will make services and support more relevant to consumer needs. Although this premise has great face validity, there is little empirical evidence on either side. What is effective in the business world where the consumer is free to choose, but must use their own resources, may not apply in the same way for publicly provided services that have restricted options. We may also find that consumer participation in some situations improved the quality and relevance of services significantly. In others, it may add little. Some UAPs have employed parents or consumers and assigned roles as an additional discipline or specialty. This may work well at an individual level where decisions directly affect the consumer. However, at the program level, issues such as representation, training, time commitment, and expertise need to be considered. In essence, many questions and practices have yet to be answered, and UAPs need to actively develop consumer empowerment models and evaluate their effectiveness.

Leadership. The expectation that UAPs would provide a leadership role was addressed in the first program description (DDD, 1972b). Leadership has been an ongoing expectation and a topic of

discussion for the past 30 years. Like many expectations, leadership is defined differently by different UAP stake holders. The university base for the program implies leadership through scholarship, research, training, discovery, challenge, and validation of new knowledge, techniques, and practices. MCH has consistently expected and required evidence that UAPs receiving Section 511 training funds prepare trainees to provide leadership in Title V programs.

Leadership was not included in the language of the DD Act or subsequent amendments until 1994 (P.L. 103-230). Consequently, the leadership expectations of the ADD have been less defined and have centered more around leadership in promoting the agencies' initiatives. Consumer organizations have also looked to UAPs to provide leadership for the initiatives they are promoting. Leadership of this nature is hard to separate from advocacy.

During the last several years, the ADD and consumer organizations have been critical of UAPs that have not aggressively championed consumer issues, including politically current language, rights, empowerment, commitment to inclusion, value-based programming, and implementation of the provisions of the ADA. The traditional academic freedom of university faculty to challenge, question, collect, and offer opposing data, has often been set aside in an effort to achieve a united front.

The leadership expectations of MCH and ADD (i.e., advocacy vs. administrative leadership) seem to be moving further apart. UAPs will need to find ways to reconcile not only these differences, but also the leadership expectations unique to university faculty (i.e., creativity, scholarship, and research). How this will be resolved or accommodated will be of major importance for the UAPs of the future.

Interdisciplinary Training. One of the significant characteristics of UAPs for the past 30 years has been their interdisciplinary nature. Although a great deal has been said in trying to define and explain what interdisciplinary is, it remains an elusive concept. In its broadest sense, interdisciplinary should be the mixture of minds and expertise, resulting in a synergistic outcome that improves the

effectiveness and relevance of service delivery. Unfortunately, research validating these assumptions, though voluminous, is by no means convincing. The issues identified more than 25 years ago by Dr. John Meier have not been adequately addressed (Meier, 1972). We do not know what value is added by the interdisciplinary process, nor do we know the best way or at what point to provide interdisciplinary training. Perhaps the most important unanswered question concerns the cost and benefits of interdisciplinary services. Interdisciplinary, like consumer outcomes, has often been treated as an end in itself rather than a means to an end. Furthermore, we seem to be mixing the interdisciplinary process with the multidiscipline teaming requested in the Education for Individuals with Disabilities Act (IDEA) and the new definition of mental retardation or the language of health care reform proposals.

The professional literature in organizational behavior research is extensive (Senge, 1990). This literature focuses on relationships, communication, and shared responsibility rather than the unique contributions or perspective of each discipline. The concept of teaming and eliminating the barriers between disciplines and administrative levels has been given little attention in UAPs (Keeran, personal communication, 1994). In the future, UAPs need to reexamine interdisciplinary program components to determine if they do add value and if they are cost-effective. We need to determine the best ways to achieve interdisciplinary training and how these presumed benefits will be maximized.

Legislative Expectations of UAPs. The last two reauthorizations of the Developmental Disabilities Act made some subtle yet important changes in the expectations of UAPs. This new language has increased the importance of technical assistance and dissemination, making the provision of exemplary services optional and placing greater emphasis on outreach training than on preservice interdisciplinary training.

Although a technical assistance workscope addresses an easy-to-identify need in the disability field, particularly a need recognized by constituency organizations and service agencies, in times of budget cuts and controlled spending, how will technical assistance activities compete

with exemplary services, research, and core training for resources? Will UAPs weaken their university-based underpinnings by becoming primarily public-supported consulting organizations? Will UAP faculty members who undertake such assignments at the expense of research and training be eligible candidates for rank and tenure promotions? To what extent is the university important as a base for future programs?

Repeated references are made to consumer outcomes and inclusion, the needs of racial and ethnic minorities, as well as cultural competencies of providers in the 1994 DD Act Amendments. In the past, such provisions have been addressed through special initiatives. However the language of the 1994 Amendments suggests these provisions must become ongoing components of every program, regardless of their location, their emphasis, or other objectives. Aside from using the appropriate language and expressing the values and commitments, it is unclear what the programmatic expectations of these values will be. How these changes are administratively addressed will have a major influence on UAPs in the future.

Perhaps the most important issue is who will address these questions, and how will decisions be made? Many UAP faculty members have let others, either within the UAP network or from other segments of the disability field, make decisions for them. If the UAP network is to remain strong and viable to emerging changes, UAP faculty must become involved participants in the decisions that affect the network as a whole. Characteristic of the first and second generation UAPs was that the directors and many of the staff made the UAP their career. As changes have occurred in the UAP leadership, some new UAP directors have invested their careers in other organizations and within their own disciplines. This leadership will be needed if the network is to influence decisions that concern its own future. The extent to which that is realized will depend on the attention to the items and issues addressed above.

The congressional election of 1994 sent shock waves through the human service field. The election results signaled, among other things, renewed determination on the part of legislators to (a) reduce the federal deficit, (b) decrease

dependency on public support, and (c) rescind regulations which allow little flexibility and few options. Although few can disagree with the principles or intent of the *Contract with America*, the way Congress proposes to achieve these ends has generated great concern. Much of the progress the disability field has experienced during the past 30 years has been made possible because advocates have appealed directly to the United States Congress and bypassed state legislators. Federal legislation has increasingly become prescriptive in an effort to compel states to make desired changes. Furthermore, much of the progress has been financed through federal deficit spending.

Clearly, the rules are changing, and new rules are just now being formulated. At this point, there is much controversy as to how such changes will be implemented. Proposed changes will generate conflict both within and outside of the disability field. Furthermore, the changes under consideration are dynamic with cross currents that will impact systems, individuals, and benefits in many ways, often with a cascading effect. Proposed changes themselves will be changed through the ongoing process of negotiations and the next election. How such issues are resolved will have a significant impact, not only on UAPs, but on the disability field as well.

Summary

The first program support to implement the expectations of UAPs was provided by MCH. As a result, health and medical issues were the first needs programmatically addressed. Furthermore, MCH has continued to be the single agency to provide the greatest amount of resources to the UAP network.

The primary concern of the first generation UAPs was health and allied health care for individuals with mental retardation. The critical shortage of trained personnel in these disciplines, and the need for coordination between clinical practice and field research received the initial programmatic attention in funding UAPs. Even though major personnel shortages existed in special education and rehabilitation, these agencies did not look to UAPs as eligible units to address these needs, and as a consequence, UAPs were seen throughout the 1970's and early 1980's as medically focused training programs.

The second-generation UAPs entered the network after 1975 and were more diverse. Few received MCH training support, and they tended not to be located in medical centers. Responding to the Developmental Disabilities Act, UAPs of the second generation developed and maintained close working relationships with the state service agencies and state DD planning counsels. Second-generation UAPs generally were smaller, had no facilities, and were required to seek support from any source available to provide the mandated programs. Leveraging core support took individual programs in many directions. This diversity can be seen as a strength, but it also presents many difficulties in defining outcomes, in describing the network, and defining common program criteria. The only time in the history of the UAP network that this dilemma did not exist, was during the first few years when the only program funds came from MCH training.

The supportive relationship between the ADD, the UAP network, and consumer organizations during the middle to late 1980s resulted in many changes in legislative service provisions. This set the stage for a new generation of UAPs.

Third-generation UAPs entering the network after 1987 were quite different than those entering earlier in that decade. Consumer issues were prominent on their agendas. Community-based services were the standard, and technical assistance, outreach training, and dissemination were emphasized more than interdisciplinary training, exemplary services, model programs, and leadership.

During the early 1990's consumer participation and satisfaction were emphasized more than scholarship. Dissemination was broadly defined to include more than publications. Technical assistance and outreach training received more attention than exemplary services, research, and interdisciplinary training. Consumer rights, outcomes, and values, all growing trends during the last decade, will each receive a great deal of attention in the future.

During the past 30 years, major changes have occurred in the disability field. The timeline presented in Appendix I identifies some of the changes that have

occurred in language, service settings, concepts, and best practices. As these changes have evolved, UAPs have often played an important role preparing training materials, disseminating information, and validating new techniques, practices or concepts through evaluation.

In 1976, the UAF Long-Range Planning Task Force concluded that:

Overall, the experience of a decade has proven the original UAF concept sound and has demonstrated beyond a doubt that the program concept is effective in meeting a significant social need (Tarjan, 1976, p. 49).

The report went further to add:

Experience...has validated each of the original program concepts state by the President's 1962 Panel: training models exemplifying a continuum of care, interdisciplinary training, UAFs as change agents, and incremental implementation and testing of the UAF concept...seed personnel...models of management, coordinated with training and research, exemplary services, and leadership training (Tarjan, 1976, p. 49).

Now, following 18 more years of experience, many additional evaluation studies and major changes in the philosophy and practices that address the needs of individuals with disabilities, we can surely add that not only was the original UAP concept sound, but the UAPs have survived and, indeed, thrived through tumultuous times. UAPs have evolved and changed as the field has grown with new techniques, values and emerging practices.

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APPENDICES

Information on Names of Organizations and Government Agencies and Acronyms Used in This Document

Acronym	Name	Comments
AAMD AAMR	American Association of Mental Deficiency American Association of Mental Retardation	The national organization of service providers and consumers concerned with mental retardation. The Association changed its name from Mental Deficiency to Mental Retardation in the mid-1980s.
AAUAP	American Association of University Affiliated Programs for Persons with Developmental Disabilities	The professional association changed its name from Association of University Affiliated Facilities to AAUAP in about 1974.
ACF	Administration on Children and Families ACF/OHDS/HHS	ACF is the organization to which ADD currently reports.
ADAUAFMR	Association of Director and Administrators of University Affiliated Facilities for the Mentally Retarded	This was the first unofficial professional organization representing UAFs.
ADD	Administration on Developmental Disabilities ADD/ACF/OHDS/HHS	ADD is currently the federal agency which administers the Developmental Disabilities Service and Bill of Rights Act. Previous names of this agency include DDD, 1972; DDO, 1977. The name was changed from DDO to ADD in 1980.
AUAF	Association of University Affiliated Facilities	This was the first name of the professional organization established in 1969.
BEH	Bureau of Education of the Handicapped BEH/OE/HEW	The federal agency which first administered federal funds for special education services and special education teacher training. BEH reported directly to the U.S. Office of Education in HEW. When Education was elevated to cabinet level under the Carter Administration, it was renamed Office of Special Education Programs (OSEP).
CB	Children's Bureau	The Children's Bureau was originally established by statute in 1912. Later it included the Maternal and Child Health and Crippled Children's Program "Services" which provided Title V of the Social Security Act Services for Children with Mental Retardation. CB was moved to Social and Rehabilitation Services in 1967. MCH and CCS were returned to U.S. Public Health Services under HSMHA. In 1970 CB was transferred to the Office of Child Development (OCD).

Acronym	Name	Comments
CCS	Crippled Children's Program (Service)	The federal agency that administered in mental retardation clinical service programs as part of Title V of the Social Security Act. CCS was originally in the Children's Bureau and transferred to the Public Health Service in 1967 along with MCH.
CEC	Council of Exceptional Children	Professional organization of special education teachers and administrators.
DD	Developmental Disabilities	DD is defined in the DD Act (P.L. 103-230) and accompanying amendments.
DMR DDD DDO	Division of Mental Retardation Division of Developmental Disabilities Developmental Disabilities Office	The federal agency administering mental retardation and UAF programs. The DMR was moved to the Rehabilitation Service Administration under Social and Rehabilitative Services in 1967. In 1971 it was changed to DDO. In 1973 it was changed to DDO reporting to the new Office of Human Development, and in 1980 it was changed to Administration on Developmental Disabilities.
DoEd	U.S. Department of Education	Established by President Carter in 1980, breaking up HEW into the Department of Education and the Department of Health and Human Services.
HSMHA	Health Services and Mental Health Administration	The federal agency under the U.S. Public Health Service which administered MCH and CCS after 1967. The HSMHA was later divided into the Substance Abuse and Mental Health Services Administration (SAMHSA).
MCH	Maternal and Child Health (Service Bureau Division)	The federal agency which administers Section V of the Social Security Act. MCH was originally in the Children's Bureau, transferred to HSMHA in the Public Health Services in 1967. MCH currently administers Section 511 training for UAPs and was recently been elevated to a bureau.
MRB	Mental Retardation Branch	The federal agency under the Division of Chronic Disease in Public Health Services, responsible for construction and later support for UAFs. The branch was elevated to the Division of Mental Retardation (DMR) in 1967 and in 1971 became the Division of Developmental Disabilities.
NARC	National Association of Retarded Children	The primary parent constituency organization that actively pursued legislation during the 1950's through the 1990's. The name was changed to ARC in the middle 1980s, and recently to "The Arc."

Acronym	Name	Comments
NICHD	National Institute of Child Health and Development	One of the national institutes administered by the National Institute of Health focusing on child development and responsible for the mental retardation research centers.
NIH	National Institute of Health	The federal agency which administers the research and study arm of the U.S. Department of Health and Human Services.
OHD(S)	Office of Human Development (Services)	The federal administering agency to which ADD reported prior to 1993.
OSERS	Office of Special Education and Rehabilitation Services	When President Carter established the Department of Education in 1978, Special Education, Rehabilitation, and the National Institute on Rehabilitation Research were placed together under the Assistant Secretary of the Office of Special Education and Rehabilitation Services.
PCMR	President's Committee on Mental Retardation	President Johnson established by executive order the PCMR. This replaced the President's Panel on Mental Retardation and the Secretary's Committee on Mental Retardation.
PHS	Public Health Service	This is the major health branch of HEW, and later was transferred to the U.S. Department of Health and Human Services.
RSA	Rehabilitation Service Administration	This federal agency was established in 1967 to administer the vocational rehabilitation service program. In the early 1970's, the DMR and later the DDD was placed under RSA with Dr. Ed Newman as Commissioner, who later became the Director of the Temple University UAP in Philadelphia.
SRS	Social and Rehabilitation Services	In 1967 SRS was organized as the federal administering agency within HEW to administer programs for dependent people--the aging, handicapped, etc. Mary Switzer was the first Director. The Division of Mental Retardation was placed under Rehabilitation Service Administration administered by Ed Newman.
UCPA	United Cerebral Palsy Association	National constituency organization for parents and others interested in promoting improved services for persons with cerebral palsy. Under Dr. Elsie Helsus, UCPA played a major role in early education coalitions for developmental disabilities.

UAFs Which Are Currently or Have Been Members of the National Network, When They Were Funded, and Source of Funding

UAF/UAP	First Generation 1964-1974		Second Generation 1975-1986		Third Generation 1987-1994	
	MCH	DD	MCH	DD	MCH	DD
Civitan International Research Center U of A Birmingham, AL (1966)*	1967	1972	X	X	X	X
U of A Tuscaloosa, AL* (Not funded by MCH or DD; dropped 1970)						
Center for Human Development U of A Anchorage, AK						1991
Institute for Human Development N A U Flagstaff, AZ						1990
Dine Center N C C Tsaile, AZ				Satellite 1979		Dropped 1989
University Affiliated Program U of AR Little Rock, AR						1989
MR Developmental Disabilities Program U of C Los Angeles, CA (1968)*	1971	1972	X	X	X	X
University Affiliated Training Program U S C Los Angeles, CA	1970	1972	X	X	X	X
Clinical Genetics in DD U of C Irvine, CA		1974		Dropped 1984		

*Programs with construction funds under P.L. 88-164

**DD Support for projects of national and regional significance

***Names of centers and components have changed

UAF/UAP	First Generation 1964-1974		Second Generation 1975-1986		Third Generation 1987-1994	
	MCH	DD	MCH	DD	MCH	DD
JFK Center for DD U of C Denver, CO (1966)*	1968	1972	Dropped 1981	X		X
A.J. Pappaniku Center on Special Education & Rehabilitation U of C So. Windsor, CT						Satellite 1987 Full UAP 1991
University of Delaware UAP U of D Newark, DE						1993
Georgetown University Child Development Center Georgetown University Washington, D.C. (1970)*	1969	1972	X	X	X	X
Mailman Center for Child Development U of M Miami, FL (1966)*	1968	1972	X	X	X	X
Georgia UAP for Persons with DD U of G Athens, GA (1967)*		1972		X		X
Georgia Mental Retardation Center Atlanta, GA (1967)*		1972		X		Dropped 1987
Hawaii UAP for DD U of H Honolulu, HI			1980 Satellite		1983 Dropped	Full UAP 1988
Idaho Center on DD U of I Moscow, ID						Satellite 1988 Full UAP 1993
Center on Disability & Human Development U of I at Chicago Chicago, IL						1990
Illinois Institute for DD Chicago, IL (Dropped in 1986. Never recognized by MCH or DD)						

UAF/UAP	First Generation 1964-1974		Second Generation 1975-1986		Third Generation 1987-1994	
	MCH	DD	MCH	DD	MCH	DD
Riley Child Development Center I U Indianapolis, IN (1970)*	1970	1972	X	X	X	X
Institute for the Student of DD I U Bloomington, IN (1970)*		1972		X		X
Iowa University Affiliated Program U of I Iowa City, IA				1975	1993	X
Institute for Life Span Studies U of K Lawrence, KS		1972		X		X
Institute for Life Span Studies U of K Kansas City, KS (1968)*	1969	1972	X	X	X	X
Institute for Life Span Studies U of K Parsons, Kansas (1968)*		1972		X		X
Human Development Institute U of K Lexington, KY		1972		X	1992	X
Human Development Center L S U New Orleans, LA				1977		X
Center for Community Inclusion U of M Orono, ME						1992
Kennedy Krieger Institute Johns Hopkins University Baltimore, MD (1967)*	1967	1972	X	X	X	X
Developmental Evaluation Center Children's Hospital Boston, MA (1967)*	1969	1972	X	X	X	X
Eunice Shriver Center Waltham, MA (1967)*	1970	1972	X	X	X	X

UAF/UAP	First Generation 1964-1974		Second Generation 1975-1986		Third Generation 1987-1994	
	MCH	DD	MCH	DD	MCH	DD
Institute for Study of MR U of M Ann Arbor, MI	1971	1972	Dropped 1980	Dropped 1982		
DD Institute Wayne State University Detroit, MI				1983		
Institute on Community Integration U of M Minneapolis, MN						Satellite 1989 Full UAP 1990
Institute for Disability Studies U of So. MS at Hattysburg Hattysburg, MS				1975		X
Mississippi UAP Dept of Mental Health Jackson, MS				1975		Dropped 1990
Institute for Disability Studies U of MS Oxford, MS				1975		Dropped
Institute for Human Development U of M Kansas City, MO				1982		X
University of Missouri Columbia, MO		1972		Dropped 1975		
University of St. Louis St. Louis, MO		1972		Dropped 1975		
Rural Insitutue on Disabilities U of M Missoula, MT				1979 Satellite		1987 Full UAP
Myer Rehabilitation Institute (Initially funded as MCH demonstration Program) U of N Omaha, NB	1972	1972	X	X	X	X
University Affiliated Program U of N Reno, NV						1991

UAF/UAP	First Generation 1964-1974		Second Generation 1975-1986		Third Generation 1987-1994	
	MCH	DD	MCH	DD	MCH	DD
Institute on Disability U of New Hampshire Durham, NH				1986	1993	
Institute for Child Study Newark State College Union, NJ		1972		Dropped 1980		
Institute of Child Study Kane College Union, NJ		1972		Dropped 1984		
Robert Wood Johnson Medical School Piscataway, NJ				1986		
New Mexico UAP U of NM Albuquerque, NM			1981		Dropped 1984	1990 Full UAP
Rose F. Kennedy Center (Initially funded as an MCH demonstration program) Yeshiva University Bronx, NY	1966	1972	X	X	X	X
Strong Center for DD U of Rochester Rochester, NY				1969 Satellite 1979		1988 Full UAP
Westchester Institute for Human Development New York Medical School Valhalla, NY (1966)*	1968	1972	X	X	X	X
Clinical Center for the Study of Development and Learning U of NC Chapel Hills, NC (1966)*	1967	1972	X	X	X	X
No. Dakota Ctr for Disabilities Minot State Univ Minot, ND						1990
Nisonger Center O S U Columbus, OH (1966)*	1968	1972	X	X	X	X
UAP Cincinnati Center for DD Cincinnati, OH (1970)*	1967	1972	X	X	X	X

UAF/UAP	First Generation 1964-1974		Second Generation 1975-1986		Third Generation 1987-1994	
	MCH	DD	MCH	DD	MCH	DD
UAP for Human Development O U Athens, OH (Planning grant from DD never funded)				1981 Dropped 1986		
UAP of Oklahoma U of O Oklahoma City, OK						1992
Center on Human Development U of O Eugene, OR (1970)*		1972		X		X
Child Development and Rehabilitation Center Oregon Health Science Univ Portland, OR (1970)*	1967	1972	X	X	X	X
Pacific Basin UAP U of H Honolulu, HI ****				1980 Satellite Dropped 1984		1988 Full UAP
Children's Seashore House U of P Philadelphia, PA					1991	
Institute on Disabilities Temple University Philadelphia, PA				1977		X
DD Institute University of Puerto Rico San Juan, PR						1992
Department of Special Education Rhode Island College Providence, RI						1993
So. Carolina UAP U of SC Columbia, SC				1975		X

**** The University of Hawaii received a special appropriation to help develop UAP services and programs in the South Pacific.

UAF/UAP	First Generation 1964-1974		Second Generation 1975-1986		Third Generation 1987-1994	
	MCH	DD	MCH	DD	MCH	DD
University Affiliated Program Winthrop College Rockhills, SC				1977 Satellite 1982 Dropped		
So.Dakota UAP U of SD Vermillion, SD		1973		X	1992	X
Boling Center for Developmental Disabilites U of T Memphis, TN (1968)*	1966	1972	X	X	X	X
Center for Persons with Disabilities USU Logan, UT (1972)*		1972		X		X
Center for DD, U of V Burlington, VT				1979 Satellite		1988 Full UAP
Virginia Institute for DD Virginia Commonwealth University Richmond, VA						Satellite 1988 Full UAP 1990
Child Development and Mental Retardation Center U of W Seattle, WA (1969)*	1969	1972	X	X	X	X
University Affiliated Center for DD of West Virginia Morgantown, WV				1979	1991	X
University Affiliated Center Southwest Medical School Dallas, TX (never recognized by ADD)			1975 Dropped 1982			
Texas UAP U of T Austin, TX						1989
Waisman Center U of W Madison, WI (1969)*	1969	1972	X	X	X	X

UAFs Funded for Special Initiatives Under Projects of National and Regional Significance by Developmental Disabilities Office or Regional Offices Between 1974 - 1979

Name of the UAF	Initiation - Project Title	Contact Person	Period	Annual Level of Funding
Kansas University Affiliated Facility, University of Kansas Kansas City, Kansas	Advocacy Mid-central Legal Center for the Developmentally Disabled	William J. Dittmeier	1 October 1977- 30 September 1988	$88,519
Georgia Retardation Center Athens Unit Athens, Georgia	Aged and Aging Community Alternatives to Institutionalization for the Elderly Developmentally Disabled in North Georgia	Jane Rhoden	30 September 1976- 29 September 1979	$50,027
Institute for the Study of MR and Related Disabilities University of Michigan Ann Arbor, Michigan	Aged and Aging Serving Aging and Aged Developmentally Disabled People	Robert Seagal	30 September 1976- 29 September 1979	$50,000
Exceptional Child Center Utah State University Logan, Utah	Aged and Aging Program Outreach for the Aging and Aged Developmentally Disabled	Alan Hofmeister	1 October 1977- 30 September 1979	$55,389
Child Development and Rehabilitation Center University of Oregon Health Science Center Portland, OR	Aged and Aging University Affiliated Training Project About Aging Developmentally Disabled Persons	LeRoy Carlson	1 October 1976- 1 October 1969	$50,000
Rose F. Kennedy Center Yeshiva University Bronx, New York	Alternatives/Independent Living Rehabilitation of Severely Retarded Adults	Herbert Cohen	1 September 1975- 29 August 1976	

Name of the UAF	Initiation - Project Title	Contact Person	Period	Annual Level of Funding
University Affiliated Facility UCLA Los Angeles, California	Case Management Systems Individualized Database	Herb Grossman Richard Eyman	15 August 1976- 14 August 1979	$427,775
Meyer Children's Rehabilitation Institute University of Nebraska Omaha, Nebraska	De-institutionalization Community Alternative Service Systems Project	Hans Brisch	30 June 1975- 30 June 1978	$188,618
University Hospital School University of Iowa Iowa City, Iowa	Dental Services	Arthur Nowalk	30 September 1977- 29 September 1981	$93,425
University Affiliated Center for Developmental Disorders University of Cincinnati Cincinnati, Ohio	Coordination of Services UAF Consortium Media Project	George Vesprani	1 October 1977- 30 September 1980	$66,328
John F. Kennedy Child Development Center University of Colorado Denver, Colorado	Coordination of Services Coordinated Interagency Model	William Frankenburg	30 September 1977- 29 September 1980	$53,618
College of Medicine and Dentistry Rutgers Medical School Piscataway, New Jersey	Juvenile & Adult Offenders	Frank Schneider	1 October 1977- 30 September 1980	$67,599
University Affiliated Program for Child Development Georgetown University Washington, D.C.	Juvenile & Adult Offenders Interdisciplinary Training and Technical Assistance for the Identification and Evaluation and Intervention of the Developmentally Disabled Youth Offender	Phyllis McGrab	3 Years	$154,931

Name of the UAF	Initiation - Project Title	Contact Person	Period	Annual Level of Funding
Institute for the Study of Mental Retardation and Related Disabilities University of Michigan Ann Arbor, Michigan	Needs Assessment Technical Assistance in Training Developmentally Disabled Personnel	Eugene Handley	30 September 1976- 29 September 1979	$103,042
Waisman Center on Mental Retardation and Human Development University of Wisconsin Madison, Wisconsin	Needs Assessment Survey of Needs of Non-Institutionalized Adults with Developmental Disabilities	Robert Erickson	30 September 1976- 29 September 1979	$54,160
Nisonger Center for Mental Retardation Ohio State University Columbus, Ohio	Planning, Monitoring, and Evaluation	Jerry Adams	1 October 1976- 30 September 1979	$90,000
Waisman Center University of Wisconsin Madison, Wisconsin	Public Awareness Regional Developmental Disabilities Program Information Center	Robert Erickson	30 June 1975- 29 June 1978	$150,662
University Affiliated Facilities Program University of South Carolina Columbia, South Carolina	Recreation and Leisure-Time Activities Recreation for the Developmentally Disabled	Gary Withers	30 September 1977- 30 September 1980	$55,543
Division of Disorders of Developmental and Learning University of North Carolina Chapel Hill, North Carolina	Recreation and Leisure Region-wide Training in Recreation and Leisure-Time Needs of Developmentally Disabled Youth and Adults	George Barrof	30 September 1977- 29 September 1980	$66,963
Child Development and Rehabilitation Center University of Oregon Health Science Center Portland, Oregon	Recreation and Leisure Demonstration and Training Project, Recreation/Leisure Time for Physically Handicapped and Mentally Retarded Adolescents/Young Adults	John Keiter	1 October 1977- 30 September 1980	$49,909

Name of the UAF	Initiation - Project Title	Contact Person	Period	Annual Level of Funding
Georgia Retardation Center University of Georgia Athens, Georgia	Rural Develop a Descriptive Model for the Education of Developmentally Disabled Pre-school Children in Rural Areas	Mahalah Harrison	3 Year Project	$58,791
The Developmental Training Center University of Indiana Bloomington, Indiana	Rural Indiana Home Teaching System: A Comprehensive Service Model for Rural Areas	E. C. Brown	1 October 1977-30 September 1980	$75,600
Child Development and Mental Retardation Center University of Washington Seattle, Washington	Rural A Model for Development of Services for the Developmentally Disable in Rural and Remote Areas	Margaret Mykut	1 October 1976-30 September 1979	$74,609
Division of Disorders of Developmental Learning University of North Carolina Chapel Hill, North Carolina	Technical Assistance Consultation to the Developmental Councils	Ron Wiegerink	1 October 1976-30 September 1978	$612,674
Developmental Training Center Indiana University Bloomington, Indiana	Technical Assistance Advocacy, and Planning for Developmentally Disabled Consumers	John Ryan	30 September 1976-29 September 1979	
John F. Kennedy Institute Johns Hopkin University Baltimore, Maryland	Technical Assistance Enhancement of Region III Capability to Provide Training and Technical Assistance for Developmental Disability Councils	A. R. Hartgrove	1 October 1976-30 September 1978	$87,874
University Affiliated Program University of Mississippi Jackson, Mississippi	Technical Assistance Mississippi Division of Mental Retardation University Affiliated Program Training Technical Assistance Project	Larry Grantham	30 September 1976-29 September 1979	$92,654

Name of the UAF	Initiation - Project Title	Contact Person	Period	Annual Level of Funding
Division of Disorders of Development and Learning University of Northern Carolina Chapel Hill, No. Carolina	Technical Assistance Regional Technical Assistance and Training in Developmental Disabilities	George Baroff	30 September 1977- 29 September 1980	$89,880
UAF Program of South Carolina University of South Carolina Columbia, South Carolina	Technical Assistance Statewide Technical Assistance and Training Project	Mary Atkinson	30 September 1977- 30 September 1978	$154,728
Division of Disorders of Development and Learning University of North Carolina Chapel Hill, No. Carolina	Technical Assistance Technical Assistance to Region IV	Ron Neufeld	30 September 1977- 29 September 1980	$117,868
Institute for the Study of Mental Retardation and Related Disabilities University of Michigan Ann Arbor, Michigan	Technical Assistance Regional Training and Technical Assistance in Human Fulfillment	Martha Dickerson	1 October 1977- 30 September 1980	$107,986
Ohio University Center for Human Development Ohio University Athens, Ohio	Technical Assistance Triage Assessment Placement and Programming Systems Technical Assistance Project	Elsie Helsel	1 October 1977- 30 September 1980	$95,000
Developmental Disabilities Center for Children Louisiana State University New Orleans, Louisiana	Technical Assistance Regional Training and Technical Assistance	Judith Harris	30 September 1976- 29 September 1979	$88,333
Kansas University Affiliated Facility University of Kansas Lawrence Kansas	Technical Assistance Training and Technical Assistance for De-institutionalization	Jim Budde	30 June 1975- 29 June 1978	$199,702

Name of the UAF	Initiation - Project Title	Contact Person	Period	Annual Level of Funding
Center for Developmental and Learning Disorders University of Alabama Birmingham, Alabama	Training Proposal for a Network of Continuing Education Centers for Managers of Agencies Serving the Developmentally Disabled	William Carove	30 September 1977- 30 September 1980	
University Affiliated Center West Virginia University Morgantown, W. Virginia	Training Prescriptive Behavior Checklist for Severely Retarded	Ranjet K. Majumber	30 June 1975- 29 June 1978	$30,168
University Affiliated Center West Virginia University Morgantown, West Virginia	Training De-institutionalized Model Training Program for Teachers and Parents of Severely Disabled Adolescents	Ranjet K. Majumber	1 October 1976- 30 September 1979	$126,170
The Waisman Center for Mental Retardation University of Wisconsin Madison, Wisconsin	Training Training Advocates to Work with Developmentally Disabled Clients	Robert Erickson	1 September 1977- 31 July 1980	$50,000
Kansas University Affiliated Facility University of Kansas Lawrence Kansas	Training Developmental Disabilities Management Specialty Training	James Budde	30 September 1977- 21 September 1981	$48,492
University Affiliated Program UCLA Los Angeles, California	Training Capacity Building for Administration of Developmental Disability Services	George Tarjan	1 September 1976- 31 August 1978	$29,399
Child Development and Rehabilitation Center University of Oregon Portland, Oregon	Training Developmental Disabilities Workshop for State Planning Council Members in Region X	LeRoy Carlson	1 September 1976- 31 August 1979	$17,857
University Affiliated Program UCLA Los Angeles, California	Training Advocacy Training for Head Start Staff	Andrew Pollard	1 September 1976- 31 August 1977	

Name of the UAF	Initiation - Project Title	Contact Person	Period	Annual Level of Funding
John F. Kennedy Center University of Colorado Denver, Colorado	Exemplary Services A Coordinated Screening, Diagnosis, and Treatment Program for Developmentally Handicapped Children	William Frankenburg	1 October 1976- 30 September 1979	$125,881
Nisonger Center for Mental Retardation Ohio State University Columbus, Ohio	Coordination of Services Region V University Affiliated Program (UAP) Consortium Project	Ronald Kozlowski	30 September 1976- 29 September 1979	$70,000
Institute for the Study of Mental Retardation and Related Disabilities University of Michigan Ann Arbor, Michigan	Vocational Services Vocational Service Component Expansion	Kevin Lynch	30 June 1975- 30 June 1978	$94,036
Center of Human Development University of Oregon Eugene, Oregon	Vocational Training Increasing Efficiency of Vocational Training for the Severely Retarded	Thomas Bellamy	1 July 1974- 30 September 1977	$10,000
Child Development and Mental Retardation Center University of Washington Seattle, Washington	Vocational Rehabilitation Services Child Development and Mental Retardation Center Vocational Service Project	Irvin Emanuel	1 April 1975- 30 April 1978	$34,928
Center on Human Development University of Oregon Eugene, Oregon	Habilitation Training Regional Training Program in Habilitation of the Developmentally Disabled	Robert Schwarz	1 September 1976- 31 August 1979	$95,000

Selected Language Concerning UAPs in the Last Four Reauthorizations of the Developmental Disabilities Act

1984 Amendments P.L. 98-527	1987 Amendments P.L. 100-146	1990 Amendments P.L. 101-496	1994 Amendments P.L. 103-230
FINDINGS AND PURPOSE, Section 101			Section 101, Funding, Purpose and Policy
"Section 101.(b)..."(C) to make grants to States and public and private, non-profit agencies to establish model programs, to demonstrate innovative habilitation techniques, and to train professional and paraprofessional personnel with respect to providing services to persons with developmental disabilities; "(D) to make grants to university affiliated facilities to assist them in administering and operating demonstration facilities for the provision of services to persons with developmental disabilities and interdisciplinary training programs for personnel needed to provide specialized services for these persons;..." COMMENTS: The 1984 amendments of the DD Act reflect the purpose of UAPs in a manner similar to that described in 1972 (i.e., establishing a model program to demonstrate innovative techniques and to provide training for professionals and paraprofessionals. The purpose of the grant was to assist in providing administrative and operating funds.	"Sec. 101.(b)..."(1)...to assure that all persons with developmental disabilities receive the services and other assistance opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity, and integration into the community... "(2) to enhance the role of the family in assisting developmental disabilities to achieve their maximum potential..." COMMENTS: The 1987 amendments added to the purpose the assurance that all persons with disabilities will receive services and assistance to maximize their potential and added the consumer outcomes of productivity, independence, and integration into the community. The purpose also added enhancing the role of the family to the purpose of the act.	"Sec. 101.(b)...(3) to provide interdisciplinary training and technical assistance to professionals, paraprofessionals, family members and individuals with developmental disabilities; (4) to advocate for public policy change and community acceptance of all people with developmental disabilities... (5) to promote the inclusion of all persons with developmental disabilities... COMMENTS: The 1990 Amendments added three more purposes to the UAP language (1) interdisciplinary training and technical assistance not only for professionals and paraprofessionals, but also family members and individuals with disabilities; (2) advocacy for policy change; and (3) the promotion of inclusion.	"Section 101.(b)...(3) to provide interdisciplinary training and technical assistance to professionals, paraprofessionals, family members, and individuals with developmental disabilities;..." "(c) POLICY.--It is the policy of the United States that all programs, projects, and activities receiving assistance under this Act shall be carried out in a manner consistent with the principles that-- (1) individuals...including the most severe...are capable...; (2) individuals...and families...have competencies and capabilities...unique strengths...; (3) individuals..family members are the primary decision makers...; (4) services, supports, and other assistance are provided in a manner that demonstrates respect for individual dignity, person preference, and cultural differences; (5) ...efforts must be made to ensure...ethnic minority backgrounds enjoy effective and meaningful opportunities...; (6) recruitment...must focus on bringing larger numbers of racial and ethnic minorities into the field...; (7)...communities that are responsive...are enriched by full and active participation...of individuals with disabilities and their families; and (8) individuals...have access to opportunities and the necessary support to be included in community life..." COMMENTS: Under purpose, the 1994 Amendments simply clean up the language of previous amendments. The new section on policy states the values and the beliefs, setting the framework for value-based programming.

1984 Amendments P.L. 98-527	1987 Amendments P.L. 100-146	1990 Amendments P.L. 101-496	1994 Amendments P.L. 103-230
DEFINITIONS, Section 102			
"Sec. 102..."(13) The term university affiliated facility means a public or nonprofit facility which is associated with, or is an integral part of, a college or university and which provides for at least the following activities: "(A) Interdisciplinary training for personnel concerned with developmental disabilities which is conducted at the facility and through outreach activities; "(B) Demonstration of-- "(i) exemplary services relating to persons with developmental disabilities in settings which are integrated in the community; and "(ii) technical assistance to generic and specialized agencies to provide services to increase the independence, productivity, and integration into the community of persons with developmental disabilities, such as the development and improvement of quality assurance mechanisms. "(C)(i) Dissemination of findings relating to the provision of services under subparagraph (B) of this paragraph, and (ii) providing researchers and government agencies sponsoring service-related research with information on the needs for further service-related research which would provide data and information that will assist in increasing the independence, productivity, and integration into the community of persons with developmental disabilities...	"Sec. 102..."(18) The term 'university affiliated program' means a program operated by a public or nonprofit private entity, including parents of persons with developmental disabilities, professionals, paraprofessionals, students, and volunteers, which is associated with, or is an integral part of, a college or university and which provides for at least the following activities;..." [The remaining language defining the activities of UAPs was the same as the 1984 Amendments.] COMMENTS: The 1987 Amendments added to the definition of the UAP an entity that includes parents of persons with developmental disabilities, professionals, paraprofessionals, students, and volunteers. Note also that in 1987 the amendments changed the name from a University Affiliated Facility to a University Affiliated Program.	"Sec. 102..."(18) The term "university affiliated program" means a program operated by a public or nonprofit private entity which is associated with, or is an integral part of a college or university and which provides for at least the following activities: (A) Interdisciplinary training for personnel concerned with developmental disabilities, including parents of persons with developmental disabilities, professional, paraprofessionals, students, and volunteers, which is conducted at a facility and through outreach activities. (B) Demonstration of--..." [The remaining language in defining UAPs was the same as in 1987.] COMMENTS: In the 1990 Amendments the words "entity, including parents of persons with developmental disabilities, professionals, paraprofessionals, students, and volunteers" was dropped from the term "university affiliated program" and put under "interdisciplinary."	"Sec. 102..."(30) UNIVERSITY AFFILIATED PROGRAMS.--The term 'university affiliated program' means a university affiliated program established under section 152." COMMENTS: The 1994 Amendments provided clarification of language in previous amendments.

1984 Amendments P.L. 98-527	1987 Amendments P.L. 100-146	1990 Amendments P.L. 101-496	1994 Amendments P.L. 103-230
Part D - UNIVERSITY AFFILIATED PROGRAMS - Purpose			
"Purpose - "Sec. 151. The purpose of this part is to provide for grants to university affiliated facilities to assist in the provision of interdisciplinary training, the conduct of service demonstration programs, and the dissemination of information which will increase and support the independence, productivity, and integration into the community of persons with developmental disabilities.	"Purpose - "Sec. 151. The purpose of this part is to provide for grants to university affiliated programs to assist in the provision of interdisciplinary training, the demonstration of exemplary services and technical assistance, and the dissemination of information which will increase and support the independence, productivity, and integration into the community of persons with developmental disabilities. COMMENTS: The 1987 Amendments changed the language which specifies that UAPs would conduct service demonstration programs, that they would demonstrate exemplary service and technical assistance programs. This is a very significant change, for initially, UAPs were expected to conduct and/or operate exemplary service programs. After 1987, the expectation was to demonstrate which could be addressed in a number of ways, including associations with exemplary service programs. Also added was the expectation of technical assistance.	"Purpose - Sec. 151. The purpose of this part is to provide for grant to university affiliated programs to assist in the provision of interdisciplinary training, the demonstration of exemplary services and technical assistance, and the dissemination of information which will increase and support the independence, productivity, and integration in the community of persons with developmental disabilities.	"Sec. 151. PURPOSE AND SCOPE OF ACTIVITIES The purpose of this part is to provide for grants to university affiliated programs that are interdisciplinary programs operated by universities, or by public or nonprofit entities associated with a college or university, to provide a leadership role in the promotion of independence, productivity, and integration and inclusion into the community of individuals with developmental disabilities through the provision of the following activities, which are conducted in a culturally competent manner: (1) Interdisciplinary preservice preparation of students and fellows, including the preparation of leadership personnel. (2) Community service activities that shall include community training and technical assistance for or with individuals with developmental disabilities, family members of individuals with developmental disabilities, professionals, paraprofessionals, students, and volunteers. Such activities may include state-of-the-art direct services including family support, individual support, personal assistance services, educational, vocational, clinical, health, prevention, or other direct services. (3) Dissemination of information and research findings, which may include the empirical validation of activities relevant to the purposes described in paragraphs (1) and (2) and contributions to the development of new knowledge in the field of developmental disabilities." COMMENTS: The 1994 language includes the expectations that UAPs will provide a leadership role in promoting independence, productivity, and inclusion. Preservice interdisciplinary training is added as an expectation, including the preparation of leadership personnel, and community service activities includes training and technical assistance. The expectation that UAPs would provide direct service is listed as optional. Additional language is added to describe research findings which include empirical validation of activities relevant to dissemination.

1984 Amendments P.L. 98-527	1987 Amendments P.L. 100-146	1990 Amendments P.L. 101-496	1994 Amendments P.L. 103-230
Part D - UNIVERSITY AFFILIATED PROGRAMS - Grant Authority			
"Grant Authority - "Sec. 152.(a) From appropriations under section 154, the Secre-tary shall make grants to university affiliated facilities to assist in the administration and operation of the activities described in section 102(13). "(b) The Secretary may make one or more grants to a university affiliated facility receiving a grant under subsection (a) to sup-port one or more of the following activities... (A) a study of the feasibility of establishing a university affiliated facility or a satellite center in an area not served by a university affiliated facility...	"Grant Authority - "Sec. 152. (a)...to assist in the administration and operation of the acti-vities described in section 102(18). "(b) (1) (A) (a) to support training projects to train personnel to address the needs of per-sons with developmental disabilities in areas of emerging national significance, particularly projects to train personnel in the areas of early intervention programs (as described in para-graph (2)), programs for elderly persons with developmental disabilities (as described in paragraph (3)), and community-based service programs (as described in paragraph (4))... COMMENTS: The 1987 Amendments added additional grant authority to support training projects in early intervention, elderly, and community-based service programs (paraprofessionals).	"Grant Authority - Sec. 152.(a)..." [Same as 1987.] "...(b)(1)(A) From amounts appropriated under section 154(b), the Secretary shall make grants to university affiliated programs receiving grants under subsection (a) to support training projects to train personnel to address the needs of persons with de-velopmental disabilities in areas of emerging na-tional significance, particularly...early inter-vention...elderly persons with developmental dis-abilities...community-based service programs... positive behavior management programs...and pro-grams in other areas of national significance as de-termined by the university affiliated program in con-sultation with the State Planning Council (as described in paragraph (7)). (B)(i) Grants awarded under this subsection shall be in the amount of $90,000... (D) The Secretary shall require appropriate technical and qualitative peer review of applications for assistance... (i) The university affiliated program shall present evidence that core training assisted by funds awarded under this section is-- (I) competency and value based; (II) designed to facilitate independence, productivity and integration for persons with developmental disabilities; and (III) evaluated utilizing state of the art evaluation techniques in the programmatic areas selected. (ii) Core training shall-- (I) represent state-of-the-art techniques (II) be conducted in consultation with the citizens advisory group ... and the state develop-mental disabilities planning council; (III) be integrated into the appropriate uni-versity affiliated program and university curriculum; (IV) be integrated with relevant state agencies... (V)...be conducted in environments where services are actually delivered;..."	"Sec. 152. GRANT AUTHORITY. (a) ADMINISTRATION AND OPEHATIONS.--From appropriations under section 154(a), the Secretary shall make grants to university affiliated programs to assist in the administration and operation of the activities described in section 151. Grants may be awarded for a period not to exceed 5 years. (b) TRAINING PROJECTS.-- (1) IN GENERAL.--From amounts appropriated under section 156(a), the Secretary shall make grants to university affiliated programs receiving grants under subsection (a) to support training projects to train personnel to address the needs of individuals with developmental disabilities in areas of emerging national significance, as described in paragraph (3). Grants awarded under this subsection shall be awarded on a competitive basis and may be awarded for a period not to exceed 5 years.... (3) AREAS OF FOCUS.--... (A) EARLY INTERVENTION... (B) AGING... (C) COMMUNITY SERVICES... (D) POSITIVE BEHAVIORAL SUPPORTS... (E) ASSISTIVE TECHNOLOGY SERVICES... (F) AMERICANS WITH DISABILITIES ACT... (G) COMMUNITY TRANSITION... (H) OTHER AREAS... (4) COURSES, TRAINEESHIPS AND FELLOWSHIPS.--Grants under this subsection may be used by university affiliated programs to- (A) assist in paying the costs of courses of training or study for personnel to provide services for individuals with developmental disabilities and their families; and (B) establish fellowships or traineeships providing such stipends and allowances as may be determined by the Secretary... (6)..." [The remaining language which describes the application and requirements of the training is similar to that provided in the 1990 Amendments, with the addition that training should be interdisciplinary to the extent possible, utilize strategies to recruit and train members from racial and ethnic minorities, and address issues of cultural competence in the training provided.]

1984 Amendments P.L. 98-527	1987 Amendments P.L. 100-146	1990 Amendments P.L. 101-496	1994 Amendments P.L. 103-230
Part D - UNIVERSITY AFFILIATED PROGRAMS - Grant Authority (continued)			
		COMMENTS: The 1990 Amendments added three training initia-tives--positive behavior management, assistive technology, and training--determined in consultation with state planning council. It set the size of the training grants, required peer reviews of applicants, and defined training requirements (i.e., competency and value-based, state-of-the-art, integrated into appropriate university curriculum, integrated with relevant state agencies, conducted in a service environment).	
APPLICATION, Section 153(a) - Standards			
'Sec. 153. (a) Not later than six months after the date of the enactment of the Developmental Disabilities Act of 1984, the Secretary shall establish by regulation standards for university affiliated facilities. Such standards shall reflect the special needs of persons with developmental disabilities who are of various ages, and shall include performance standards relating to each of the activities described in section 102(13)...	'Sec. 153. (a) Not later than six months after the date of the enactment...the Secretary shall establish by regulation standards for university affiliated programs. Such standards shall reflect the special needs of all persons with developmental disabilities who are of various ages, and shall include performance standards relating to each of the activities described in section 102(18).	'Sec. 153.(a) Not later than six months after the date of the enactment of the Developmental Disabilities Act of 1984, the Secretary shall establish by regulation standards for university affiliated programs. Such standards shall reflect the special needs of all persons with developmental disabilities who are of various ages, and shall include performance standards relating to each of the activities described in section 102(18).... (e)(1)...(4) including on-site visits or inspections as necessary. Such peer review shall be coordinated as appropriate, with the peer review described in section 152(b)(1)(D). COMMENTS: The standards included site visits or inspections as necessary, along with peer reviews.	'Sec. 153. APPLICATIONS... (b) STANDARDS.-- Not later than 12 months after the date of the enactment of the developmental disabilities assistance and bill of rights act amendments of 1994, the Secretary shall establish by regulation standards for university affiliated programs. such standards shall reflect the special needs of all individuals with developmental disabilities who are of various ages, and shall include performance standards relating to each of the activities described in section 151... (d) CONSUMER ADVISORY COMMITTEE.--The Secretary shall only make grants under section 152(a) to university affiliated programs that establish a consumer advisory committee comprised of individuals with developmental disabilities, family members of individuals with developmental disabilities, representatives of State protection and advocacy systems, State developmental disabilities councils (including State service agency directors), local agencies, and private nonprofit groups concerned with providing services for individuals with developmental disabilities which may include representatives from parent, training, and information centers. The consumer advisory committee shall reflect the racial and ethnic diversity of the geographic area served by the university affiliated program...' COMMENTS: The language concerning standards is virtually the same although slightly clarified. The 1994 Amendments added the requirement of the consumer advisory and describes the representation of the committee. The language through the 1994 Amendments stresses expanded services to racial and ethnic minorities and cultural competence.

University Affiliated Program Funding Patterns

Fiscal Data Reported 1975-76 (Farlee, 1976)				Fiscal Data Reported 1980-81 (Boggs, 1983)			
Source	# UAPs Reporting	Amount	Range	Source	# UAPs Reporting	Amount	Range
Federal		$		Federal		$	
DDO	36	5,569,000	$25,000 - $250,000	ADD Core Support	41	7,000,000	$126,515 - $348,211
Other DDO		not reported separately		Other ADD	11	1,243,813	$33,000 - $200,000
MCH Training	23	15,560,000	$180,000 - $2,415,000	MCH Training	21	16,676,289	$50,000 - $1,779,297
Other MCH		not reported separately		Other MCH	8	1,648,600	$14,900 - $594,507
Education (BEH)	24	3,092,000	$5,000 - $871,000	Education (OSEP)	25	5,826,550	$30,000 - $1,354,109
Other federal agencies	25	6,908,000	$12,000 - $1,124,000	Other federal agencies	19	4,990,958	$23,300 - $1,034,414
Total Federal	43	$31,129,000		Total federal		$37,368,210	
Non-federal				Nonfederal			
General Funds	26	7,980,000	$3,000 - $2,095,000	General Funds	33	20,271,372	$8,675 - $4,802,269
State and local grants & contracts	36	36,783,000	$1,000 - $11,640,000	State and local grants & contracts	32	36,532,490	$41,892 - $13,958,755
Fees	12	1,195,000	$4,000 - $313,000	Fees	21	2,126,103	$700 - $428,583
Other state and local support	18	6,029,000	$6,000 - $1,795,000	Other state and local support	32	4,228,650	$2,400 - $1,165,033
Total Non-federal	45	$51,987,000		Total Non-Federal	46	$63,157,615	
TOTAL		$83,116,000		TOTAL		$99,271,405	

DDO funding includes UAP core funds and special projects

Summary of Data on UAP Fiscal Support
Reported as Part of the National Information Reporting System (NIRS)*

Source of Information Year	"Annual Report" 1987	"Making a Difference" 1988	"Data Trends" 1989	"Data Trends" 1990	"Data Reference" 1991
University General Funds	n=42 36,000**	n=46 32,100	n=52 33,300	n=54 28,000	n=54 30,089
Fees, including insurance and reimbursement	18,000	16,200	23,100		28,779
In-kind match	9,900	11,500	8,300	11,000	7,836
Other Source	5,000	2,300	2,400	5,000	6,120
Grants and Contracts		90,300	114,800	119,000	143,625
Federal Agencies	78,000			78,000	
ADD Core Support					
MCH					
Grants from DD Councils and State Agencies	36,000			14,000	
Grants from Local Service and Provider Agencies				19,000	
Total of all sources of support	**n=42 141,764**	**152,400**	**191,500**	**203,000**	**237,835**

* Documents prepared by AAUAP as part of the National Information and Reporting System funded by MCH and ADD.

** In Thousands

Early Health, Education, and Welfare Activities Addressing the Needs of the Mentally Retarded*

Date	Activity
1954	Mental retardation identified as a Title V program priority in report to Congress.
1955	Mental retardation, a departmental priority. Secretary's Committee on Mental Retardation established. Specific program components assigned to units in the department. Clinical services, evaluation, diagnosis, management, assistance to families, assigned Title V agencies. National Association of Retarded Children "Federal Program of Action" called for development of clinical services.
1956	Authorized use of Title V funds to assist state Maternal and Child Health programs launch special projects to provide alternatives to institutional care. Funds also authorized for training of staff to deliver these services.
1957	Congressional appropriation increased Title V of the Social Security Act and earmarked special projects for children with mental retardation.
1959	Title V Technical Advisory Committee established with representation from state agencies and medical centers, parents, and consumers. Objectives include: 1. Primary prevention (PKU screening and treatment) 2. Diagnostic adjuncts to clinical services to improve diagnosis. 3. Expansion of multi-disciplinary teams (OTs, PTs, nutrition, child development specialists. 4. Training of personnel to provide these services (orientation, inservice, undergraduate, and graduate.
1960	At least one special project in MR in 46 states. 14,000 children and families being served, three-fourths under 10 years of age. 25,000 professionals receiving short-term training. Fourteen states were operating special projects via subcontracts with pediatric departments in medical schools. Amendments to Title V of the Social Security Act, P.L. 88-778 (Maternal and Child Health and Crippled Children Programs) to provide special projects grants, 12½% of the total amount of appropriation. These amendments provided the basis for earmarked special mental retardation funds to institutions of higher education for special demonstration, traveling clinics, field trials, screening, and bio-chemical laboratory procedures.

* Hormuth (1981)
Hormuth (1964)
Braddock (1986a)
Children's Bureau (1964)

Date	Activity
1962	President's Panel on Mental Retardation appointed. October 1962 Panel's Report published "A Proposed Program for National Action to Combat Mental Retardation". Of the more than 95 recommendations for action, the following 5 recommendations relate specifically to Title V programs: 1. Need to develop a primary prevention program 2. Expansion and increased appropriations to clinical programs 3. Extension and expansion of newborn screening, management of metabolic disorders 4. Expansion of cytogenetics laboratories and genetics counseling 5. Recommend earmarked funds for children's programs similar to the 1956 Appropriations Committee action
1963	P.L. 88-157 "of the Maternal and Child Health and Mental Retardation Planning Amendments of 1963"--an Act "to amend the Social Security Act to assist the states and communities in preventing and combatting mental retardation through expansion and improvement of Maternal and Child Health and Crippled Children's Programs through provisions of prenatal, maternal and infant care for individuals with conditions associated with childbearing which may lead to mental retardation, and through planning for comprehensive data to combat mental retardation, and for other purposes." P.L. 88-164 the Mental Retardation Facilities and Community Mental Health Centers Construction Act. Authorization for construction of university affiliated facilities, staffing not included.
1964	P.L. 88-156 and P.L. 88-268, an additional $5 million to Maternal and Child Health and Services for Crippled Children, and $5 million for special projects for Maternal and Infant Care. Earmarked funds for special projects for mentally retarded children.
1965	P.L. 88-605, increase of $30 million in Title V appropriations and CC earmarked funds for increased services to the mentally retarded. MR/Child Development clinics, newborn screening, increased training opportunities. Secretary's Committee on Mental Retardation recommends assigning responsibility for Title V Health Service Training within UAFs under construction. Section 516 of Title V of the Social Security Amendments, P.L. 89-97, provided authority for Title V agency to support training in UAFs.
1967	Section 516 changed to Section 511 and broadened to include training of personnel for health-care related service for mothers and children. Special attention given to undergraduate training.

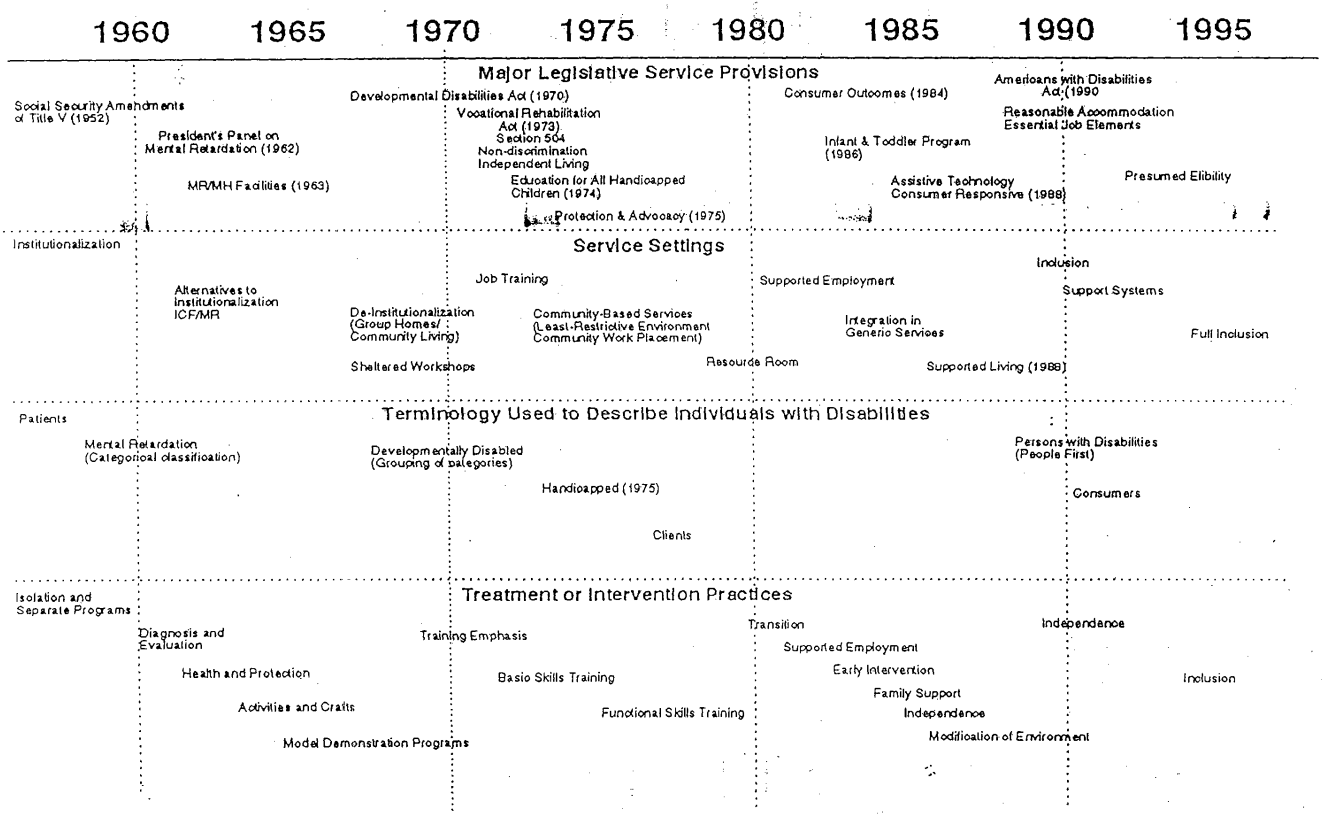
FEDERAL AGENCY RESPONSIBLE FOR THE
UNIVERSITY AFFILIATED PROGRAM,
AGENCIES TO WHICH IT REPORTED,
NAMES AND DATES OF DIRECTORS

Date	UAP Administering Agency	Director	Supervisory Organization or Agency
1964	Mental Retardation Branch	Dr. Paul Pearson, Director	Division of Chronic Disease in the U.S. Public Health Service
1966	Mental Retardation Branch	Dr. Robert Jazlow, Director	
1967	Mental Retardation Division	Dr. Robert Jazlow, Director	Rehabilitation Service Administration under Dr. Edward Newman within the new agency Social and Rehabilitation Services
1971	Division of Developmental Disabilities	Francis X. Lynch, Director	Rehabilitation Service Administration under Dr. Newman
1977	Developmental Disabilities Office	Francis X. Lynch, Director	Office of Human Development
1980	Administration on Developmental Disabilities	Evelyn Provitt, Director	Office of Human Development
1982	Administration on Developmental Disabilities	Francis X. Lynch, Acting	Office of Human Development
1983	Administration on Developmental Disabilities	Dr. Jean Elder, Commissioner	Office of Human Development Services in the Department of Health and Human Services
1987	Administration on Developmental Disabilities	Casey Wichlacz, Acting Bob Stovernor, Acting Lucy Biggs, Commissioner	Office of Human Development Services in the Department of Health and Human Services
1988	Administration on Developmental Disabilities	Carolyn Doplett Gray, Commissioner	Office of Human Development Services in the Department of Health and Human Services
1989	Administration on Developmental Disabilities	William Wolstine, Acting	Office of Human Development Services in the Department of Health and Human Services
1989	Administration on Developmental Disabillities	Deborah McFadden, Commissioner	Office of Human Development Services in the Department of Health and Human Services
1993	Administration on Developmental Disabilities	William Wolstine, Acting Robert Williams, Commissioner	Administration on Youth and Families

Leadership of AAUAP

Date	AAUAP President	AAUAP Executive Director
1967-79	Robert W. Deishler	
1969-70	William M. Gibson	Cynthia Strudevant
1970-71	Margaret P. Giannini	Robert McNeill
1971-72	Charles C. Davis	Robert McNeill
1972-73	Robert G. Jordan	Robert McNeill
1973-74	John H. Meier	Robert McNeill
1974-75	Harvey A. Stevens	Robert McNeill
1975-76	Paul H. Pierson	Robert NcNeill
1976-77	Charles V. Keeran	Seldon Todd
1977-78	Phyllis R. Magab	Seldon Todd
1978-79	Jack H. Rubinstein	Seldon Todd
1979-80	Victor D. Menashe	Seldon Todd
1980-81	Herbert G. Cohen	Seldon Todd
1981-82	James F. Budde	Leonard Hall
1982-83	Alan C. Crocker	Leonard Hall
1983-84	Alfred Healy	Leonard Hall
1984-85	Marvin G. Fifield	Leonard Hall
1985-86	Hugo W. Moser	William Jones
1986-87	Michael J. Guralnick	William Jones
1987-88	Ansley Bacon	William Jones
1988-89	Terrence R. Dolan	William Jones
1989-90	Gerald Golden	William Jones
1990-91	Robert Stempfel	William Jones
1991-92	Deborah Spitalnik	William Jones
1992-93	Gary W. Goldstein	William Jones
1993-94	Carl Calkin	William Jones

Paradigm Shifts in the Disability Field Over the Past 30 Years



Period in Which Service Elements or Initiatives Were Undertaken
by First Generation UAPs

Program Initiative or Service Element	Prior to 1975		1975 - 1980		1981 - 1985		1986 - 1990		1991 or currently active	
	n	%	n	%	n	%	n	%	n	%
Tertiary Diagnostic Evaluation	21	72	0	0	0	0	0	0	24	83
Clinical Training for health and Allied Health Personnel	22	76	1	3	0	0	0	0	25	86
Education, Demonstration, Treatment Program	18	62	1	3	0	0	0	0	17	59
Applied Research	21	72	3	10	1	3	1	3	27	93
Prevention	9	31	4	14	1	3	4	14	20	69
Case Management	10	34	2	7	1	3	12	41	24	83
Genetics	18	62	0	0	1	3	0	0	20	69
Manpower Planning	8	28	4	14	2	7	3	10	19	66
Telecommunications	5	17	3	10	3	10	1	3	15	52
Alternatives to Institutionalization	7	24	6	21	3	10	3	10	17	59
Rights of Individuals with Disabilities	7	24	4	14	3	10	0	0	16	55
Special Needs/Adoption/Foster Care	0	0	4	14	3	10	7	24	13	45
Establish Satellite Centers	1	3	3	10	4	14	1	3	4	14
Mainstreaming/Least Restrictive Placement/Eductional Inclusion	3	10	11	38	5	17	1	3	20	69
Service to Adults with Disabilities	9	31	7	24	7	24	1	3	25	86
Volunteerism	4	14	1	3	2	7	0	0	5	17
Service to Aging Individuals with Developmental Disabilities	1	3	2	7	4	14	10	34	16	55

Program Initiative or Service Element	Prior to 1975		1975 - 1980		1981 - 1985		1986 - 1990		1991 or currently active	
	n	%	n	%	n	%	n	%	n	%
Work with Community College	8	28	3	10	4	14	4	14	16	55
Community-based Service	7	24	9	31	3	10	4	14	26	90
Minority Recruitment	7	24	4	14	1	3	11	38	22	76
Service to Minority Clients	19	66	1	3	2	7	1	3	24	83
Historic Black College Initiative	0	0	1	3	1	3	0	0	1	3
Early Intervention Implementation	2	7	3	10	1	3	16	55	25	86
Direct Care Service Training	6	21	4	14	3	10	9	31	18	62
Employment Initiative	2	7	3	10	7	24	5	17	15	52
Dual Diagnosis	4	14	3	10	1	3	7	24	17	59
Family Support	6	21	5	17	5	17	6	21	21	72
UAP Program Evaluation	3	10	3	10	8	28	7	24	22	76
Assistive Technology	2	7	1	3	0	0	15	52	18	62
Non-MR/DD	13	45	3	10	2	7	2	7	22	76
Agent Orange	0	0	0	0	0	0	10	34	11	38
HIV Pediatric AIDS	0	0	0	0	3	10	9	31	14	48
Transition	3	10	2	7	7	24	6	21	19	66
Autism	5	17	6	21	3	10	2	7	17	59
UAP Consumer Advisory Council	4	14	0	0	3	10	14	48	25	86
Advocacy Training	3	10	6	21	4	14	3	10	17	59
High-Risk Infant Followup	4	14	4	14	7	24	6	21	24	83

APPENDIX K
The Impact of Legislative Provisions on UAPs

Legislation	First Generation n=29			Second Generation n=11			Third Generation n=10		
MRDD		n	%		n	%		n	%
(1) PL 88-164 Mental Retardation Construction Program 29	high	20	68.97	high			high		
	moderate	2	6.90	moderate			moderate	2	20
	limited	7	24.14	limited	11	100.00	limited	8	80
(2) PL 91-517 DD Service and Facilities Construction Act 29	high	20	68.97	high	1	9.09	high	2	20
	moderate	4	13.79	moderate		0.00	moderate	2	20
	limited	5	17.24	limited	10	90.91	limited	6	60
(3) PL 94-103 DD Assistance & Bill of Rights Act, 1975 Amendments 30	high	11	37.93	high	1	9.09	high		
	moderate	7	24.14	moderate	4	36.36	moderate	3	30
	limited	12	41.38	limited	6	54.55	limited	7	70
(4) PL 95-602 DD Assistance & Bill of Rights Act, 1978 Amendments 29	high	7	24.14	high	1	9.09	high	1	10
	moderate	11	37.93	moderate	5	45.46	moderate	2	20
	limited	11	37.93	limited	5	45.46	limited	7	70
(5) PL 98-527 DD Assistance & Bill of Rights Act, 1984 Amendments 29	high	7	24.14	high	6	54.55	high	3	30
	moderate	14	48.28	moderate	3	27.27	moderate	3	30
	limited	8	27.59	limited	2	18.18	limited	4	40
(6) PL 100-146 DD Assistance & Bill of Rights Act, 1987 Amendments 29	high	8	27.59	high	1	9.09	high		
	moderate	11	37.93	moderate	10	90.91	moderate	4	40
	limited	10	34.48	limited		0.00	limited	6	60
(7) PL 101-496 DD Assistance & Bill of Rights Act, 1990 Amendments 29	high		0.00	high	1	9.09	high		
	moderate	12	41.38	moderate	6	54.55	moderate	3	30
	limited	17	58.62	limited	4	36.36	limited	7	70

Legislation	First Generation n=29			Second Generation n=11			Third Generation n=10		
Social Security		n	%		n	%		n	%
(1) Title V Social Security Amendments of 1955 established the Division of MCH 29	high	9	31.03	high		0.00	high		
	moderate	6	20.69	moderate		0.00	moderate	1	10
	limited	14	48.28	limited	11	100.00	limited	9	90
(2) PL 86-778 Social Security Amendments of 1960, Special Projects Grants of National Significance 33	high	5	17.24	high	1	9.09	high	1	10
	moderate	13	44.83	moderate	1	9.09	moderate	2	20
	limited	11	37.93	limited	9	81.82	limited	7	70
(3) PL 89-77 Social Security Amendments of 1965, Section 516 Training 29	high	4	13.79	high		0.00	high		
	moderate	6	20.69	moderate	2	18.18	moderate	2	20
	limited	19	65.52	limited	9	81.82	limited	8	80
(4) PL 90-248 Social Security Amendments of 1966, Section 511 Training 29	high	6	20.69	high	1	9.09	high		
	moderate	8	27.59	moderate		0.00	moderate	4	40
	limited	15	51.72	limited	10	90.91	limited	6	60

Legislation	First Generation n=29			Second Generation n=11			Third Generation n=10		
Education		n	%		n	%		n	%
(1) PL 89-750 ESEA Amendments of 1966 established Bureau of Education for the Handicapped 29	high	5	17.24	high		0.00	high		
	moderate	2	6.90	moderate	1	9.09	moderate	1	10
	limited	22	75.86	limited	10	90.91	limited	9	90
(2) PL 93-380 ESEA Amendments of 1975, Buckley Amendments 29	high	2	6.90	high		0.00	high		
	moderate	8	27.59	moderate		0.00	moderate	2	20
	limited	19	65.52	limited	11	100.00	limited	8	80
(3) PL 94-142 Education for All Handicapped Children Act of 1975 29	high	18	62.07	high	4	36.36	high	3	30
	moderate	9	31.03	moderate	4	36.36	moderate	4	40
	limited	2	6.90	limited	3	27.27	limited	3	30
(4) PL 98-199 EAHC 1983 Amendments, Trans 29	high	4	13.79	high	1	9.09	high	1	10
	moderate	10	34.48	moderate	4	36.36	moderate	3	30
	limited	15	51.72	limited	6	54.55	limited	6	60
(5) PL 99-457 29	high	8	27.59	high		0.00	high		
	moderate	19	65.52	moderate	7	63.64	moderate	9	90
	limited	2	6.90	limited	4	36.36	limited	1	10
(6) PL 101-476 29	high		0.00	high		0.00	high	2	20
	moderate	10	34.48	moderate	7	63.64	moderate	4	40
	limited	19	65.52	limited	4	36.36	limited	4	40

Legislation	First Generation n=29			Second Generation n=11			Third Generation n=10		
Rehabilitation		n	%		n	%		n	%
(1) Title III	high	4	13.79	high	1	9.09	high	1	10
	moderate	4	13.79	moderate	1	9.09	moderate	3	30
29	limited	21	72.41	limited	9	81.82	limited	6	60
(2) Title VII	high		0.00	high		0.00	high	1	10
	moderate	4	13.79	moderate		0.00	moderate	1	10
29	limited	25	86.21	limited	11	100.00	limited	8	80
(3) Title VIII	high	1	3.45	high		0.00	high		
	moderate	3	10.34	moderate	1	9.09	moderate	3	30
29	limited	25	86.21	limited	10	90.91	limited	7	70
(4) Part A	high	3	10.34	high	1	9.09	high	1	10
	moderate	4	13.79	moderate		0.00	moderate	1	10
29	limited	22	75.86	limited	10	90.91	limited	8	80
(5) Part B	high	1	3.45	high	1	9.09	high		
	moderate	5	17.24	moderate	1	9.09	moderate	1	10
29	limited	23	79.31	limited	9	81.82	limited	9	90
(6) Part C	high	5	17.24	high		0.00	high		
	moderate	5	17.24	moderate	5	45.46	moderate	4	40
29	limited	19	65.52	limited	6	54.55	limited	6	60
(7) Section 504	high	5	17.24	high		0.00	high	2	20
	moderate	4	13.79	moderate	5	45.46	moderate	1	10
29	limited	20	68.97	limited	6	54.55	limited	7	70
Assistive Technology	high	3	10.34	high	2	18.18	high		
	moderate	5	17.24	moderate	4	36.36	moderate	2	20
29	limited	21	72.41	limited	5	45.46	limited	8	80
Americans with Disabilities Act PL 100-336	high	6	20.69	high	1	9.09	high	1	10
	moderate	6	20.69	moderate	5	45.46	moderate	2	20
29	limited	17	58.62	limited	5	45.46	limited	7	70