

THE IMPACT OF THE AMENDMENT
OF THE DEFINITION OF
"DEVELOPMENTALLY DISABLED"
ON THE DD PROGRAM
IN FY '79 AND FY '80

A SPECIAL REPORT FROM ICP

THE IMPACT OF THE AMENDMENT
OF THE DEFINITION OF
"DEVELOPMENTALLY DISABLED"
ON THE DD PROGRAM
IN FY '79 AND FY '80

by

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SECTION I

INTRODUCTION

PURPOSE OF THIS REPORT

DEFINITION OF DEVELOPMENTALLY DISABLED
IN PL 94-103 AND PL 95-602

DISABLED POPULATION

DEVELOPMENTAL DISABILITIES BUDGETS

PROCESS USED IN REPORT DEVELOPMENT

SUMMARY

Council/Administrative Agencies
Protection and Advocacy Program
Special Projects
University Affiliated Facilities

PURPOSE OF THIS REPORT

This report was especially prepared to inform the United States Congress of the "impact of the amendment of the definition of 'developmentally disabled' on the DD program as required by Section 503(2) of PL 95-602, Title V, the Amendment to the Developmental Disabilities Services and Facilities Construction Act. "

Section 502(b)(2) of the Developmental Disabilities Assistance and Bill of Rights Act is, PL 95-602, Title V:

(2) *The Secretary of Health, Education, and Welfare shall submit to Congress not later than January 15, 1981, a special report concerning the impact of the amendment of the definition of "developmentally disabled" made by paragraph (1). This report shall include--*

(A) an analysis of the impact of the amendment on each of the categories of persons with developmental disabilities receiving services under the Developmental Disabilities Assistance and Bill of Rights Act before the date of enactment of this Act, and for the fiscal year ending on September 30, 1979 and for the succeeding fiscal year, including--

(i) the number of persons with developmental disabilities in each category served before and after such date of enactment; and

(ii) the amounts expended under such Act for each such category of persons with developmental disabilities before and after such date of enactment; and

(B) an assessment, evaluation and comparison of services provided to persons with developmental disabilities provided before the date of enactment of this Act and for the fiscal year ending September 30, 1979 and for the succeeding fiscal year.

This report contains an analysis of the expenditure of Federal funds provided under the Developmental Disabilities Assistance and Hill of Rights Act tor each of three fiscal years. The three fiscal years are FY '76, FY '79, and FY '80.

The basic assumption of the report is that the DD community expended its FY '78 funds responsive to the definition of developmental disabilities as contained in PL 94-103 and that the DD community expended its FY '79 and FY '80 funds responsive to the definition of developmental disabilities as contained in PL 95-602.

By accounting for the expenditure of funds in each of the three fiscal years and identifying the intended target population by disability of the expenditures of those funds, the impact of the change in definition will be apparent.

This report contains an analysis of the expenditure of the Federal funds appropriated for FY '78, FY '79, and FY '80 for each of the four components of the Developmental Disabilities community. The four components of the Developmental Disabilities community are:

Developmental Disabilities Councils/
Administrative Agencies
Protection and Advocacy Program
Special Projects
University Affiliated Facilities

The Federal funds appropriated for each of the four components of the Developmental Disabilities community are identified by the programs and projects for which funds were expended. The target population by disability group for which funds were expended is identified for each of the four program components. The report contains a presentation of:

- (1) The number of persons with developmental disabilities served in each category of disability, and
- (2) The amounts expended under the Act for each category of persons with developmental disabilities.

Particular attention in the report is focused on those individuals served who are mentally retarded, cerebral palsied, epileptic, and autistic since these are the four categories of individuals who are developmentally disabled who are specifically named in the definition of developmental disabilities in PL 94-103.

It is assumed that Congress wanted a comprehensive report that would show the amount of funds expended on the mentally retarded, cerebral palsied, epileptic, and autistic by the developmental disabilities community as it became responsive to the change in definition in PL 95-602. The evidence of impact on these four populations is contained in this report.

The mandate for this report also requires that evidence be presented containing "an assessment, evaluation and comparison of services provided to persons with developmental disabilities" in FY '78, FY '79, and FY '80.

This report provides comparative information concerning the service providers and service network used in FY '78, FY '79, and FY '80 by each of the four program components of the Developmental Disabilities Act. In order to delineate the quality of programs used and funded by the DD community, particular attention was paid

to the use of Federal and State standards in programs which were fully or partially funded through funds appropriated under the Developmental Disabilities Act for each of the three fiscal years.

It is assumed for the purpose of the "assessment, evaluation and comparison" that Fiscal '78 is the base year or control year and that Fiscal '79 and Fiscal '80 are the experimental years. It is assumed that the service network used and funded in Fiscal '78 was responsive to the definition of developmental disabilities in PL 94-103 and that the service network used and funded in Fiscal '79 and Fiscal '80 was responsive to the definition of developmental disabilities contained in PL 95-602. The assumption that FY '79 and FY '80 are responsive to the definition contained in PL 95-602 must be tempered by the realization that no system can automatically change from one definition of its target population to a different definition. It takes time to implement such a change.

A change in a definition and eligibility does not always have immediate implementation in program activities and service agencies. The assumption that FY '79 is a reliable experimental year probably is an overstatement and FY '79 should be assumed to be a transitional year. However, FY '80 is probably a more reliable experimental year than is FY '79 in demonstrating the impact of the new definition on the Developmental Disabilities Program. It should be kept in mind that the full impact of the definition of developmental disabilities in PL 95-602 may not be demonstrated in either FY '79 or FY '80.

The data contained in this report has been provided by each component of the Developmental Disabilities Program. All sections of each component participated in contributing requested data and the report therefore contains the most comprehensive statistical picture of the Developmental Disabilities Program in the United States at the present time. The report, at times, is over responsive to the mandate of Section 502(b)(2) of PL 95-602, Title V but in such instances valuable to the reader in understanding the complexity and comprehensive role of this small but dynamic program which benefits the individuals who are developmentally disabled in the United States.

DEFINITION OF DEVELOPMENTAL DISABILITIES IN PL 94-103 AND PL 95-602

The definition of developmental disabilities, as contained in PL 95-602, Title V, Section 102(7), the "Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978", is defined as:

(7) The term 'developmental disability' means a severe, chronic disability of a person which —
(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
(B) is manifested before the person attains the age twenty-two;
(C) is likely to continue indefinitely;
(D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic sufficiency; and
(E) reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of life-long or extended duration and are individually planned and coordinated.

PL 95-602, Title V, Sec. 107(7)

The definition of 'developmental disability' which is contained in PL 95-602, Title V, varies from the definition of 'developmental disability' which is contained in PL 94-103. The definition contained in PL 94-103, Section 102(7) is:

(7) The term 'developmental disability' means a disability of a person which--
(A)(i) is attributable to mental retardation, cerebral palsy, epilepsy, or autism;
(ii) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons; or
(iii) is attributable to dyslexia resulting from a disability described in clause (i) or (ii) of this subparagraph; and

(B) originates before such person attains age
eighteen;
(C) has continued or can be expected to continue
indefinitely; and
(D) constitutes a substantial handicap to such
person's ability to function normally in society.

PL 94-103, Sec. 102(7)

The definition of developmental disability contained in PL 95-602, sometimes referred to as the new definition of developmental disability, is based solely on an individual's functional limitations, rather than the diagnosis or nature of his or her disabling condition. The definition of developmental disability contained in PL 94-103, the one used by the developmental disabilities community up to November, 1978, generally applies to persons who suffer from one of the four handicapping conditions listed: mental retardation, cerebral palsy, epilepsy or autism.

In order to understand the definition of developmental disabilities which was incorporated in PL 95-602, Title V, the Developmental Disabilities Assistance and Bill of Rights Act, one must take a brief look at the historical evolution of this legislation. The DD legislation in 1970 replaced legislation enacted in 1963 as a result of recommendations of President Kennedy's Panel on Mental Retardation. The 1963 legislation provided Federal assistance for the construction of facilities "primarily for the mentally retarded." In regulations, "primarily for the mentally retarded" was interpreted to mean that more than 50 percent of the people who used the service housed in the facility would be mentally retarded. In practice, it was found that such facilities were usually built to accommodate persons who were moderately, severely or profoundly retarded.

The mildly retarded persons who were among the candidates for use of these facilities usually were those who had additional other handicaps of a physical, sensory or emotional nature. Even in the early 60's the large component of moderately retarded persons were more generally accommodated in buildings and programs which were at least partially integrated with other people. Both the mildly and moderately retarded program needs tended to be more adequately covered either by the educational system or by the vocational rehabilitation system. At that time, the systems were not addressing the needs of the most severely handicapped. The mental retardation planning amendments of 1963 addressed the needs of those persons who, because of their mental retardation and related disorders, would benefit from ongoing programming involving different agencies and professional services.

Mental retardation is, by definition, a disabling condition which begins early in life. It is a developmental disorder, interfering with normal development. There are, of course, a variety

of other handicapping conditions experienced by children which interfere to some extent, either directly with their development or indirectly with their schooling and social experience as children. Not all of these handicapping conditions persist as substantial handicaps into adult life.

It has become apparent that the conditions which contribute to the disability of an adult and which are of early onset are quite different from those conditions experienced by adults who become disabled after they are adults. This fact is confirmed by the Social Security Administration which has had over 20 years of experience in examining the disabilities of adults who are entitled to Social Security benefits because of the chronicity of their disability since childhood. Furthermore, it is also apparent that the conditions which contribute most to adult disabilities originating in childhood are mental retardation, cerebral palsy, epilepsy, autism, and various childhood psychoses.

These major diagnoses just mentioned account for between 75 and 80 percent of persons who become entitled to Social Security benefits as a result of disabilities originating in childhood. Each individual who qualifies for an adult disabled child's benefit has received a diagnosis of his work disability against a national norm. It is also apparent that these disabilities do not always occur as discrete entities but frequently occur together or in combination with other impairments and disorders such as hearing deficits, speech problems, visual problems, other orthopedic problems, and emotional complications.

Thus, in 1970 when the term "developmental disabilities" was first introduced into Federal law, the mentally retarded were perceived as a major portion of a larger population whose substantial, continuing handicaps originating early in life necessitated a coordinated and ongoing programmatic approach without limitation by age, discipline, or service system. The individuals, whether as children or adults, would need special attention from health agencies, education agencies, agencies concerned with employment, dependency, housing, and social services. Thus, persons in this target group had a uniquely urgent need for interagency planning, coordination, and continuity. They also had a need for certain types of direct services which were very frequently unavailable in the communities in which they lived or even in the segregated residential institutions to which they were often sent.

The attempt to write a definition of this population suitable for incorporation in legislation has been fraught with difficulty and controversy. In 1975 the Congress asked for a special study to develop a definition which would be "appropriate." An expert panel of approximately 50 people, many of them directly involved in DD planning and service delivery, proposed a so-called noncategorical definition which placed emphasis upon the criteria of chronicity, early onset, multiple impairment, and need for ongoing services involving a multiplicity of service providers.

In order to emphasize the complexity and "substantiality" of the disabling conditions to be addressed by the DD Program, the Task Force proposed that persons who were to be considered as part of the primary target group of the program would be impaired in at least three major life activities among seven enumerated. The result of the Task Force's efforts is the definition of developmental disabilities contained in PL 95-602, Title V, heretofore quoted in this section of the report.

The concepts of substantiality and severity are critical to this definition. The Task Force appeared to equate severity of disability for purposes of this Act with the presence of several limitations related to different specific life functions. The emphasis of the Developmental Disabilities Program using the definition in PL 95-602 is clearly focused on the substantially handicapped. The fact that emphasis is placed on the substantially handicapped is no different, as we have seen, from the focus of the initial legislation in 1963 and its later amendments in 1970 and 1975.

The mandated study in PL 95-602, which is the reason for this report, is the corollary to the mandated study in PL 94-103. The results of the mandated study in PL 94-103 brought about the definition of developmental disabilities found in PL 95-602. The mandated study in PL 95-602 requires that the Administration on Developmental Disabilities report on the impact of the definition on the Developmental Disabilities Program during the first two years of implementation.

DISABLED POPULATION

One of the first impacts of the definition of developmental disabilities contained in PL 95-602 can be found in the planning process performed by the Developmental Disabilities State Planning Councils and Administering Agencies. Each State is required to submit a State Plan in order to participate in the Developmental Disabilities Program.

One element of information required in each State Plan is an estimate of the developmentally disabled population within the State. In order to ascertain the total estimated developmentally disabled population within the United States one can total the estimated population submitted by each of the States in their State Plans.

Table 1 presents a comparison of the estimated DD population for FY '78 and FY '80 and percent of change between the two years as presented by the DD State Planning Councils. The assumption is, and a stated fact in most State Plans, that the FY '78 estimate of the DD population is based on the definition of developmental disabilities contained in PL 94-103 and that the FY '80 population is based on the definition of developmental disabilities contained in PL 95-602.

The impact of the definition of developmental disabilities as contained in PL 95-602 on the estimated DD population is to reduce the estimated population by 1,358,981, or 26%, from the estimated DD population in FY '78 based on the definition contained in PL 94-103.

The majority, 32, or 59%, of the States stated that the estimated DD population decreased as a result of applying the definition of developmental disabilities contained in PL 95-602 when compared with the estimated DD population which resulted from applying the definition of developmental disabilities contained in PL 94-103. These States estimated the population decreased from a maximum of 76% to a minimum of 5%.

Seventeen, or 31%, of the States stated that the estimated DD population increased as a result of applying the definition contained in PL 95-602 when compared with the estimated DD population which resulted from applying the definition in PL 94-103. These States estimated the DD population increased a maximum of 902% to a minimum of 2%. Six States estimated that the DD population increased in excess of 100% as a result of applying the definition in PL 95-602. Five States, or 10% of the States, stated that the DD population did not change from the FY '78 population when the definition in PL 95-602 was applied.

TABLE I-1. COMPARISON OF ESTIMATED DD POPULATION FOR FY '78 AND FY '80 AND PERCENT OF CHANGE AS ESTIMATED BY THE DD STATE PLANNING COUNCILS

Regions/States	Estimated DD population for Fiscal Year '78	Estimated DD population for Fiscal Year '80	Percent of increase/ decrease from FY '78
Region I	190,289	165,960	- 13
Connecticut	19,772	38,200	+ 93
Maine	43,792	16,587	- 62
Massachusetts	93,210	80,474	- 14
New Hampshire	5,974	12,542	+ 110
Rhode Island	6,115	9,957	+ 63
Vermont	21,426	8,200	- 62
Region II	409,541	347,790	- 15
New Jersey	125,855	116,670	- 7
New York	125,980	70,520	- 44
Puerto Rico	156,583	156,492	0
Virgin Islands	1,123	4,108	+ 266
Region III	510,276	429,689	- 16
Delaware	30,760	16,660	- 46
Dist. of Col.	12,033	11,390	- 5
Maryland	23,510	69,317	+ 195
Pennsylvania	318,919	164,519	- 48
Virginia	104,990	156,500	+ 49
West Virginia	20,064	11,303	- 44
Region IV	1,180,261	608,310	- 48
Alabama	132,996	52,695	- 60
Florida	240,457	118,793	- 51
Georgia	153,707	102,380	- 33
Kentucky	128,470	61,137	- 52
Mississippi	57,399	33,633	- 41
North Carolina	197,686	126,000	- 36
South Carolina	110,579	23,299	- 79
Tennessee	158,967	90,373	- 43
Region V	926,064	751,464	- 19
Illinois	190,581	192,272	0
Indiana	46,292	70,814	+ 53
Michigan	206,060	148,512	- 28
Minnesota	95,015	98,739	+ 4
Ohio	298,701	157,706	- 47
Wisconsin	89,415	83,421	- 7

TABLE I-1. COMPARISON OF ESTIMATED DD POPULATION FOR FY '78 AND FY '80 AND PERCENT OF CHANGE AS ESTIMATED BY THE DD STATE PLANNING COUNCILS (Continued)

Regions/States	Estimated DD population for Fiscal Year '78	Estimated DD population for Fiscal Year '80	Percent of increase/ decrease from FY '78
Region VI	844,648	488,364	- 42
Arkansas	112,364	45,880	- 59
Louisiana	43,047	43,884	0
New Mexico	17,275	20,300	+ 18
Oklahoma	156,806	159,723	+ 2
Texas	515,156	218,577	- 58
Region VII	395,693	508,889	+ 29
Iowa	47,939	45,598	- 5
Kansas	89,533	105,458	+ 18
Missouri	252,088	333,000	+ 32
Nebraska	6,133	24,833	+ 305
Region VIII	96,691	81,012	- 16
Colorado	48,203	28,269	- 41
Montana	7,560	12,403	+ 64
North Dakota	7,173	7,173	0
South Dakota	12,071	8,520	- 29
Utah	13,272	22,599	+ 70
Wyoming	8,412	2,048	- 76
Region IX	601,076	422,980	- 30
Arizona	98,404	40,479	- 59
California	476,100	359,854	- 24
Guam	295	2,956	+ 902
Hawaii	12,711	10,637	- 16
Nevada	13,566	9,054	- 33
Region X	111,355	102,455	- 8
Alaska	7,288	7,378	0
Idaho	35,368	15,453	- 56
Oregon	8,905	24,720	+ 178
Washington	59,794	54,894	- 8
Total	5,265,894	3,906,913	- 26

It is apparent from an analysis of the data that States are focusing on the substantially handicapped to a greater extent in estimating the DD population in FY '80 than when they estimated the DD population in FY '78.

The 54 States reported their estimated DD population by categories of the cause of disability in FY '78. Most of the States reported their estimated population by the cause of disability in FY '79. Many States used the same figures as provided in FY '78 for their FY '79 estimate. It must be noted that PL 95-602 was signed in November, 1978 and FY '79 State Plans were due on or before October 1, 1978. Therefore, most States would have used the definition of developmental disabilities in PL 94-103 in their FY '79 State Plans. Only ten States, or 19% of the programs, reported their FY '80 estimated population by the cause of disability in their State Plans.

Table 2 shows the estimated DD population by disabilities for each of the three fiscal years.

TABLE I-2. NUMBER AND PERCENT OF THE ESTIMATED DD POPULATION CATEGORIZED BY MENTAL RETARDATION, CEREBRAL PALSY, EPILEPSY, AUTISM, AND OTHERS FOR FISCAL YEARS '78, '79 AND '80

Cause of disability	Fiscal Year '78		Fiscal Year '79		Fiscal Year '80	
	Number	%	Number	%	Number	%
Mental Retardation	3,518,742	65.5	3,291,862	64.3	2,140,988 ¹	54.8
Cerebral Palsy	505,269	9.4	623,909	12.2	558,688	14.3
Epilepsy	1,064,479	21.8	1,007,646	19.7	679,802	17.4
Autism	79,866	1.5	75,431	1.5	62,510	1.6
Other	97,490	1.8	120,011	2.3	464,925	11.9
Total	5,265,846	100	5,118,859	100	3,906,913	100

1 The numbers in this column are extrapolated numbers derived from the percents provided by 10 States which provided categorical information in their FY '80 State Plans.

Most States estimated their DD population identifying these four causes of disability: mental retardation, cerebral palsy, epilepsy and autism. However, seven States did estimate a fifth category of the cause of disability, the category of which varied from State to State. Five of the States have some combination of multiple handicapping conditions in this category, while two States estimated the population of learning disabled as a separate category.

The 'other' category of disability which increased from 1.8% of the estimated DD population in FY '78 to 11.9% of the estimated DD population in FY '80, an increase of 10.1%, contains several handicapping conditions. Most States used those conditions listed by the Definition Task Force for this category in their estimated DD population. The 'other' category included socially impaired learning disabled, deaf-blind, multiple handicapped, cystic fibrosis, spina bifida, muscular dystrophy, deaf, and osteogenesis imperfecta.

TABLE I-3. COMPARISON OF THE PERCENT OF THE ESTIMATED DD POPULATION INCLUDING PERCENT OF CHANGE CATEGORIZED BY MENTAL RETARDATION, CEREBRAL PALSY, EPILEPSY, AUTISM, AND OTHER HANDICAPPING CONDITIONS FOR FISCAL YEAR '78 AND FISCAL YEAR '80

Cause of disability	Fiscal Year '78	Fiscal Year '80	Percent increase/decrease
Mental Retardation	65.5	54.8	- 10.7
Cerebral Palsy	9.4	14.3	+ 4.9
Epilepsy	21.8	17.4	- 4.4
Autism	1.5	1.6	+ .1
Other	1.8	11.9	+ 10.1

It is apparent from the information presented in Table 3 that the DD community estimates that the percent of mentally retarded when compared to the entire DD population will be reduced approximately 10 percent when applying the definition in PL 95-602 rather than using the definition in PL 94-103. The DD community indicates that there is almost a 5% increase in the cerebral palsy population under the definition in PL 95-602 as compared to the definition in PL 94-103. The same statistical analysis indicates an estimate of over a 4% decline in the epilepsy population, and no significant change in the autistic population. The major shift in the population is the addition of a variety of handicapping conditions which the DD community estimates accounts for 10% of the DD population when applying the definition of developmental disabilities contained in PL 95-602 as compared to the projected population under PL 94-103.

The impact of the definition of developmental disabilities contained in PL 95-602 when compared to the estimated population under PL 94-103 is a 27% decrease in the estimated population from almost 5.3 million to an estimated 3.9 million. It is estimated that "other handicapping conditions" added to the population as a result of applying the definition in PL 95-602 represent 10% of the total DD population. This addition of other conditions is offset by a decrease in the estimated percentage of the mentally retarded population within the total DD population.

DEVELOPMENTAL DISABILITIES BUDGETS

The Developmental Disabilities Program consists of four major components: Basic Grants to States, Protection and Advocacy Grants, Special Projects, and University Affiliated Facilities. These four components provide the following basic functions with the monies received:

1. Formula Grants to the States and Territories for planning, administration and services. In PL 95-602 there is a mandate for 65% of the money to be expended in one or two priority service areas;
2. Formula Grants to the States for the operation of a system to protect and advocate the rights of the developmentally disabled population;
3. Special Project Grants to improve the quality of services, demonstrate established programs which hold promise of improving services, help eliminate attitudinal and environmental barriers through public awareness and public education, coordinate available community resources, demonstrate services to persons with developmental disabilities who are economically disadvantaged, provide technical assistance related to services and facilities, provide training of specialized personnel, demonstrate new or improved techniques in the development of services, and gather and disseminate information; and
4. Project Grants to Universities or Affiliated Facilities for administrative and operations support for interdisciplinary training programs for specialized personnel, clinical services and research program services to serve the developmentally disabled.

Table 4 shows the amount of Federal funds allotted to each of the program components for Fiscal Years '78, '79 and '80. The table also contains the comparative percent of resources each program component has in relation to the other program components.

There was no increase in the appropriated funds from FY '78 to FY '79. For each fiscal year the appropriation for the total program was \$59,125,000. In FY '80 the amount appropriated for the program was \$62,436,000, which represented an increase of \$3,311,000, or 5.6% increase over the FY '79 level.

It is apparent that the Basic State Grants account for the major part of the program resources. In FY '78 the \$30 million represented just over 50% of the program resources. In FY '79 the amount for Basic State Grants was increased to just over \$35 million without an increase of the total amount appropriated for the DD Program. The \$35 million represented almost 60% of the program resources. In FY '80 the Basic State Grants received just over \$43 million and represented 69% of the program resources. Between FY '78 and FY '80 Basic State Grants were increased \$13 million, or 20% of the program funds.

TABLE I-4. FEDERAL APPROPRIATION FOR THE DD PROGRAM BY PROGRAM COMPONENT FOR FY '78, FY '79, AND FY '80

(In thousands of dollars)						
Program component	Fiscal Year '78		Fiscal Year '79		Fiscal Year '80	
	Amount	%	Amount	%	Amount	%
Basic State Grants	\$30,058	50.8	\$35,331	59.8	\$43,180	69.2
Protection & Advocacy	3,000	5.1	3,801	6.4	7,500	12.0
Special Projects	19,567	33.0	12,573	21.3	4,756	7.6
University Affil. Fac.	6,500	11.1	7,420	12.5	7,000	11.2
Total	\$59,125	100	\$59,125	100	\$62,436	100

Special Projects were fiscally emphasized in FY '78 and provided 33% of the program monies. In FY '79 the Special Projects monies were reduced by \$6,994,000 and represented only 21.3% of the program allocation. In FY '80 the Special Project allotment was reduced below subsistence level to \$4,756,000 and represented only 7.6% of the total program allotment. This radical decrease of fiscal support for Special Projects in a three year period significantly changed the direction of the DD Program in the United States and eliminated the major resource for research and the development of model programs for the developmentally disabled in this country.

Protection and Advocacy is the newest of the four components of the DD Program. The legislative mandate for Protection and Advocacy first appeared in PL 94-103, Section 113. This law was passed in 1975. The Protection and Advocacy Program was implemented in all 54 States and Territories on or before October 1, 1977. The P&A Program started its fourth year of operation on October 1, 1980.

In FY '78 the Protection and Advocacy Program was modestly funded at \$3,000,000 with a minimum allotment State receiving only \$20,000 to implement a statewide system of Protection and Advocacy. The \$3 million represented only 5.1% of the total program budget. In FY '79 the allotment was increased to \$3.8 million due to the fact that PL 95-602 required that each minimum allotment State receive no less than \$50,000 for its system of Protection and Advocacy. In FY '80 the total allotment for Protection and Advocacy was \$7.5 million and represented 12% of the total program budget.

Funding for the University Affiliated Facilities Program in FY '78 was \$6.5 million, or 11% of the program resources. The UAF's received \$7.4 million in FY '79, which represented 12% of the program resources. The amount appropriated in FY '80 was \$7.0 million, or 11.2% of the program budget and a decrease of \$400,000, or 5%, from the FY '79 level of funding.

Table 5 shows the percentage of change in funding which each of the four program elements of the DD Program has experienced since FY '78 until FY '80. It is apparent that the program, through its funding, has de-emphasized the Special Projects part of the legislation, reducing funding of this component by approximately 76% between FY '78 and FY '80, and increased emphasis on the Basic State Grants component of the program. The increase of 150% for Protection and Advocacy during the two year period is not significant since the base of \$3 million in the control year of FY '78 was inadequate to meet the mandate of the legislation.

TABLE I-5. PERCENT OF CHANGE IN FUNDING FOR THE FOUR COMPONENTS OF THE DD PROGRAM FROM FY '78 THROUGH FY '80

Program component	FY '78 (Control year) %	FY '79 (Experimental year) %	FY '80 (Experimental year) %
Basic State Grants	100	+ 17.5	+ 43.7
Protection & Advocacy	100	+ 26.7	+150.0
Special Projects	100	- 35.7	- 75.7
University Affil. Fac.	100	+ 14.0	+ 7.7
Total	100	0	+ 5.6

The Basic State Grants and the Protection and Advocacy Grants are distributed to States according to the Hill Burton Formula.

The total Federal expenditures currently used in services for developmentally disabled persons are estimated to annually exceed \$4.4 billion.

The Developmental Disabilities Program appropriation of \$62 million is only a small portion, 1.5%, of the total annual expenditures. The developmental disabilities appropriation is not fiscally the driving force in provision of services for developmentally disabled persons.

However, the Developmental Disabilities Program is program-mically necessary in order to provide leverage, accessing and coordination of all service program provisions funded under other appropriations for the benefit of the developmentally disabled. Also, the Developmental Disabilities Program is necessary to seek out and call attention to gaps in the service network which, if not filled, create destructive interruption of developmental services for individuals who tend to suffer regressions in skills from such interruptions of services.

The following pages contain an accounting of the programs and activities provided by each of the four components of the DD Program for the Fiscal Years '78, '79, and '80. The report also contains an assessment of the impact of the definition of developmental disabilities as contained in PL 95-602 on the services provided to individuals with mental retardation, cerebral palsy, epilepsy and autism for FY '79 and FY '80.

PROCESS USED IN REPORT DEVELOPMENT

The process used to collect the data contained in the report was a research design which ensured the validity of the information from each of the four components of the Developmental Disabilities Program. The four components from which data was collected and verification secured were:

1. 54 Developmental Disabilities Planning Councils and Administrative Agencies
2. 54 Protection and Advocacy Agencies
3. All Grants of National Significance and Special Projects for FY '78, FY '79, and FY '80
4. The output of the telecommunication system for the University Affiliated Facilities

The research design for data collection required a pro-active approach to data collection. The approach used was to develop a printout of all information known about each of the program components, mail the printout to the relevant program component and request verification of the information and/or changes of incorrect or unavailable data. The verified information was then returned and tabulated for inclusion in the report. This pro-active approach to data collection was followed and the response from all components of the DD community was excellent.

The process used for the Developmental Disabilities Planning Councils and Administrative Agencies began with a comprehensive examination of each State Plan for each State for each of the three fiscal years. A total of 162 State Plans were reviewed during this process.

The DD community, through its State Planning Councils/Administrative Agencies, has in place one of the most comprehensive planning programs of any program in the country. The Administration on Developmental Disabilities and its forerunner, the Bureau of Developmental Disabilities, has expended energy and funds over a five year period to develop this nationwide, program specific, comprehensive planning process. The State Plan produced by a DD Council/Administrative Agency contains a wealth of information and is an effective tool for pro-active planning and evaluation.

Each State Plan contains essential information describing the Developmental Disabilities Program within the State. This essential information includes:

- A listing of the membership and the activities of the State Planning Council
- A description and enumeration of the developmental disabilities population in the State
- A description of the service needs of individuals who are developmentally disabled in the State
- A comprehensive description of the services and service network for individuals who are developmentally disabled in the State
- A description of the gaps which exist in the service system
- The goals and objectives which are to be undertaken for the effective period of the plan
- A categorical budget for the fiscal year showing planned expenditures by service area

The comprehensive plan is a product of the legislative mandate. Section 133 of PL 94-103 as amended in PL 95-602 specifies the information required in the State Plan. The DD community, through the leadership of the administration, has planned and implemented a uniform planning process throughout the entire 54 State and Territory program network.

Three information elements were extracted from each of the 162 State Plans for the purpose of this report. The three information elements extracted were:

- The estimated DD population for each of the three fiscal years for each State
- The plan year objectives for each of the three fiscal years for each State
- The budget by category for each of the three fiscal years for each State

The extracted information was assembled with uniform tables and a State specific questionnaire. The assembled information extracted from each State Plan was then sent to the appropriate State for verification.

Each State reviewed the assembled information, verified the information, and completed the questionnaire, reporting the amount of funds expended on each plan year objective. Each State also

reported the number of plan year objectives achieved, the number of individuals served, the target population for which the objective was planned, and the standards by which quality accountability was achieved or measured in each program. Each State also reviewed and verified the estimated DD population information and the fiscal information.

It is important to realize that each State responded to the request for information. The timely response of each of the DD Councils/Administrative Agencies is ample evidence of the responsibility and interest which the DD Councils and Administrative Agencies have in the Developmental Disabilities Program and its intended population.

The data contained in the report also reflects the total participation of the DD Councils/Administrative Agencies. There is complete information on all expenditures of Federal funds for each of the three years for which the accounting is required.

The Protection and Advocacy Agencies were as cooperative in their participation in supplying requested data for this report as were the DD Councils/Administrative Agencies. Each of the 54 Protection and Advocacy Agencies supplied the requested statistical and narrative information.

Preparing for the Protection and Advocacy presentation was somewhat easier and less time consuming than the time required to prepare for the State Councils/Administrative Agencies. The P&A Agencies had contributed relevant information for the report prepared for Congress in the spring of 1979. The report entitled *Protection and Advocacy in the United States - The First Two Years* contains identical information requested for the present report. The spring report contained the activity of the P&A Program for FY '78 and FY '79.

The statistical data provided by each P&A Agency for the first report was duplicated for each State with space to fill in statistical accomplishments for FY '80. Each P&A Agency was requested to update the narrative part of the report in order to present the activity of each agency over a three year period.

It cannot be repeated often enough that each of the 54 P&A Agencies supplied the requested information. It is important to understand that the program implementors do cooperate when requested and maintain reliable information for program accountability.

The process used to verify information concerning the Projects of National Significance and Special Projects was equal in producing reliable information to that used for collecting the information from the DD Councils/Administrative Agencies and the P&A Agencies.

A list of Projects of National Significance was made for each of the three fiscal years. A list of the Special Projects funded at the Regional level Was created for each of the ten Health and Human Services Regions. The list of Projects of National Significance was verified by the personnel in the Central Office of the Administration on Developmental Disabilities. Each list of Special Projects was verified by each of the Regional Directors of Developmental Disabilities.

The output of the telecommunications system for the University Affiliated Facilities was used to secure the data contained in the report on the University Affiliated Facilities Program. The base of the telecommunications system is housed in the offices of the American Association of University Affiliated Facilities in Washington, D.C.

The UAF telecommunications system contains data on the UAF Program activities including client demographics and service data, training activities, and information on research activities. The telecommunications system also contains information concerning fiscal resources of each of the 48 University Affiliated Facilities. The available information on the UAF Program was analyzed and the data which resulted from the analysis is included in this report.

The DD community as a whole, and each component of the DD community has cooperated in providing the information contained in this report. This report contains verified information which accurately demonstrates the impact of the definition of 'developmental disabilities' as contained in PL 95-602, Title V.

SUMMARY

COUNCILS/ADMINISTRATIVE AGENCIES

PL 95-602 authorizes Basic Formula Grants, based on the Hill Burton Formula, to the States for planning, administration, and services. The basic goal of the program is to provide for a significant improvement in the quality, scope and extent of services for persons with developmental disabilities through comprehensive planning for current and future service needs of the developmentally disabled population, coordination of services and resources for the developmentally disabled, and development and demonstration programs to fill existing gaps in service.

Since 1970, the legislation has placed emphasis on coordinated action for the development of a network of Federal/state/local program services for developmentally disabled persons to receive the special and generic services they require. The State must coordinate at least the nine Federal/State programs listed in the Act.

As a result of a provision under PL 95-602, each State is required to expend at least 65% of its allocation (or \$100,000, whichever is greater) in provision of direct services, selecting one or two priority areas of service for emphasis.

Table 6 shows the distribution of the Federal Basic Formula Grant funds for each of the three Fiscal Years '78, '79, and '80. The total appropriation is divided between the monies and percent expended for planning and administration and the money and percent expended for service activities and programs.

TABLE I-6. AMOUNT AND PERCENT OF FEDERAL BASIC FORMULA GRANT FUNDS EXPENDED FOR PLANNING AND ADMINISTRATION AND SERVICES BY THE 54 STATES AND TERRITORIES PARTICIPATING IN THE DD PROGRAM IN FY '78, FY '79, AND FY '80

Fiscal Year	Total appropriation		Planning/Administration		Services	
	Amount	%	Amount	%	Amount	%
Fiscal '78	\$30,058,000	100	\$ 7,632,815	25.4	\$22,425,185	74.6
Fiscal '79	35,331,000	100	9,520,956	26.9	25,810,044	73.1
Fiscal '80	43,180,000	100	10,295,161	23.8	32,884,439	76.2

States must assure that every program funded under the Basic State Grants Program has an Individualized Habilitation Plan for each developmentally disabled person receiving services and that they provide for annual review of each plan. Because developmentally disabled clients more than other handicapped persons require services of several agencies at one time, the development and implementation of the Individualized Habilitation Plan is an intricate activity. Many of the services are provided under Federal program services which have separate and difficult requirements for individual plans.

An important component of the Developmental Disabilities Program is the State Planning Council. The Council is appointed by the Governor, and by law it must be composed of three major groups concerned with services: State Agency administrators of human service programs within the State, local service providers, and individuals eligible for services to the developmentally disabled or their representatives.

State Planning Councils determine and set priorities, policies and procedures for expenditure of the Formula Grant funds in accordance with their findings on the needs of the developmentally disabled population to be served. The Council is responsible for planning, influencing other Federal/State program service resources, coordination of Federal and State program services, and evaluating and monitoring the implementation of the State Plan for services for developmentally disabled persons.

The impact of the definition of developmental disabilities contained in PL 95-602 is measurable. The DD Councils and State Administrative Agencies started using the definition in FY '79 and have been implementing programs and using it in planning almost exclusively in FY '80. Apparently, the application of the definition contained in PL 95-602 has caused a 10% change in the types of disability which individuals have who are served by programs and planning activities conducted with Federal Basic Formula funds.

Table 7 shows the percent of individuals served who were mentally retarded, cerebral palsied, epileptic, and autistic, and all other individuals served by programs and planning activities funded with Federal Basic Formula Grant funds for FY '78, FY '79, and FY '80.

TABLE I-7. PERCENT OF INDIVIDUALS WHO WERE MENTALLY RETARDED, CEREBRAL PALSID, EPILEPTIC, AND AUTISTIC AND ALL OTHER INDIVIDUALS SERVED BY PROGRAMS FUNDED WITH FEDERAL BASIC FORMULA GRANT FUNDS IN FY '78, FY '79, AND FY '80

Disability groups	FY '78 %	FY '79 %	FY '80 %
MR-CP-E-A	98.4	95.8	88.2
All Others	1.6	4.2	11.8

It is apparent that the percent of individuals served with disabilities other than mental retardation, cerebral palsy, epilepsy and autism has increased in FY '79 and FY '80. However, because the amount of appropriations for the Federal Basic Formula Grant funds increased nearly 44% in FY '80 over the FY '78 level, the actual amount of money expended on individuals who were disabled because of mental retardation, cerebral palsy, epilepsy and autism actually increased in FY '80 from the amount expended on the same groups of disabled in FY '78.

Application of the definition of developmental disabilities in PL 95-602 apparently has had little impact on the type of services or the quality of services provided to individuals who are developmentally disabled. Statistical and narrative reports indicate that, if anything, improvement has been made in the quality of services provided under Federal Basic Formula Grant funds.

PROTECTION AND ADVOCACY PROGRAM

In order to participate in the Basic State Grant Program, a State must have a Protection and Advocacy system which can take necessary action to protect the rights of the developmentally disabled persons in the State. The State Protection and Advocacy systems have the authority to pursue legal, administrative, and other appropriate remedies, and must be free of any conflict of interest or appearance of conflict. To that end, the law mandates that the Protection and Advocacy State systems be independent of public and private providers of services.

In FY '78, only \$3 million was appropriated to implement the program in States. In FY '79, the appropriation for the Protection and Advocacy Program was \$3.8 million, and the minimum allotment to States was set at \$50,000. In FY '80, the appropriation was increased to \$7.5 million. To supplement their limited budgets, many of the States have secured support from other sources such as Title XX, CETA, VISTA, Basic State Grant funding, and State appropriations. This supplementary funding amounted to \$5.2 million in FY '80.

The placement of the Protection and Advocacy offices designated to implement the State systems varies among the States. At the beginning of FY '81, 32 of the States were placed in non-profit, private corporations especially incorporated to house the P&A Agencies. Thirteen of the agencies are placed in State Government and nine agencies are operated by non-profit private organizations which existed prior to the implementation of the Protection and Advocacy Program.

The Protection and Advocacy system has served in excess of 68,000 individuals in its first three years of operation. Problems solved by the P&A Agencies cover a variety of areas. Twenty-seven percent of the cases were education problems, 8% were employment problems, 12% fiscal entitlement problems, 13% inappropriate living arrangements, and 5% medical problems. The system also solved problems related to architectural barriers, zoning, transportation, and participation in social functions.

The impact of the definition of developmental disabilities contained in PL 95-602 is measurable. The P&A system started its program in FY '78 using the definition contained in PL 94-103. The P&A Agency now operates the program using the definition from PL 95-602. Apparently, the application of the definition contained in PL 95-602 has caused a 15% change in the types of disabilities which individuals have who are served by the P&A system.

TABLE I-8. PERCENT OF INDIVIDUALS SERVED WHO WERE MENTALLY RETARDED, CEREBRAL PALSIED, EPILEPTIC AND AUTISTIC AND ALL OTHER INDIVIDUALS SERVED BY P&A AGENCIES FOR FY '78, FY '79, AND FY '80

Category of disability	FY '78 %	FY '79 %	FY '80 %
MR - CP - E - A	86.9	75.5	71.3
All others	13.1	24.5	28.7
Total	100	100	100

It is apparent that the percent of cases for individuals with disabilities other than mental retardation, cerebral palsy, epilepsy and autism has increased in FY '79 and FY '80. However, because the actual number of individuals served by the P&A Agencies in each of these years has increased, the actual number of individuals served who are mentally retarded, cerebral palsied, epileptic and autistic has increased in each of the years. Detailed analysis of the impact of the definition is contained in Section III of this report.

Application of the definition in PL 95-602 apparently has little impact on the type of services or the quality of services provided by the P&A system. Statistical and narrative reports indicate that the types of cases and problem areas of cases have not changed during the three year period.

SPECIAL PROJECTS

Section 145 of the Act, as amended, authorizes demonstration grants to accomplish a broad range of objectives in services, technical assistance, training and coordination.

There was a change in emphasis for Special Projects with the amendments to the DD Act in 1978. Section 145 was amended to employ the four priority service areas identified in the law and to assist the implementation of the advocacy program authorized under Section 113 of PL 95-602.

The areas of service for which Special Project funds could be used which were carried over from PL 94-103 to PL 95-602 were public awareness, coordination of services, demonstration projects, technical assistance, training, model programs, information dissemination, improved quality of services, and projects for special groups.

Funding for projects under Section 145 was substantially cut over the three year period of this report. In FY '78, the funding level was \$19,567,000; in FY '79, it was cut 35% to \$12,573,000; and in FY '80, it was cut to \$4,756,000, or down 76% from its FY '78 level. The Special Projects component of the DD Program is so depleted at the present time it ceases to be a program factor.

A complete analysis of the Special Projects and their contribution to the DD Program over the three year period is contained in Section IV of this report.

The application of the definition of developmental disabilities in PL 95-602 has had some effect on Special Projects during FY '79 and FY '80. This effect is measurable in the amount of Special Project funds expended from the total funds expended in a fiscal year for individuals with disabilities other than mental retardation, cerebral palsy, epilepsy and autism. This amount increased 11.4% from the percentage of funds expended for that population in FY '78.

Table 9 shows the percent of Special Project funds expended for those individuals who were mentally retarded, epileptic, cerebral palsied, and autistic and all other individuals for which Special Project funds were used in FY '78, FY '79, and FY '80.

TABLE I-9. PERCENT OF SPECIAL PROJECT FUNDS USED FOR INDIVIDUALS WHO WERE MENTALLY RETARDED, CEREBRAL PALSID, EPILEPTIC, AND AUTISTIC AND ALL OTHER INDIVIDUALS SERVED BY SPECIAL PROJECTS IN FY '78, FY '79, AND FY '80

Category of disability	FY '78 %	FY '79 %	FY '80 %
MR - CP - E - A	97.4	90.1	86.0
All others	2.6	9.9	14.0
Total	100	100	100

The shift of just over 11% to handicaps other than the mentally retarded, cerebral palsied, epileptic, and autistic group corresponds to the 15.6% shift identified for the same population in the Protection and Advocacy Program between FY '78 and FY '80. Also, this percentage of 10% of shift of funds to individuals with handicaps other than mental retardation, cerebral palsy, epilepsy, and autism for the expenditure of Federal Basic Formula Funds between FY '78 and FY '80 correlates with the 11% shift herein identified.

Application of the definition in PL 95-602 apparently has little impact on the type of services or quality of services provided by the projects funded under Section 145 appropriation because of identical or similar resources being used to conduct the projects. However, since this component of the DD Program has been devoid of significant funding in FY '80, it is hard to ascertain the impact on services since most of FY '80 funds were used for continuation of projects funded in FY '78 and FY '79.

UNIVERSITY AFFILIATED FACILITIES

During the 1960's, \$44 million in Federal funds were spent under PL 88-164 to construct twenty facilities affiliated with universities for the purpose of providing interdisciplinary training of professionals serving or who would serve mentally retarded persons.

In 1972, funds became available to States under PL 91-517, the Developmental Disabilities Act, to administer and operate University Affiliated Facilities. There are now 48 facilities and five satellite centers funded under the DD Act.

Basic Federal support for most University Affiliated Facilities comes from three principal sources. Besides the \$7.0 million basic support from the DD Act, the UAF's receive basic support from Maternal and Child Health and the Bureau of Education of the Handicapped.

The UAF's operate on an annual budget of approximately \$105 million. In a traditional year, about 65% of the funds are received from Federal, State and local grants. About 22% of the funds are obtained from university general funds in support of the UAF. Just over 13% of the funds for UAF's come from reimbursement for direct client services provided by the UAF's. The rest of UAF funds are derived from in-kind contributions of the university as match for grant funds.

The University Affiliated Facilities provide three types of program activities for the benefit of individuals who are developmentally disabled. The UAF's provide:

1. Direct client services
2. Training
3. Research

In FY '79, twenty-one UAF's had a total of 23,793 individuals for whom they were providing direct services. The UAF's provide direct services in a variety of areas, which are enumerated in Section IV of this report.

The UAF's provide training for four classifications of individuals. The UAF's: (1) provide academic instruction to university students, (2) have university students who major in a program of instruction to become a professional serving the developmentally disabled, (3) have university students participate in non-academic training activities conducted by UAF members, and (4) have individuals from the general public who are interested in the developmentally disabled involved in training activities.

In FY '79, thirty-eight UAF's reported that 14,549 university students took courses conducted by UAF faculty members. Twenty of the UAF's reported having 391 students majoring in a UAF program.

There were 32,495 university students who participated in non-academic programs in FY '79 in twenty-five UAF's. Twenty-eight UAF's reported that they provided training to 98,911 individuals from the general public during FY '79.

The UAF's are active in conducting basic and applied research. In FY '78 and FY '79, there were a total of 69 different research projects reported by the UAF's involving nearly \$8.9 million. Forty percent of these research projects were financed by DD Special Project monies made available under Section 145 of PL 95-602.

The definition of developmental disabilities contained in PL 95-602 has had little impact on the population served by the UAF's in their direct client services, training and research activities. The UAF's provide services to individuals with a variety of handicapping conditions which have a variety of causes. The UAF's serve individuals who have handicaps caused by:

Mental retardation	Epilepsy
Autism	Deafness
Emotional handicaps	Blindness
Cerebral palsy	Dyslexia
Physical handicaps	Learning disabled
Metabolic disorder	

In FY '79 there were 11,210 individuals receiving direct services carried over from FY '78, and 10,853 new individuals admitted to services during the year. Fifty-five percent of these individuals were diagnosed as mentally retarded. There appears to be no significant change in the clientele of the UAF's as a result of the definition of developmental disabilities contained in PL 95-602.

The UAF's are now operating under standards according to the mandate contained in the 1978 Amendments to the DD Act. The requirement is:

Sec.122(a) Not later than six months after the date of the enactment of the Rehabilitation Comprehensive Services, and Developmental Disabilities Amendments of 1978, the Secretary shall establish by regulation standards for university affiliated facilities. These standards for facilities 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(10).

PL 95-602, Sec.122

With the promulgation of the standards for UAF's, the services at UAF's have become standardized. Also, most direct services provided by UAF's are under State and Federal rules and regulations. The services provided by UAF's have, if there has been any change in FY '79 and FY '80, increased in quality.

SECTION II

COUNCILS/ADMINISTRATIVE AGENCIES

LEGISLATIVE MANDATE

APPROPRIATIONS

UTILIZATION OF RESOURCES

SERVICES PROVIDED

POPULATIONS SERVED

SERVICE PROVIDERS

IMPACT OF DEFINITION

ASSESSMENT OF QUALITY

LEGISLATIVE MANDATE

The genius of the Developmental Disabilities Program lies in the fact that a group of interested individuals in each State and Territory meet on a regular basis to discuss, plan for, and advocate for services for individuals who are developmentally disabled. The group of individuals is the State Planning Council on Developmental Disabilities. The Council is appointed by the Governor of the State. The Council composition is dictated in Section 137 of PL 95-602, Part V. The first part of Section V is as follows:

Sec. 137(a)(1) Each State which receives assistance under this part shall establish a State Planning Council which will serve as an advocate for persons with developmental disabilities (as defined in Section 102(7)). The members of the State Planning Council of a State shall be appointed by the Governor of the State from among the residents of that State. The Governor of each State shall make appropriate provisions for the rotation of membership on the Council of his respective State. Each State Planning Council shall at all times include in its membership representatives of the principal State agencies, higher education training facilities, local agencies, and nongovernmental agencies and groups concerned with services to persons with developmental disabilities in that State.

(2) At least one-half of the membership of each such Council shall consist of persons who--
(A) are persons with developmental disabilities or parents or guardians of such persons, or
(B) are immediate relatives or guardians of persons with mentally impairing developmental disabilities,

who are not employees of a State agency which receives funds or provides services under this part, who are not managing employees (as defined in Section 1126(b) of the Social Security Act) of any other entity which receives funds or provides services under this part, and who are not persons with an ownership or control interest (within the meaning of Section 1124(a)(3) of the Social Security Act) with respect to such an entity.

(3) Of the members of the Council described in paragraph (2)--

(A) at least one-third shall be persons with developmental disabilities, and

(B)(i) at least one-third shall be individuals described in subparagraph (B) of paragraph (2), and
(ii) at least one of such individuals shall be an immediate relative or guardian of an institutionalized person with a developmental disability.

The mandate for the Council to have individuals who are eligible for services for the developmentally disabled or their representatives for one-half of its membership is an increase in this type of representation from that required in PL 94-103. In the earlier legislation, PL 94-103, the requirement was that one-third of the Council be individuals who are eligible for services for individuals who are developmentally disabled and/or their representatives.

The Council brings together three groups of individuals who are concerned with the lives and services of individuals who are developmentally disabled. PL 95-602 requires State officials at the policy level whose departments provide services to individuals who are developmentally disabled to be members of the Council. The law mandates that fifty percent of the Council be individuals who are eligible to receive services or their representatives. The law also requires representation of providers of service and local government be on the Council.

Each Council has the following mandated responsibilities:

- (b) Each State Planning Council shall –
- (1) develop jointly with the State agency or agencies designated, under Section 133(b)(1)(B) the State plan required by this part, including the specification of areas of services under Section 133(b) (4) (A) (ii);
 - (2) monitor, review, and evaluate, not less often than annually, the implementation of such State plan;
 - (3) to the maximum extent feasible, review and comment on all State plans in the State which relate to programs affecting persons with developmental disabilities; and
 - (4) submit to the Secretary, through the Governor, such periodic reports on its activities as the Secretary may reasonably request, and keep such records and afford such access thereto as the Secretary finds necessary to verify such reports.

PL 95-602, Sec. 137

The Administrative Agency of the Developmental Disabilities Program has the responsibility of aiding in the development of the State Plan. The Administrative Agency also must implement the program of planning and service presented in the State Plan. The Administrative Agency is also the fiscal and administrative State Agency for the Developmental Disabilities Formula Grant Program and the State Planning Council.

The Developmental Disabilities Program is unique in human service programs in that it contains the requirement of maximum participation of users of services at the policy level in the State Planning Council.

The Developmental Disabilities Program is unique in that it provides for an organized Council to constantly review the services and life conditions of the most vulnerable population existent in the nation. The developmentally disabled are the most severely handicapped individuals in the nation, have the need for service all or most of their lives, and cannot in some instances speak for themselves. The developmentally disabled are the victims of abuse, neglect, indifference, apathy, and exploitation. The Developmental Disabilities Program has made and continues to make a difference in the lives of the individuals who are developmentally disabled.

The emphasis of the Developmental Disabilities Program for State Councils/Administrative Agencies was changed with the passage of PL 95-602 from the emphasis in prior years. The change was activated in two ways in these amendments. The change in definition of developmental disabilities has already been discussed in Section I of this report and is the subject of this report.

The second activator of change in the DD Program was the mandate that 65% of the Basic Formula Grant had to be expended in services and support of services in four priority areas in FY '79 and thereafter. The four priority areas in which the 65% monies must be expended are:

1. Child development services
2. Case management services
3. Alternative community living arrangement services
4. Nonvocational social developmental services

Each State is required to select at least one and no more than two of the four priority areas and expend at least 65% of its Basic Formula Grant monies in that or those areas of service. A State may select to emphasize a State option priority service area along with one of the four priority service areas heretofore listed.

The Developmental Disabilities Program has, then, as its catalyst, a DD State Planning Council which sets the basic policies for evaluation, provision of services and identification of gaps in services available to individuals who are developmentally disabled. The State Council selects the priority area of service and/or areas of service for emphasis each plan year.

In cooperation with the Administrative Agency, the State Planning Council writes and submits to the Administration on Developmental Disabilities a plan which describes the DD population, service network, needs and objectives for a three year period. The Administrative Agency implements the program described in the State Plan and the State Planning Council evaluates the process of implementation and the results of the program in order to be able to continue the planning process which increases the quantity and quality of services to the individuals who are developmentally disabled.

APPROPRIATIONS

The Developmental Disabilities Program is not designed nor intended to be a consistent provider of service monies to the developmentally disabled. The program is designed to be an advocate, to seek out and fill gaps in the service system, to find alternative program funding resources, and ensure the quality of programs provided for individuals who are developmentally disabled.

The funds for the Basic Formula State Grants of the Developmental Disabilities Program are authorized in Section 131 of PL 95-602, Title V. This is the first section which appears in Part C of the law. Part C is entitled "Grants for Planning and Provision of Services for Persons with Developmental Disabilities." Therefore, the funds provided to States in the Basic Formula are sometimes referred to as "Part C monies."

The Developmental Disabilities Program makes use of the Hill Burton Formula for the distribution of funds to each of the States. The minimum allotment to any State is \$250,000 regardless of size, population or need. The minimum allotment to each of the four Territories which participate in the program is \$135,000.

Table 1 shows the total amount appropriated for Basic Formula Grants for FY '78, FY '79, and FY '80. The table also contains a comparison of the percent of change in funding level from the control year FY '78 and the two experimental years, FY '79 and FY '80.

**TABLE II-1. AMOUNT OF APPROPRIATION AND PERCENT OF CHANGE FROM FY '78
FOR PART C MONIES FOR FY '78, FY '79, AND FY '80**

DD Program component	Approp. for FY '78	Approp. for FY '79	Per- cent	Approp. for FY '80	Per- cent
Basic State Grants	\$30,058,000	\$35,331,000	+18	\$43,180,000	+44

In FY '78, there was \$30,058,000 appropriated for Basic Formula Grants under PL 94-103. The minimum allotment to any one State in that year was \$150,000. The allotment to each of the four Territories which participated in the program was \$50,000.

In FY '79, after the passage of PL 95-602, Title V, the appropriation was increased for Basic Formula Grants to \$35,331,000. This appropriation increase of 18% over the FY '78 level was executed internal to the Developmental Disabilities Program with no increase to the overall DD budget. The money for the \$5.2 million increase in Basic Formula Grants was transferred from Section 145 monies.

The need to increase the Basic Formula Grants in FY '79 resulted from the provision in PL 95-602, Title V, which raised the minimum level provided to any State from \$150,000 to \$250,000. Also, the amount to Territories was increased from \$50,000 to \$100,000.

In FY '80, the amount appropriated for Basic Formula Grants was \$43,180,000. This amount represented a 44% increase from the FY '78 level. The overall appropriation for the DD Program was only increased by just over 5% but internal shifting of program monies between program components resulted in this increase in the appropriation for Basic Formula Grants.

States had begun the selection of priority areas during FY '79 and early FY '80. PL 95-602 provided for a transitional period for States to come into compliance with the required four priority areas of service. By FY '80, most States had selected their priority areas of service and by the beginning of FY '81, all States had selected their priority areas of service. During the current fiscal year, FY '81, 65% of the Basic Formula Grant monies will be expended on services and support of services in the four priority service areas or an approved State option.

Table 2 shows the amount and percent of Federal Basic Formula Grant monies distributed to each of the States categorized in the ten Health and Human Services regions. As has been stated, the monies are distributed to the States on the basis of the Hill Burton Formula.

In FY '78, the Federal allotment of Part C monies totalled \$30,058,000. The States in Region I received 6.4%, or just over \$19 million. The States in Region II received just under 12%, or \$3.5 million. The second largest single State appropriation is made to New York, which received just under 7% of the total Basic Formula Grant monies. The States in Region III received 11.6% of the monies, or nearly the same amount as the States in Region II. The States in Region IV received 18.1% of the monies, or \$5.4 million. The States in Region V received 19.4% of the monies, or \$5.8 million. Region VI States received just under 11% of the monies at the \$3.2 million level. The States in Region VII, of which there are four, received 5.4% of the Basic Formula appropriation, or \$1.6 million. The six States in Region VIII received 3.5% of the Basic Formula appropriation, just over \$1 million. States in Region IX received 9.6% of the Basic Formula appropriation in FY '78. The State receiving the largest single grant is

TABLE II-2. AMOUNT AND PERCENT OF FEDERAL BASIC FORMULA GRANTS PROVIDED TO EACH STATE FOR FY '78, FY '79, AND FY '80 PRESENTED BY HEALTH AND HUMAN SERVICES REGIONS

Region/State	FY '78		FY '79		FY '80	
	\$ Amount	%	\$ Amount	%	\$ Amount	%
HHS Region I	1,926,673	6.4	2,225,854	6.3	2,539,260	5.9
Connecticut	345,905	1.2	398,338	1.1	505,193	1.2
Maine	178,230	.6	252,191	.7	255,790	.6
Massachusetts	951,941	3.1	819,226	2.4	1,020,801	2.3
New Hampshire	150,000	.5	252,033	.7	252,492	.6
Rhode Island	150,597	.5	252,033	.7	252,492	.6
Vermont	150,000	.5	252,033	.7	252,492	.6
HHS Region II	3,557,125	11.8	4,327,186	12.2	5,404,409	12.5
New Jersey	824,234	2.7	935,727	2.6	1,164,247	2.7
New York	2,069,527	6.9	2,570,624	7.3	3,131,645	7.2
Puerto Rico	613,364	2.0	720,078	2.0	972,171	2.3
Virgin Islands	50,000	.2	100,757	.3	136,346	.3
HHS Region III	3,495,104	11.6	4,073,128	11.5	4,906,745	11.4
Delaware	150,606	.5	252,033	.7	252,492	.6
District/Columbia	150,000	.5	250,837	.7	252,492	.6
Maryland	470,757	1.6	534,070	1.5	654,088	1.5
Pennsylvania	1,676,518	5.5	1,836,742	5.2	2,291,467	5.3
Virginia	687,146	2.3	755,917	2.1	955,865	2.2
West Virginia	360,077	1.2	443,529	1.3	500,341	1.2
HHS Region IV	5,441,164	18.1	6,169,669	17.5	7,814,941	18.1
Alabama	644,065	2.1	714,855	2.0	894,730	2.1
Florida	1,013,516	3.4	1,186,982	3.4	1,513,608	3.5
Georgia	713,464	2.4	827,609	2.3	1,062,265	2.5
Kentucky	613,106	2.0	670,953	1.9	837,593	1.9
Mississippi	440,326	1.5	501,512	1.4	632,558	1.5
North Carolina	875,460	2.9	980,359	2.8	1,230,712	2.8
South Carolina	462,382	1.5	523,923	1.5	659,797	1.5
Tennessee	678,845	2.3	763,476	2.2	983,678	2.3
HHS Region V	5,840,951	19.4	6,444,218	18.3	8,143,885	18.9
Illinois	1,302,097	4.4	1,441,974	4.1	1,819,644	4.2
Indiana	736,324	2.4	813,878	2.3	1,023,533	2.4
Michigan	1,173,207	3.9	1,299,667	3.7	1,645,403	3.8
Minnesota	544,482	1.8	583,002	1.7	735,038	1.7
Ohio	1,414,841	4.7	1,583,950	4.5	2,013,187	4.7
Wisconsin	670,000	2.2	721,747	2.0	907,080	2.1
HHS Region VI	3,226,297	10.8	3,665,806	10.4	4,553,776	10.5
Arkansas	358,760	1.2	401,399	1.1	519,668	1.2
Louisiana	608,010	2.0	694,876	2.0	871,691	2.0
New Mexico	178,329	.6	252,152	.7	262,271	.6
Oklahoma	411,694	1.4	456,267	1.3	577,297	1.3
Texas	1,669,504	5.6	1,861,112	5.3	2,322,849	5.4
HHS Region VII	1,627,168	5.4	1,789,600	5.1	2,242,610	5.2
Iowa	424,866	1.4	450,260	1.3	567,711	1.3
Kansas	299,210	1.0	328,108	.9	418,320	1.0
Missouri	679,688	2.3	758,789	2.2	957,928	2.2
Nebraska	223,404	.7	252,443	.7	298,651	.7
HHS Region VIII	1,060,086	3.5	1,606,695	4.5	1,695,570	4.0
Colorado	283,944	.9	346,406	1.0	414,722	1.0
Montana	150,000	.5	252,033	.7	252,492	.6
North Dakota	150,000	.5	252,033	.7	252,492	.6
South Dakota	150,000	.5	252,033	.7	250,000	.6
Utah	176,142	.6	252,157	.7	273,372	.6
Wyoming	150,000	.5	252,033	.7	252,492	.6
HHS Region IX	2,872,941	9.6	3,718,611	10.5	4,348,206	10.0
Arizona	277,927	.9	333,459	.9	404,168	.9
California	2,245,014	7.5	2,780,329	7.9	3,302,708	7.6
Guam	50,000	.2	100,757	.3	136,346	.3
Hawaii	150,000	.5	252,033	.7	252,492	.6
Nevada	150,000	.5	252,033	.7	252,492	.6
HHS Region X	1,010,491	3.4	1,310,233	3.7	1,530,598	3.5
Alaska	150,000	.5	250,000	.7	252,492	.6
Idaho	150,000	.5	250,000	.7	252,492	.6
Oregon	293,573	1.0	330,676	.9	423,662	1.0
Washington	416,918	1.4	479,557	1.4	601,952	1.3
Total United States	30,058,000	100	35,331,000	100	43,180,000	100

California. California received 7.5% of the total appropriation for the DD Basic Formula Grant Program in FY '78. States in Region X received 3.4% of the Basic Formula Grant appropriation.

There was an increase of \$5,273,000 in the appropriation for the Basic Formula Grant in FY '79. This increase was an 18% increase and provided mainly for the increase in minimum allotment State fundings. PL 95-602 requires that the minimum allotment States receive no less than \$250,000 and the Territories receive no less than \$100,000. Therefore, the percentages of Basic Formula money going into each of the States in the various HHS regions experienced a slight change in FY '79.

Region I received the same percentage as in FY '78. The States in Region I received 6.3%, or \$2.2 million. States in Region II received 12.2% of the Basic Formula Grant and New York received 7.3% of the total appropriation. States in Region III received 11.5% of the Basic Formula Grant in FY '79. The States in Region IV received 17.5% of the Basic Formula Grant, or \$6.1 million. States in Region V received 18.3%, or \$6.4 million. States in Region VI received 10.4% of the Basic Formula Grant appropriation, or \$3.6 million. States in Region VII received 5.1% of the Basic Formula Grant appropriation. The States in Region VIII received 4.5% of the Basic Formula Grant, an increase of a full one percent of the Basic Formula Grant funding over the percentage received in FY '78. This increase is the direct result of the region having five minimum allotment States within its jurisdiction. Each minimum allotment State received an additional \$100,000 in funding over the FY '78 level. States in Region IX received 10.5% of the Basic Formula Grant appropriation. California received 7.9% of the total Basic Grant appropriation. States in Region X received 3.7% of the Basic Formula Grant appropriation in FY '79.

There was a 44% increase in funding in FY '80 over the level of funding in FY '78. This increase amounted to \$18,395,000 and was distributed throughout the DD community. The States in Region I received 5.9% of the Basic Formula Grant funding, or \$2.5 million. States in Region II received 12.5% of the funding, or \$5.4 million. States in Region III received 11.4% of the funding and the States in Region IV received 18.1% of the funding. The States in Region V received 18.9% of the funding and the States in Region VI received 10.5% of the funding in FY '80. States in Region VII received 5.2% of the funding and States in Region VIII received 4.0% of the funding in FY '80. States in Region IX received 10% of the funding and States in Region X received 3.5% of the funding.

The increase in funding in FY '80 was equitably distributed throughout with the exception of minimum allotment States which remained at \$250,000 in basic funding. The \$250,000, which is the minimum allotment funding, was the identical sum that minimum allotment States received in FY '79.

The fact that the Basic Formula monies are distributed according to population and size and an analysis of need in the Hill Burton Formula is reflected in the distribution of the monies through the three fiscal years covered by this report. There is not a dramatic change in the percentage received by the various States of the Basic Formula Grant with the exception of the shift caused by the increase to minimum allotment States in FY '79.

PL 95-602, Section 133(3)(D) requires that "there will be reasonable State financial participation in the cost of carrying out the State plan."

The requirement of State financial participation is referred to as State match. There is a requirement that the State match the Federal appropriations by at least 25% of the Part C monies provided to the State. In poverty areas and/or rural areas, the required match is 10% of the Basic Formula Grant. The State can either match the Federal appropriation with State monies or "in-kind" services.

Table 3 shows the amount and percent of State matching funds for Basic Formula Grants for each State for the three fiscal years included in this report. It is interesting to note that the States exceeded the 25% requirement of participation in each of the three years by as much as 7% in FY '78 and as little as 3% in FY '79.

In FY '78, the States matched the \$30 million Federal Basic Formula Grant monies with \$14,057,923. Five and seven-tenths percent of this amount was provided by the States in Region I. Seven teen and six-tenths percent was provided by the States in Region II and 22.7% was provided by the States in Region III. The States in Region IV provided 14.8% of the match of the Federal dollars and the States in Region V provided 15.1%. States in Region VI provided 7.4% of the Basic Formula Grant match monies for FY '78, and the States in Region VII provided 2.6% of the monies. The six States in Region VIII provided just under 5% of the match monies and the States in Region IX provided 6.9% of the match monies. The States in Region X provided 2.3% of the match monies in FY '78.

In FY '79, the percentage of match was somewhat less than in FY '78. However, it must be pointed out that the increase in appropriation was not approved and distributed to the States until the last three months of the fiscal year 1979. The reason for the delay in the distribution of the increase in appropriation was the fact that supplemental appropriations were not made to the DD Bill until after it had been signed in November of 1978. The supplemental appropriation then had to move through the Congress and the Administration. Therefore, the basis of match by the States was the \$30 million level instead of the supplemented \$35 million level which was eventually distributed to the States. The match that is displayed on Table 3 is really a match of a \$30 million level rather than a \$35 million level. The reader must keep this in mind when scrutinizing the figures contained within the referenced table.

TABLE II-3. AMOUNT AND PERCENT OF STATE MATCHING FUNDS FOR BASIC FORMULA GRANTS FOR EACH STATE FOR FY '78, FY '79, AND FY '80 PRESENTED BY HEALTH AND HUMAN SERVICES REGIONS

Region/State	FY '78		FY '79		FY '80	
	\$ Amount	%	\$ Amount	%	\$ Amount	%
HHS Region I	806,374	5.7	784,685	5.7	634,818	3.3
Connecticut	115,301	.8	119,694	.9	119,694	.6
Maine	300,700	2.1	300,700	2.2	85,000	.4
Massachusetts	239,861	1.6	180,291	1.2	180,291	1.0
New Hampshire	50,000	.4	50,000	.4	83,333	.4
Rhode Island	50,512	.4	84,000	.6	138,500	.7
Vermont	50,000	.4	50,000	.4	28,000	.2
HHS Region II	2,477,033	17.6	3,011,343	22.1	3,241,838	17.1
New Jersey	461,773	3.3	884,358	6.5	967,959	5.1
New York	910,512	6.4	908,472	6.7	1,055,366	5.5
Puerto Rico	1,089,748	7.8	1,203,513	8.8	1,203,513	6.4
Virgin Islands	15,000	.1	15,000	.1	15,000	.1
HHS Region III	3,186,417	22.7	2,211,801	16.2	2,156,731	11.4
Delaware	50,303	.4	50,000	.4	83,333	.4
District/Columbia	50,000	.4	60,192	.4	63,227	.3
Maryland	312,758	2.2	374,741	2.7	659,800	3.5
Pennsylvania	2,235,357	15.9	597,839	4.4	600,000	3.2
Virginia	232,802	1.6	232,802	1.7	228,127	1.2
West Virginia	305,197	2.2	896,227	6.6	522,244	2.8
HHS Region IV	2,076,892	14.8	2,150,955	15.8	2,551,029	13.5
Alabama	269,116	1.9	260,676	1.9	298,244	1.6
Florida	377,212	2.7	337,839	2.5	324,162	1.7
Georgia	237,584	1.7	237,584	1.8	237,821	1.3
Kentucky	204,369	1.5	271,740	2.0	493,966	2.6
Mississippi	140,095	1.0	165,131	1.2	334,565	1.8
North Carolina	348,593	2.5	305,781	2.2	323,610	1.7
South Carolina	174,618	1.2	257,795	1.9	253,322	1.3
Tennessee	325,305	2.3	314,409	2.3	285,339	1.5
HHS Region V	2,121,824	15.1	1,960,384	14.4	2,566,758	13.6
Illinois	434,032	3.0	480,658	3.5	606,548	3.2
Indiana	247,971	1.8	247,971	1.8	184,081	1.0
Michigan	563,380	4.0	357,487	2.6	543,055	2.9
Minnesota	181,494	1.3	182,124	1.4	242,595	1.3
Ohio	471,614	3.4	469,715	3.5	691,104	3.7
Wisconsin	223,333	1.6	222,429	1.6	299,375	1.5
HHS Region VI	1,032,330	7.4	994,835	7.3	1,294,363	6.8
Arkansas	93,655	.7	49,339	.4	97,164	.5
Louisiana	202,670	1.4	231,625	1.7	290,564	1.5
New Mexico	42,272	.3	22,974	.2	83,333	.4
Oklahoma	137,231	1.0	153,422	1.1	202,932	1.1
Texas	556,502	4.0	537,475	3.9	620,370	3.3
HHS Region VII	369,185	2.6	372,590	2.7	763,255	4.0
Iowa	20,000	.1	20,000	.1	190,000	1.0
Kansas	99,736	.7	102,840	.8	123,423	.7
Missouri	174,981	1.3	174,981	1.3	314,833	1.6
Nebraska	74,468	.5	74,769	.5	134,999	.7
HHS Region VIII	687,594	4.9	460,333	3.4	602,364	3.2
Colorado	115,602	.8	115,602	.9	151,104	.8
Montana	34,689	.3	54,950	.4	88,960	.5
North Dakota	104,249	.7	93,369	.7	91,667	.5
South Dakota	51,000	.4	67,000	.5	94,661	.5
Utah	58,779	.4	74,412	.5	84,305	.4
Wyoming	323,275	2.3	55,000	.4	91,667	.5
HHS Region IX	973,555	6.9	1,387,995	10.1	1,774,849	9.4
Arizona	97,000	.7	505,800	3.6	756,000	4.0
California	771,000	5.4	771,000	5.6	817,930	4.3
Guam	5,555	.0	11,195	.1	15,000	.1
Hawaii	50,000	.4	50,000	.4	83,333	.4
Nevada	50,000	.4	50,000	.4	102,586	.6
HHS Region X	326,719	2.3	321,205	2.3	3,348,326	17.7
Alaska	50,000	.4	50,000	.4	83,333	.4
Idaho	50,000	.4	50,000	.4	84,300	.4
Oregon	91,000	.6	91,000	.6	3,019,938	16.0
Washington	135,719	.9	130,205	.9	160,755	.9
Total United States	14,057,923	100	13,656,126	100	18,934,331	100

In FY '79, the States matched the Federal Basic Formula Grant funds with \$13,656,126. Of this amount, 5.7% came from the States in Region I. Twenty-two and one-tenth percent was from States in Region II. Sixteen and two-tenths percent was from States in Region III. There was 15.8% of the match from States in Region IV and 14.4% from States in Region V. There was 7.3% match from the States in Region VI and 2.7% of the match generated during FY '79 came from the States in Region VII. There was 3.4% of the match from the States in Region VIII and 10.1% of the match from the States in Region IX. Two and three-tenths percent of the match came from the States in Region X.

It must be kept in mind that when we are displaying the match of Federal dollars to State programs, the match can be in-kind or in program dollars and is provided at the discretion of the State to be utilized in any category of program activity. The point in providing an assessment of the matching dollars is to demonstrate that the DD program has met its required fiscal obligation in each of the fiscal years covered in the report. Also, this display is made to demonstrate that not only has the totality of the program met its mandated fiscal obligation, but each State has indeed met and exceeded, in many cases, its obligation to match Federal dollars.

In FY '80, the DD community matched the Federal Basic Formula Grant with \$18,934,331. The State match in FY '80 was a significant increase over the level of match in FY '79 and reflected the increase in Basic Formula Grant monies. The States in Region I provided 3.3% of the match. States in Region II provided 17.1% of the total amount in match. States in Region III provided 11.4% of the funds and in-kind services used to match Federal Basic Formula Grant monies. The States in Region IV provided 13.5% and the States in Region V provided 13.6% of the match. States in Region VI provided 6.8% and States in Region VII provided 4.0% of the match. States in Region VIII provided 3.2% of the match and States in Region IX provided 9.4% of the match. States in Region X provided 17.7% of the match.

Generally, looking across the contributions by the States to the DD Program in relationship to the Basic Formula Grant Program, there is not a significant change with the exception of Region X States in FY '80 from its FY '78 and FY '79 levels.

The source of the data on Table 3 is the approved State Plan budget submission by each of the States for each of the three fiscal years.

Table 4 contains a summary of the total amount and percent of Federal Part C monies and non-Federal monies appropriated for the Developmental Disabilities Program for each of the Fiscal years '78, '79, and '80. As can be seen from the information displayed on the table, in FY '78, \$44,115,923 was budgeted for the DD Program in the 54 States and Territories participating in

the program. Sixty-eight percent of the money was Federal allotment monies and 32% was non-Federal, State matching dollars.

In FY '79, the total amount was increased to \$48,987,126 with \$35.3 million being appropriated by the Federal dollars and \$13.6 million, or 28%, being appropriated in State match, either in-kind or in dollars. The reader must note the explanation for the apparent decrease in State match in relationship to the percentage of Federal funding that has heretofore been provided.

In FY '80, the Basic Formula Grant budget was \$62,114,331, of which 70%, or \$43,180,000, was Federal dollars and 30%, or \$18,934,331, was State match.

The Basic Formula Grant Program, then, increased in FY '79 and FY '80 over the FY '78 level. The most dramatic increase was in FY '80. The increase was just over 40% of the FY '78 level.

**TABLE II-4. AMOUNT OF APPROPRIATION AND PERCENT OF CHANGE FROM FY '78
FOR PART C MONIES FOR FY '78, FY '79, AND FY '80**

Fiscal Year	Federal		Non-Federal		Total	
	Amount	%	Amount	%	Amount	%
Fiscal '78	\$30,058,000	68	\$14,057,923	32	\$44,115,923	100
Fiscal '79	35,331,000	72	13,656,426	28	48,987,126	100
Fiscal '80	43,180,000	70	18,934,331	30	62,114,331	100

UTILIZATION OF RESOURCES

PL 95-602 requires that the funds be used in "strengthening services for persons with developmental disabilities through agencies in the various political subdivisions of the State." The law further requires that "part of the funds will be made available by the State to public or non-profit private entities."

In FY '78, at the time when the DD Program operated under the amendments contained in PL 94-103, the States were requested to submit budgets in four categories. The four required categories were:

Council Planning - This is the amount of funds used by the Council for its staff, Council operations, expense of meeting, and expense of developing and producing the required State Plan.

Other Planning - This is the amount of funds used for planning activities other than those identified in Council planning.

Administration - This is the amount of funds used by the Administrative Agency(ies) to carry out its tasks of aiding in the development of the State Plan, implementing the programs within the State Plan, and providing administrative and fiscal support to the State DD Planning Council. There can be no more than 5%, or \$50,000, of the Federal Basic Formula Grant used for this purpose in any State.

Services - This is the amount of funds used to fill identified gaps in the service system. Gaps in the service system are filled by providing seed money for new programs, provide augmentation to existing programs, and/or support specific identified services for individuals or groups of individuals,. In FY '78, at least 30% of the Federal Basic Formula Grant was to be used for programs in deinstitutionalization. In FY '79 and '80, the States were to strive to use at least 65% in one or more of the four priority service areas or an approved State specific option service area.

Table 5 shows the amounts and percent of Federal Basic Formula Grant funds expended in each of the four budget categories for each of the three fiscal years by the States and Territories participating in the DD Program.

TABLE 11-5. AMOUNT AND PERCENT OF FEDERAL BASIC FORMULA GRANT FUNDS EXPENDED FOR COUNCIL PLANNING, OTHER PLANNING, ADMINISTRATION, AND SERVICES FOR FY '78, FY '79, AND FY '80 BY STATES PARTICIPATING IN THE DEVELOPMENTAL DISABILITIES PROGRAM

Fiscal year	Total appropriation		Council planning		Other planning		Administration		Services	
	Amount	%	Amount	%	Amount	%	Amount	%	Amount	%
Fiscal '78	\$30,058,000	100	\$4,074,833	13.6	\$2,673,384	8.9	\$ 884,598	2.9	\$22,425,185	74.6
Fiscal '79	35,331,000	100	6,596,444	18.6	2,118,963	6.0	805,549	2.3	25,810,044	73.1
Fiscal '80	43,180,000	100	7,537,948	17.4	1,688,991	3.9	1,068,622	2.5	32,884,439	76.2

In FY '78, the total Federal appropriation of Part C monies under PL 94-103 was \$30,058,000. Of these monies, 13.6% was expended for Council Planning, and 8.9% was expended for other types of planning activities. There was 2.9% of the Federal allotment used for administration in FY '78. There was 74.6% of the Federal allotment used to provide services to individuals who were developmentally disabled. The total dollar amount of Basic Federal Formula funds expended for services in FY '78 was \$22,425,185.

There was an 18% increase in the Basic Formula funds appropriation in FY '79 over the FY '78 level. The total appropriation was \$35,331,000. Of this amount, 18.6% was expended for Council planning and 6.0% for other planning activities. There was only 2.3% of the Federal funds used for administration in FY '79, a decrease of six-tenths of a percent over the FY '78 level. The DD community spent 73.1% of the Basic Formula monies on services for the developmentally disabled, or \$25,810,044.

There was a 44% increase in the Federal Basic Formula funds appropriation in FY '80 over the FY '78 level. The total appropriation was \$43,180,000. There was 76.2% of this money expended for services for the developmentally disabled during this year. Only 2.5% of the money was expended for administration. The Councils used 17.4% of the money for Council planning, and 3.9% was expended for other types of planning activities.

It is apparent that the change in PL 95-602 requiring 65% of the Basic Formula Grant funds to be expended for priority services has not had a significant impact on the percentage of expenditures for services in the DD Program. The percentage of expenditures of Federal Basic Formula funds for services in FY '80 increased only 1.6% over the FY '78 level. The percentage of expenditures for services in FY '79 decreased 1.5% from the FY '78 level. However, these changes in percentage between the three fiscal years do not represent a significant change in program expenditure of funds.

It is of interest to examine the category of expenditures by the various States over the three year period. As to the information contained on the next three tables, it is important to recognize the composition of the States which are located in each of the ten regions of the Department of Health and Human Services. Generally, the information presented indicates that those regions which have a majority of minimum allotment States contribute a lower percentage of the Federal Basic Formula funds to services than those States which exceed the minimum allotment.

One major factor in the above occurrence is that in the lesser populated States, there are great distances to travel and a significant rural area to cover in the service system. Also, the required composition of the DD Council and minimum staffing pattern are identical within the law. Therefore, there is a minimum cost incurred for Council planning and operation no matter the size of the appropriation. It is demonstrated in the next pages that the minimum allotment States require a larger percentage of their Basic Formula funds to operate their Councils than do the more populous and affluent States.

Table 6 shows the amount and percent of Federal Basic Formula funds expended by States for Council planning, other planning, administration, and services for FY '78 displayed in Health and Human Services Regions.

TABLE 11-6. AMOUNT AND PERCENT OF FEDERAL BASIC FORMULA FUNDS EXPENDED BY STATES FOR COUNCIL PLANNING, OTHER PLANNING, ADMINISTRATION, AND SERVICES FOR FY '78 DISPLAYED BY HEALTH AND HUMAN SERVICES REGIONS

Health & Human Services Region	No. of States	Total appropriation		Council planning		Other planning		Adminis- tration		Services	
		Amount	%	Amount	%	Amount	%	Amount	%	Amount	%
Region I	6	\$ 1,926,673	100	\$ 387,151	20	\$ 189,261	10	\$ 84,338	4	\$ 1,267,983	66
Region II	4	3,557,125	100	383,567	11	8,500	0	0	0	3,165,058	89
Region III	6	3,495,104	100	397,648	11	562,911	16	87,904	3	2,446,641	70
Region IV	8	5,441,164	100	641,748	12	948,995	17	161,548	3	3,688,873	68
Region V	6	5,840,951	100	778,070	13	356,223	6	212,180	4	4,494,478	77
Region VI	5	3,226,297	100	217,271	7	50,000	2	146,503	4	2,812,523	87
Region VII	4	1,627,168	100	43,128	3	432,416	26	44,870	3	1,106,754	68
Region VIII	6	1,060,086	100	318,964	30	61,706	6	37,041	3	642,375	61
Region IX	5	2,872,941	100	613,315	21	30,440	1	74,687	3	2,154,499	75
Region X	4	1,010,491	100	296,031	29	32,932	3	35,527	4	646,001	64
Total	54	\$30,058,000	100	\$4,076,893	13	\$2,673,384	9	\$884,598	3	\$22,425,185	75

In FY '78, the percent of Federal Basic Formula funds used for Council planning ranged from 30% in Region VIII, which has a majority of minimum funded States, to 3% for the States in Region VII. The 3% for Region VII States must be viewed in the light of these States expending 26% of the Basic Formula Grant funds for planning activities other than Council planning.

In FY '78, the percent of Federal Basic Formula funds used for other planning activities ranged from 26% for the States in Region VII to the States in Region II which used less than one percent for this purpose. It must be pointed out that specific instructions as to items and activities listed under this budget category were not clarified, and in many cases a State option. Therefore, a composite picture of the planning activity for the State DD program may be seen by combining the amount contained under Council planning and other planning.

The percentage used for administration ranged between 4% for States in several HHS regions to the States in Region II which did not use any Federal funds for this purpose in FY '78.

The percentage of Federal funds used for services in FY '78 ranged from 8% for the States in Region II to 61% for the States in Region VIII. Again, it must be pointed out that Region VIII is almost entirely composed of minimum allotment States, as are many of the regions which have the lower percentage of funds expended for services.

Table 7 contains the amount and percent of Federal Basic Formula funds expended in the four budget categories by States in FY '79.

TABLE 11-7. AMOUNT AND PERCENT OF FEDERAL BASIC FORMULA FUNDS EXPENDED BY STATES FOR COUNCIL PLANNING, OTHER PLANNING, ADMINISTRATION, AND SERVICES FOR FY '79 DISPLAYED BY HEALTH AND HUMAN SERVICES REGIONS

Health & Human Services Region	No. of States	Total appropriation		Council planning		Other planning		Adminis- tration		Services	
		Amount %		Amount %		Amount %		Amount %		Amount %	
		Amount	%	Amount	%	Amount	%	Amount	%	Amount	%
Region I	6	\$ 2,225,854	100	\$ 594,324	26	\$ 18,774	1	\$ 56,217	3	\$ 1,556,539	70
Region II	4	4,327,186	100	534,415	12	9,000	0	56,000	1	3,727,771	86
Region III	6	4,073,128	100	983,293	24	158,740	4	74,021	2	2,857,074	70
Region IV	8	6,169,669	100	750,930	12	536,532	9	147,631	2	4,734,576	77
Region V	6	6,444,218	100	1,523,455	23	621,558	10	192,466	3	4,106,739	64
Region VI	5	3,665,806	100	364,314	10	225,763	6	70,497	2	3,005,232	82
Region VII	4	1,789,600	100	93,227	5	357,395	20	62,199	4	1,276,779	71
Region VIII	6	1,606,695	100	509,822	31	61,849	4	44,024	3	991,000	62
Region IX	5	3,718,611	100	792,394	21	129,352	4	66,591	2	2,730,274	73
Region X	4	1,310,233	100	450,270	34	0	0	35,903	3	824,060	63
Total	54	\$35,331,000	100	\$6,596,444	19	\$2,118,963	6	\$805,549	2	\$25,810,044	73

Council planning required 19% of the appropriation in FY '79. The range of expenditures was from 31% for the States in Region VIII to 5% in Region VII. However, Region VII had the highest percent of funds used in other planning activities, with 20% going for this purpose. Region II States had less than one percent of funds for other planning in FY '79.

Only the States in Region VII had 4% of their funds expended for administration. There were States in four regions which expended 3% for this purpose. The States in Region II expended 1% for administration.

There was 73% of the Basic Formula Grant funds expended for services in FY '79. The range in percent was from 62% on the low end to 86% on the top end of the range.

Table 8 shows that 76% of the Federal Basic Formula was used for services in FY '80. Seventeen percent was used for Council planning and 4% was used for other planning. Three percent of the Federal Basic Formula funds was used for administration.

TABLE 11-8. AMOUNT AND PERCENT OF FEDERAL BASIC FORMULA FUNDS EXPENDED BY STATES FOR COUNCIL PLANNING, OTHER PLANNING, ADMINISTRATION, AND SERVICES FOR FY '80 DISPLAYED BY HEALTH AND HUMAN SERVICES REGIONS

Health & Human Services Region	No. of States	Total appropriation		Council planning		Other planning		Adminis- tration		Services	
		Amount	%	Amount	%	Amount	%	Amount	%	Amount	%
Region I	6	\$ 2,539,260	100	\$ 589,482	23	\$ 155,213	6	\$ 55,392	2	\$ 1,740,073	69
Region II	4	5,404,409	100	724,834	13	37,846	1	97,576	2	4,543,153	84
Region III	6	4,906,745	100	674,181	14	240,208	5	146,423	3	3,845,933	78
Region IV	8	7,814,941	100	976,356	12	279,429	4	238,596	3	6,320,560	81
Region V	6	8,143,885	100	1,796,341	22	399,556	5	231,040	3	5,716,948	70
Region VI	5	4,553,776	100	325,318	7	576,739	13	87,124	2	3,564,595	78
Region VII	4	2,242,610	100	396,615	18	0	0	53,842	2	1,792,153	80
Region VIII	6	1,695,570	100	544,922	32	0	0	65,526	4	1,085,122	64
Region IX	5	4,348,206	100	1,097,600	25	0	0	78,559	2	3,172,047	73
Region X	4	1,530,598	100	412,199	27	0	0	14,544	1	1,103,855	72
Total	54	\$43,160,000	100	\$7,537,848	17	\$1,688,991	4	\$1,068,622	3	\$32,884,439	76

There was a range of 32% of funds used in FY '80 for Council planning in Region VIII to 7% in Region VI. However, it must be noted that the States in Region VI used 13% of the Basic Formula funds for other planning activities during FY '80. The States in Region VII through X had no expenditures in other planning activities listed in FY '80.

The percentage of monies used for administration remained consistent in FY '80 when compared to prior years.

There was 64% of the monies in the States in Region VIII expended for services in FY '80. The States in Region II expended 84% of their allotment for this purpose.

In summary, it is apparent that a certain percent of Basic Formula Grant monies are needed to implement PL 95-602 and get maximum participation from the DD community. However, it is also apparent that the DD community is exceeding the requirement of 65% expenditures on services and service related activities and has so exceeded this mandate in each of the last three fiscal years.

SERVICES PROVIDED

There were a variety of different services provided to individuals who are developmentally disabled as a result of the activity of the State Planning Councils and Administrative Agencies in FY '78, FY '79, and FY '80. Approximately 75 cents of every Federal Basic Formula dollar was spent on services in each of the three years.

The type of services which were purchased for the developmentally disabled varied from State to State as each Council surveyed the needs and explored the gaps in the service system. It is apparent that there are a variety of services which must be provided for the developmentally disabled since a person must have a "need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated" in order to be diagnosed as developmentally disabled.

In FY '78, the OD Program under PL 94-103 focused on sixteen services which were listed in those amendments to the Developmental Disabilities Act. The sixteen services listed in the Act were:

- Diagnosis
- Evaluation
- Treatment
- Personal care
- Day care
- Domiciliary care
- Special living arrangements
- Training
- Education
- Sheltered employment
- Recreation
- Counseling
- Protection and social services
- Information and referral
- Follow-along
- Transportation

Federal funds were used to provide services in any one or all of the above service areas in FY '78. The areas selected by each State Planning Council and Administrative Agency depended upon the identified need and results of the planning process.

In FY '79, the focus of the DD Program was narrowed with the introduction of four priority service areas in PL 95-602. The term 'services for persons with developmental disabilities' is stated as "priority services (as defined in subparagraph (B)), and any other specialized services or special adaptations of generic services for persons with developmental disabilities..."

The DD community began to hold conferences on the four priority service areas attempting to understand and implement this new emphasis in the DD legislation. Section 102 of PL 95-602, paragraph B contains the definition of priority service:

The term 'priority service' means ease management services (as defined in subparagraph (C)), child development services (as defined in subparagraph (D)), alternative community living arrangement services (as defined in subparagraph (E)), and nonvocational social developmental services (as defined in subparagraph (F)) .

The authors of the legislation defined, as one can see from the text, each of the four priority services, listing many of the sixteen services listed in PL 94-103 under the appropriate priority service area.

The DD Councils and Administrative Agencies were given the mandate to select at least one and no more than two of the four priority areas and to expend at least 65% of the Federal Formula appropriation for programs in that or those priority area(s) selected.

There is broad latitude as to the type of program or support services which can be funded under each of the four priority service areas. The service activities which can be supported through the use of Federal Formula funds are contained in Section 133 of PL 95-602, Paragraph (4)(B)(iv). The paragraph is as follows:

For purposes of this subparagraph, the term 'service activities' includes, with respect to an area of service, provisions of services in the area, model service programs in the area, activities to increase the capacity of institutions and agencies to provide services in the area, coordinating the provision of services in the area with the provision of other services, outreach to individuals for the provision of services in the area, the training of personnel to provide services in the area, and similar activities designed to expand the use and availability of services in the area.

PL 95-602, Sec. 133(4)(B)(iv)

The DD community had been providing programs and services in the four priority areas prior to the passage of PL 95-602. Table 9 shows the expenditure of Federal Formula monies for services by program categories for FY '78, FY '79, and FY '80. For the purposes of this report, the programs funded with Federal Formula dollars have been divided into ten categories. The categories are:

Child development
Case management
Alternative living arrangements
Nonvocational social development
Training
Employment/vocational development
Advocacy
Standards/needs assessment
Public awareness
Council activities

The first four categories of service programs are the four priority service areas contained in PL 95-602 heretofore referenced. The definition of each of these areas of service used for this report is the definition contained in PL 95-602. These definitions are as follows:

The term 'child development services' means such services as will assist in the prevention, identification, and alleviation of developmental disabilities in children, and includes (i) early intervention services, (ii) counseling and training of parents, (iii) early identification of developmental disabilities, and (iv) diagnosis and evaluation of such developmental disabilities.

PL 95-602, Sec. 102(8)(D)

The term 'case management' means such services to persons with developmental disabilities as will assist them in gaining access to needed social, medical, educational, and other services, and such term includes – (i) follow-along services which ensure, through a continuing relationship, lifelong if necessary, between an agency or provider and a person with a developmental disability and the person's immediate relatives or guardians, that the changing needs of the person and the family are recognized and appropriately met; and (ii) coordination of services which provide to persons with developmental disabilities support, access to (and coordination of) other services, information on programs and services, and monitoring of the person's progress.

PL 95-602, Sec. 102(8)(C)

The term 'alternative community living arrangements' means such services as will assist persons with developmental disabilities in maintaining suitable residential arrangements in the community, and includes

inhouse services (such as personal aids and attendants and other domestic assistance and supportive services). family support services, foster care services, group "living services, respite care, and staff training, placement, and maintenance services.

PL 95-602,Sec.102(8)(E)

The term 'nonvocational social-developmental services' means such services as will assist persons with developmental disabilities in performing daily living and work activities.

PL 95-602,Sec.102(8)(F)

There are six additional categories of programs funded by Federal monies expended for service projects in FY '78, FY '79, and FY '80 in this report. The definitions used for programs funded in each of these categories are as follows:

Training is a category which contains programs such as management training of a variety of personnel, general conferences and seminars for professionals, para-professionals and the general public on specific issues concerning individuals who are developmentally disabled and all other training programs in which specific topics and/or target populations were not specifically identified.

Employment/vocational development contains all programs in which employment and/or specific occupational and vocational instruction was conducted.

Advocacy contains all the programs in which the Council and Administrative Agency provided financial support to the State designated advocacy agency and advocacy programs conducted within the State by organizations other than the State designated advocacy agency.

Standards/needs assessment category contains programs identified as establishing standards for services for the developmentally disabled, conducting needs assessment and/or developing evaluation tools and procedures for services provided to individuals who are developmentally disabled.

Public awareness category contains all programs in which media materials were prepared, public awareness campaigns conducted, and public relations activities carried on which attempted to inform the general public about the needs and abilities of individuals who are developmentally disabled.

Council activities is a category that contains those service programs specifically related to the development of the skills, knowledge and operation of the members of the Councils in being or becoming more effective Council members.

Each of the service programs funded in each State in FY '78, FY '79, and FY '80 was placed in one of the ten categories.

TABLE 11-9. NUMBER OF PROJECTS, AMOUNT AND PERCENT OF FEDERAL FORMULA RESOURCES USED FOR SERVICE ACTIVITIES IN FY '78, FY '79, AND FY '80 BY CATEGORICAL HEADINGS FOR ALL STATES AND TERRITORIES PARTICIPATING IN THE DEVELOPMENTAL DISABILITIES PROGRAM

Category of project	Fiscal '78			Fiscal '79			Fiscal '80		
	No. of Proj.	Amount	%	No. of Proj.	Amount	%	No. of Proj.	Amount	%
Child Development	111	\$ 2,638,042	11.8	159	\$ 3,944,961	15.3	208	\$ 5,441,543	16.6
Case Management	29	833,325	3.7	25	1,168,849	4.5	76	2,950,171	9.0
Alternative Liv. Arrg.	258	8,313,648	37.1	277	8,744,883	33.9	285	11,641,408	35.4
Nonvoc. Social Devel.	209	3,901,899	17.3	224	4,732,156	18.3	208	6,060,840	18.4
Training	20	734,415	3.3	31	1,295,233	5.0	34	1,122,501	3.4
Employment/Voc. Devel.	61	1,184,897	5.3	60	1,066,260	4.1	24	918,269	2.8
Advocacy	52	2,935,637	13.1	71	3,214,136	12.5	47	2,894,019	8.8
Standards/Needs Asses.	19	581,916	2.6	17	530,267	2.1	15	395,927	1.2
Public Awareness	49	738,310	3.3	43	497,693	1.9	36	633,280	1.9
Council Activities	30	563,096	2.5	35	615,606	2.4	24	826,481	2.5
Total	838	\$22,425,185	100	942	\$25,810,044	100	957	\$32,884,439	100

There was a total of \$22,425,185 of the Federal Formula funds used for 838 different service activities in FY '78. Nearly 70% of these funds was used for service activities in one of the four priority areas of services identified in PL 95-602. Over one-third, 37.1%, of all service monies was used in the area of alternative living arrangements. Nonvocational social developmental service activities received 17.3% of the funds, child development service activities 11.8% of the funds, and 3.7% of the funds went to the case management area of service.

Advocacy programs received 13.1% of the service money in FY '78. Employment/vocational development received 5.3%, training 3.3%, and public awareness 3.3% of the service money expended. The Councils and Administrative Agencies expended 2.6% of the monies for the development of standards, and 2.5% for Council development and awareness.

In FY '79, \$25,810,004 of the Federal Formula funds were expended for service activities. Of this amount, 72% was expended for activities in the four priority service areas identified in PL 95-602. Just over one-third, 33.9%, of the service dollars was expended in the area of alternative living arrangements. There was 18.3% expended for nonvocational social development, 15.3% for child development, and 4.5% for case management.

Advocacy programs received 12.5% of the service monies in FY '79. Employment/vocational development programs received 4.1%, and training projects received 5.0% of the funds. Public awareness programs received 1.9% of the funds. Council development was supported with 2.4% of the funds, and 2.1% of the funds was used to develop standards for the DD Program.

In FY '80, \$32,884,439 of the Federal Formula funds were expended for service activities. Of this amount, almost 80% was expended for activities in the four priority areas of service. As in FY '78 and FY '79, just over one-third of all service funds, 35.4%, was used for services for alternative living arrangements. Almost the same percentage as was expended in FY '79 was expended for nonvocational social development in FY '80. Child development programs received 16.6% of the funds in FY '80. The category which received the largest increase in percentage of service monies in FY '80 compared to FY '79 was case management. Nine percent of the service dollars was spent for case management programs in FY '79.

Advocacy programs received 8.8% of the service dollars in FY '80. Employment/vocational development received 2.8%, and training was funded with 3.4% of the service dollars. Exactly the same percent of funds was expended in FY '80 as was expended in FY '79 for public awareness programs, while 2.5% was expended for Council development, and 1.2% expended for the development of standards.

Table 10 contains a comparison of the percent of Federal Formula funds expended for services between FY '78, FY '79, and FY '80 by all 54 States and Territories participating in the DD Program. The information on the table shows the increase or decrease in percent of funds used in FY '79 and FY '80 for programs in each category when compared to the percent expended in FY '78.

The overall change in percent of expenditure over the three year period came in the area of programs in the four priority service areas. There has been an increase of 9.5% in the percentage of funds expended in the four areas of service compared to the percentage expended in FY '78. Case management programs received the largest increase in percentage of funds, closely followed by the programs in the area of child development. The percentage provided for alternative living arrangement programs decreased from FY '78 to FY '80. It must be kept in mind that there was a

Category of project	Fiscal '78	Fiscal '79		Fiscal '80	
	Percent of funds	Percent of funds	Increase/decrease from FY'78	Percent of funds	Increase/decrease from FY'78
Priority Area Total	69.9	72.0	+ 2.1	79.4	+ 9.5
Child Development	11.8	15.3	+ 3.5	16.6	+ 4.8
Case Management	3.7	4.5	+ .8	9.0	+ 5.3
Alternative Liv. Arrg.	37.1	33.9	- 3.2	35.4	- 1.7
Nonvoc. Social Devel.	17.3	18.3	+ 1.0	18.4	+ 1.1
Other Direct Service Total	21.7	21.6	- .1	15.0	- 6.7
Advocacy	13.1	12.5	- .6	8.8	- 4.3
Employment/Voc. Devel.	5.3	4.1	- 1.2	2.8	- 2.5
Training	3.3	5.0	+ 1.7	3.4	+ .1
Support Service Total	8.4	6.4	- 2.0	5.6	- 2.8
Public Awareness	3.3	1.9	- 1.4	1.9	- 1.4
Standards/Needs Asses.	2.6	2.1	- .5	1.2	- 1.4
Council Activities	2.5	2.4	- .1	2.5	0

considerable increase in the dollar amount expended for services between FY '78 and FY '80. Therefore, although the percentage of funds decreased between the funding years for alternative living arrangements, the actual dollar amount increased in FY '80 over that expended in FY '78 by over \$3.3 million. There was a 1.1% increase in the percentage devoted to programs in nonvocational social developmental areas of service from FY '78 to FY '80.

The percentage devoted to programs in advocacy decreased from 13.1% in FY '78 to 8.8% in FY '80. Employment/vocational development programs went from the 5.3% funding level in FY '78 to 2.8% in FY '80. The percent of funds used for training rose in FY '79 from the FY '78 level but returned to the FY '78 level in FY '80.

Programs in the support services of public awareness, standards/needs assessment, and Council activities experienced a decrease in the percent of funding level from FY '78 to FY '80. However, the actual dollar amount for programs in these three areas actually increased from FY '78 to FY '80 because of the increase in the amount expended for service projects in FY '80 over the amount expended in FY '78.

In summary, the implementation in the change in the definition of developmental disabilities from the one contained in PL 94-103 to the one contained in PL 95-602 apparently has not affected the services provided with the Federal Formula funds by the DD Planning Councils and Administrative Agencies.

The apparent effect of PL 95-602 on the provision of services is that States are, in fact, focusing almost all of their service dollars in the four priority service areas. In FY '78, the States expended 75% of the Federal Formula dollars for services, of which 70% went into programs in the four priority areas of service identified in PL 95-602. In FY '79, the States expended 73% of the Federal Formula funds for services, of which 72% went into programs in the four priority service areas. In FY '80, over 76% of the Federal Formula funds was spent for services, of which almost 80% went into programs in the four priority areas of service identified in PL 95-602.

The percent of Federal Formula Grant resources used for services remained constant over the three year period. However, in FY '78, 70% was used for programs in the four priority service areas, while in FY '80, almost 80% was used in these four areas of service. This 10% increase in the percentage of funds devoted to the priority service areas clearly demonstrates that the DD community is focusing its resources on the areas of services identified in the law and complying with the program direction and mandate.

POPULATIONS SERVED

The Federal Formula Basic State Grant monies of PL 94-103 and PL 95-602 are used, as has been demonstrated, in four primary activities. The four primary activities are:

- Council planning
- Other planning activities
- Administration
- Service activities and programs

The breakdown of expenditures of the Federal Formula funds has been heretofore provided in this report. The expenditure of funds can be categorized into three categories in order to ascertain the disability groups which were served through the expenditure of funds.

The mandated report requires that "the number of persons with developmental disabilities in each category served before and after such date of enactment" be included in the report. However, because of the fact that much of the Federal Basic Formula Grant funds are used in support and augmentation of existing programs, accurate and valid population statistics are difficult to present. The actual number of persons served through Federal Formula funds can legitimately be listed as the entire estimated developmental disabilities population of 5.2 million in FY '78, or 3.9 million in FY '80, or as the total number of individuals involved in specific projects fully or partially funded with Federal Formula Grant funds.

Since Federal Basic Formula Grant funds are used for a variety of activities including comprehensive planning, developing the network of services, and providing seed monies for specific program activities, enumeration of the population served has been omitted from this report. It is assumed that the tracking of the Federal Basic Formula dollars to the appropriate disability group provides more reliable data as to the impact of the definition of developmental disabilities in PL 95-602 than would a forced or incomplete enumeration of the population served.

The first category of expenditures is those expenditures which include the support of the Council, all planning activities, and the expenditures for administration. The expenditures in this group would encompass the entire developmental disabilities community within the State, and therefore these expenditures should be distributed in accordance to the estimated percentage of each disability group within each State. Table 11 contains the amount and percent of Federal Basic Formula funds used for Council planning, other planning, and administration in the three fiscal years of the report.

There was a total of \$7,632,815 of Federal Formula funds used for planning activities and administration in FY '78. Of this amount, 53.4% was used for Council planning, 35% was used for other planning activities, and 11.6% was used for program administration.

TABLE II-11. AMOUNT AND PERCENT OF FEDERAL FORMULA FUNDS USED FOR COUNCIL PLANNING, OTHER PLANNING, AND ADMINISTRATION BY THE 54 STATES AND TERRITORIES PARTICIPATING IN THE DD PROGRAM IN FY '78, FY '79, AND FY '80

Program activity	Fiscal '78		Fiscal '79		Fiscal '80	
	Amount	%	Amount	%	Amount	%
Council Planning	\$4,074,833	53.4	\$6,596,444	69.3	\$7,537,948	73.3
Other Planning	2,673,384	35.0	2,118,963	22.2	1,688,991	16.4
Administration	884,598	11.6	805,549	8.5	1,068,622	10.3
Total	\$7,632,815	100	\$9,520,956	100	\$10,295,561	100

There was a total of \$9,520,956 of Federal Formula funds used for planning activities and administration in FY '79. Of this amount, 69.3% was used for Council planning, 22.2% was used for other planning activities, and 8.5% was used for program administration.

There was a total of \$10,295,561 of Federal Formula funds used for planning activities and administration in FY '80. Of this amount, 73.3% was used for Council planning, 16.4% was used for other planning activities, and 10.3% was used for program administration.

The information presented in Section I of this report under the topical heading of Disabled Population is used in order to distribute the expenditures shown in Table 11 to the proper disability groups. Table 12 contains the results of that distribution and shows the expenditures according to the relevant disability groups for each of the three fiscal years.

TABLE II-12. AMOUNT AND PERCENT OF FEDERAL FORMULA FUNDS EXPENDED FOR PLANNING AND ADMINISTRATION DISTRIBUTED ACCORDING TO DISABILITY GROUPS FOR FY '78, FY '79, AND FY '80

Disability group	Fiscal '78		Fiscal '79		Fiscal '80	
	Amount	%	Amount	%	Amount	%
Mental Retardation	\$4,999,494	65.5	\$6,121,974	64.3	\$ 5,641,967	54.8
Cerebral Palsy	717,485	9.4	1,161,557	12.2	1,472,265	14.3
Epilepsy	1,663,954	21.8	1,875,628	19.7	1,791,428	17.4
Autism	114,492	1.5	142,814	1.5	164,729	1.6
Other	137,390	1.8	218,983	2.3	1,225,172	11.9
Total	\$7,632,815	100	\$9,520,956	100	\$10,295,561	100

The DD Councils and Administrative Agencies estimated that the developmental disabilities community consisted of 65.5% of individuals who were mentally retarded in FY '78. It was estimated that 9.4% of the DD community were individuals who were cerebral palsied and 21.8% of the DD community were individuals who had epilepsy. It was estimated that 1.5% of the DD community was composed of individuals who were autistic, while 1.8% of the DD community were individuals who were disabled because of conditions other than those listed.

In FY '79, the estimate of the composition of the DD community did not change radically from that presented in FY '78. The fact that most State Plans were submitted for FY '79 prior to the President signing PL 95-602 was reflected in that the DD planners used the definition contained in PL 94-103 to make their estimates of the composition of the DD population.

The impact of the definition of developmental disabilities contained in PL 95-602 can be seen in the estimated composition of the DD population in FY '80. In this year, it is estimated that 54.8% of the DD community is made up of individuals who are mentally retarded. The DD community consists of 14.3% of individuals with cerebral palsy and 17.4% of individuals who are epileptic. The individuals who are autistic represent 1.6% of the DD community. It is estimated that conditions other than mental retardation, epilepsy, cerebral palsy and autism make up 11.9% of the DD community as a result of the implementation of the definition of developmental disabilities contained in PL 95-602.

The majority of Federal Basic Formula funds were expended for service activities and programs. The expenditures for each category of service activities has heretofore been enumerated.

The service activities funded by States with Federal Formula Grant monies can be divided into two groups in order to assess the populations served by the service activities. The two groups of service activities are:

1. Activities affecting the entire DD community;
2. Activities specifically funded for one or more disability groups.

Each of the service activities and programs funded during the three year period of this report was assigned to one of the two groups.

All of the projects funded in the categories of training, advocacy, standards/needs assessment, public awareness, and Council activities were assigned to the group which affects the the entire DD community.

It is assumed that projects in the five categories listed above affect the entire DD community within the State. It is understood that individual projects in each of the categories may be targeted to a particular disability group or to a specific geographical section of the State. However, an analysis of the data which describes the service activities indicates that specifically targeted programs are not statistically significant when compared to the universe of service activities funded in the five categories of projects.

Table 13 shows the amount of funds and percentage of Federal Formula funds used for each of the five categories of projects which affect the entire DD community.

TABLE II-13. AMOUNT AND PERCENT OF FEDERAL FORMULA FUNDS USED FOR SERVICE ACTIVITIES IN TRAINING, ADVOCACY, STANDARDS/NEEDS ASSESSMENT, PUBLIC AWARENESS, AND COUNCIL ACTIVITIES FOR FY '78, FY '79, AND FY '80 BY ALL 54 STATES AND TERRITORIES PARTICIPATING IN THE DD PROGRAM

Category of projects	Fiscal '78		Fiscal '79		Fiscal '80	
	Amount	%	Amount	%	Amount	%
Training	\$ 734,415	13.2	\$1,295,233	21.1	\$1,122,501	19.1
Advocacy	2,935,637	52.9	3,214,136	52.2	2,894,019	49.3
Standards/Needs Assessment	581,916	10.5	530,267	8.6	395,927	6.7
Public Awareness	738,310	13.3	497,693	8.1	633,280	10.8
Council Activities	563,096	10.1	615,606	10.0	826,481	14.1
Total	\$5,553,374	100	\$6,152,935	100	\$5,872,208	100

There was a total of \$5,553,374 Federal Formula funds expended for service activities which affected the entire DD community in FY'78. The majority of these funds, 52.9%, were devoted to programs in advocacy. There was 13.3% of the funds expended for public awareness, 13.2% for training, and 10.5% for the development of standards and needs assessment. Council activities required 10.1% of these funds.

There was a total of \$6,152,935 Federal Formula funds expended for service activities which affected the entire DD community

in FY '79. As in FY '78, over 52% of these monies was expended for advocacy programs. There was 21.1% of the money used for training activities in FY '79. The development of standards and needs assessment required 8.6% of the money, and public awareness programs required 8.1%. Ten percent of the money was expended on Council activities in FY '79.

There was a total of \$5,872,208 Federal Formula funds expended for service activities which affected the entire DD community in FY '80. Nearly 50% of these monies was expended for programs in advocacy. Just under 20% was used for training, and 10.8% was used for public awareness. There was 6.7% of the funds used to develop standards and needs assessment. There was a total of 14.1% of the service funds expended in Council activities and awareness in FY '80.

It is assumed that the projects and service activities of training, advocacy, standards, public awareness, and Council activities are conducted for the benefit of the entire DD community. Therefore, the amounts of expenditures for these activities are proportioned to the disability groups according to the best estimate heretofore described for the three years. Table 14 contains the results of the proportional distribution of the expenditures for the projects and service activities which were conducted for the general developmental disabilities population.

TABLE II-14. AMOUNT AND PERCENT OF FEDERAL BASIC FORMULA FUNDS EXPENDED FOR TRAINING, ADVOCACY, STANDARDS, PUBLIC AWARENESS, AND COUNCIL ACTIVITIES DISTRIBUTED BY DISABILITY GROUPS FOR FY '78, FY '79, AND FY '80

Disability group	Fiscal '78		Fiscal '79		Fiscal '80	
	Amount	%	Amount	%	Amount	%
Mental Retardation	\$3,637,460	65.5	\$3,956,337	64.3	\$3,217,970	54.8
Cerebral Palsy	522,018	9.4	750,658	12.2	839,726	14.3
Epilepsy	1,210,636	21.8	1,212,128	19.7	1,021,764	17.4
Autism	83,300	1.5	92,294	1.5	93,955	1.6
Other	99,960	1.8	141,518	2.3	698,793	11.9
Total	\$5,553,374	100	\$6,152,935	100	\$5,872,208	100

There was a total of \$5,553,374 Federal Formula funds expended for training, advocacy, standards, public awareness, and Council activities in FY '78. Of this amount, 65.5%, or \$3,637,460, was expended for individuals who were mentally retarded, \$522,018, or 9.4%, for individuals who were cerebral palsied, and \$1,210,636, or 21.8%, for individuals with epilepsy. There was 1.5% of this amount expended for individuals who were autistic, and 1.8% of the funds expended for individuals who were disabled by causes other than those listed.

There was a total of \$6,152,935 Federal Formula funds expended for the five categories of service activities in FY '79. Of this amount, \$3,956,337, or 64.3%, was expended for individuals who were mentally retarded. There was a total of \$750,658 for individuals who were cerebral palsied, and \$1,212,128, or 19.7%, of the amount expended for individuals who were epileptic. There was 1.5% expended for individuals who were autistic, and 2.3% was expended for individuals whose disability was caused by conditions other than those listed.

There was a total of \$5,872,208 Federal Formula funds expended for training, advocacy, standards, public awareness, and Council activities in FY '80. Of this amount, 54.8%, or \$3,217,970, was expended for individuals who were mentally retarded. There was a total of \$839,726, or 14.3%, expended for individuals who were cerebral palsied, and \$1,021,764, or 17.4%, expended for individuals who were epileptic. There was 1.6% of the funds expended for individuals who were autistic. There was 11.9%, or \$698,793, expended for individuals whose disabilities were caused by other than mental retardation, cerebral palsy, epilepsy, or autism.

The majority of Federal Formula funds was expended for service activities in the four priority areas of service listed in PL 95-602 and for employment/vocational development programs. These service activities were usually designed for individuals in specific disability groups. Therefore, it is possible to identify with a great degree of confidence the amount of funds expended for each disability group in five categories of service projects. Table 15 contains the amount and percent of Federal Formula funds expended for programs in child development, case management, alternative living arrangements, nonvocational social development, and employment/vocational development for each of the three years covered by this report.

There was a total of \$16,871,811 Federal Formula funds expended for programs in the four priority service areas and employment in FY '78. Nearly one-half, 49.3%, was expended for programs in alternative living arrangements. There was 23.1% expended for programs in nonvocational social development, and 15.7% expended for programs in child development. There was a total of 4.9% of the funds expended for case management programs, and 7% for programs in employment.

TABLE II-15. AMOUNT AND PERCENT OF FEDERAL FORMULA FUNDS USED FOR SERVICE ACTIVITIES FOR PROGRAMS IN CHILD DEVELOPMENT, CASE MANAGEMENT, ALTERNATIVE LIVING ARRANGEMENTS, NONVOCATIONAL SOCIAL DEVELOPMENT, AND EMPLOYMENT/VOCATIONAL DEVELOPMENT IN FY '78, FY '79, AND FY '80 BY THE 54 STATES AND TERRITORIES PARTICIPATING IN THE DD PROGRAM

Category of programs	Fiscal '78		Fiscal '79		Fiscal '80	
	Amount	%	Amount	%	Amount	%
Child Development	\$ 2,638,042	15.7	\$ 3,944,961	20.1	\$ 5,441,543	20.2
Case Management	833,325	4.9	1,168,849	5.9	2,950,171	10.9
Altern. Living Arrg.	8,313,648	49.3	8,744,883	44.5	11,641,408	43.1
Nonvoc. Social Dev.	3,901,899	23.1	4,732,156	24.1	6,060,840	22.4
Employment/Voc.Dev.	1,184,897	7.0	1,066,260	5.4	918,269	3.4
Total	\$16,871,811	100	\$19,657,109	100	\$27,012,231	100

There was a total of \$19,657,109 expended for programs in the four priority service areas and employment in FY '79. Of this amount, 44.5% was expended for programs in alternative living arrangements, and 24.1% for programs in nonvocational social development. There was 20.1% of the funds expended for programs in child development in FY '79. Nearly 6% was expended for case management programs, and just over 5% was spent for employment programs.

There was a total of \$27,012,231 expended for programs in the four priority service areas and employment in FY '80. Of this amount, 43.1% was expended for programs in alternative living arrangements, and 22.4% for programs in nonvocational social development. There was 20.2% of the funds expended for programs in child development in FY '80. Nearly 11% was expended for case management programs, and just over 3% for programs in employment.

The majority of service activities and programs were designed for specific individuals in an identifiable disability group. Table 16 contains the distribution by disability group of the amount and percent of Federal Formula funds and for programs and service activities in the four priority service areas listed in PL 95-602 and for employment programs.

TABLE II-16. AMOUNT AND PERCENT OF FEDERAL FORMULA FUNDS BY DISABILITY GROUP EXPENDED FOR PROGRAMS IN CHILD DEVELOPMENT, CASE MANAGEMENT, ALTERNATIVE LIVING ARRANGEMENTS, NONVOCATIONAL SOCIAL DEVELOPMENT, AND EMPLOYMENT IN FY '78, FY '79, AND FY '80 BY THE 54 STATES AND TERRITORIES PARTICIPATING IN THE DD PROGRAM

Disability group	Fiscal '78		Fiscal '79		Fiscal '80	
	Amount	%	Amount	%	Amount	%
Mental Retardation	\$12,653,858	75.0	\$13,799,291	70.2	\$17,503,926	64.8
Cerebral Palsy	1,434,103	8.5	2,476,796	12.6	2,971,345	11.0
Epilepsy	1,771,540	10.5	1,297,369	6.6	2,296,040	8.5
Autism	759,232	4.5	982,855	5.0	1,080,489	4.0
Other	253,078	1.5	1,100,798	5.6	3,160,431	11.7
Total	\$16,871,811	100	\$19,657,109	100	\$27,012,231	100

There was a total of \$16,871,811 Federal Formula funds expended in the five categories of service areas in FY '78. Of this amount, 75% was expended for individuals who were mentally retarded. There was just over 10% expended for individuals who were epileptic, and 8.5% for individuals who were cerebral palsied. There was 4.5% expended for the autistic, and 1.5% expended for individuals with disabilities other than those listed.

There was a total of \$19,657,109 Federal Formula funds expended in the five categories of service areas in FY '79. Of this amount, just over 70% was expended for individuals who were mentally retarded. There was 12.6% expended for individuals who were cerebral palsied, and 6.6% expended for individuals who were epileptic. Five percent was expended for the autistic, and 5.6% for disabilities other than those listed.

There was a total of \$27,012,231 Federal Formula funds expended in the five categories of service areas in FY '80. Of this amount, 64.8% was expended for individuals who were mentally retarded. There was a total of just under \$3 million, or 11%, of the funds expended for individuals who were cerebral palsied, and 8.5% was expended for individuals who were epileptic. There was 4% expended for individuals with autism. There was 11.7% of the service funds in the four priority areas and employment expended for the disabled with conditions other than mental retardation, cerebral palsy, epilepsy, or autism in FY '80.

Table 17 contains the distribution of all Federal Formula funds by disability groups for FY '78, FY '79, and FY '80.

The total amount of Federal Formula funds expended in FY '78 was \$30,058,000. There was 70.8% of the funds expended for individuals who were mentally retarded. There was 15.5% of the funds expended for individuals who were epileptic, and 8.9% expended for individuals who were cerebral palsied. There was 3.2%, or just under one million dollars, expended for individuals who were autistic. Just under one-half million dollars, or 1.6%, of the funds was used for individuals who were disabled for reasons other than those listed.

TABLE II-17. AMOUNT AND PERCENT OF ALL FEDERAL FORMULA FUNDS BY DISABILITY GROUPS FOR FY '78, FY '79, AND FY '80

Disability group	Fiscal '78		Fiscal '79		Fiscal '80	
	Amount	%	Amount	%	Amount	%
Mental Retardation	\$21,290,812	70.8	\$23,877,602	67.6	\$26,363,863	61.1
Cerebral Palsy	2,673,606	8.9	4,389,011	12.4	5,283,336	12.2
Epilepsy	4,646,130	15.5	4,385,125	12.4	5,109,232	11.8
Autism	957,024	3.2	1,217,963	3.4	1,339,173	3.1
Other	490,428	1.6	1,461,299	4.2	5,084,396	11.8
Total	\$30,058,000	100	\$35,331,000	100	\$43,180,000	100

There was a total of \$35,331,000 Federal Formula funds expended in FY '79. Of this amount, 67.6% was expended for individuals who were mentally retarded. There was a total of 12.4% expended for individuals who were cerebral palsied, and 12.4% expended for individuals who were epileptic. There was 3.4% of the Federal Formula funds expended for individuals who were autistic. A total of 4.2% of the funds was used for individuals who were disabled for reasons other than those listed.

There was a total of \$43,180,000 Federal Formula funds expended in FY '80. Of this amount, 61.1% was expended for individuals who were mentally retarded. There was a total of 12.2% expended for individuals who were cerebral palsied, and

11.8% expended for individuals who were epileptic. There was 3.1% of the funds used for individuals who were autistic. There was 11.8% used for individuals whose disability was other than mental retardation, cerebral palsy, epilepsy, or autism in FY '80.

Table 18 contains the difference in percent of expenditures of Federal Formula funds for each disability group for FY '79 and FY'80 when compared to the expenditures in FY '78. This comparison shows the apparent impact of the implementation of the definition of developmental disabilities contained in PL 95-602.

TABLE II-18. COMPARISON OF THE DIFFERENCE IN THE PERCENT OF EXPENDITURES OF FEDERAL FORMULA FUNDS FOR EACH DISABILITY GROUP IN FY '79 AND FY '80 FROM THE EXPENDITURES IN FY '78

Disability group	Percent expended in FY '78	Difference in expenditure in FY '79	Difference in expenditure in FY '80
Mental Retardation	70.8	- 3.2	- 9.7
Cerebral Palsy	8.9	+ 3.5	+ 3.3
Epilepsy	15.5	- 3.1	- 3.7
Autism	3.2	+ .2	+ .1
Other	1.6	+ 2.6	+ 10.2

There was a decrease of 3.2% in the percent of Federal Formula funds used for individuals with mental retardation in FY '79 from the percent used for this disability group in FY '78. There was also a decrease of 3.1% in the percent of Federal Formula funds used for individuals with epilepsy in FY '79 from the percent used for this disability group in FY '78. There was an increase of 3.5% in the percent of Formula funds used for individuals with cerebral palsy in FY '79 when compared to the percent used for the group in FY '78. The percent was increased by .2% in FY '79 over the FY '78 percent level for autistic individuals. There was a 2.6% increase in the percent expended for individuals with disabilities other than those listed.

There was a decrease of 9.7% in the percent of Federal Formula funds used for individuals with mental retardation in

FY '80 from the percent used for this disability group in FY '78. There was a decrease of 3.7% in the percent of Federal Formula funds used for individuals with epilepsy in FY '80 from the percent used for this disability group in FY '78. There was an increase of 3.3% in the percent of Federal Formula funds used for individuals with cerebral palsy in FY '80 when compared to the percent used for the group in FY '78. The percent was increased by .1% in FY '80 over the FY '78 percent level for autistic individuals. There was a 10.2% increase in the percent expended for individuals with disabilities other than mental retardation, cerebral palsy, epilepsy, and autism in FY '80.

The apparent affect of the implementation of the definition of developmental disabilities contained in PL 95-602 the first two years is an increase of just over 10% in the percent of projects funded for individuals with disabilities other than those caused by mental retardation, cerebral palsy, epilepsy, or autism.

SERVICE PROVIDERS

There has been over the past three years an effort on the part of the State DD Planning Councils and Administrative Agencies to identify the service network which is providing services to individuals who are developmentally disabled. In order to effectively discover service gaps in the service network, it is apparent that knowledge of the total service system must be at hand. Therefore, the requirement in the State Plan to identify the agencies and organizations which provide services to individuals who are developmentally disabled is an attempt to have each Council/Administrative Agency look at the continuum of services from birth to death for individuals who are developmentally disabled.

The continuum of service is necessary because the individuals who are developmentally disabled will require "a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated." There must be coordinated transitions between service agencies within specific age groups and along the continuum of service in order for an individual to participate in a continuum of services and activities which allow the individual maximum participation in society.

PL 95-602, Sec.133, paragraph 3 instructs States to make part of the Federal Formula funds available to public or non-profit private entities. In order to identify the service network used for the service projects and activities heretofore described, each of the projects was examined as to the provider used by each of the States. A variety of service providers were used by the various States for implementing the program and activities specified in the State Plan. There were four categories of service providers used in implementing the service activities and programs. The four categories of service providers used are:

1. Non-profit organizations
2. Universities
3. State Governments
4. Associations

Non-profit organizations were used for their specialized services and knowledge in providing services to individuals who are developmentally disabled. Especially are non-profit organizations used in providing alternative living arrangement facilities and programs and in providing nonvocational social development programs. Also, non-profit organizations are sometimes used to provide employment/vocational development programs for the developmentally disabled.

Universities, especially University Affiliated Facilities, were used as service providers for service activities and programs within various States. Universities were especially used for

training activities and for technical assistance to Councils and in the area of child development, especially in the area of prevention and genetic counseling.

State Governments were used because in many States the State Government is the major supplier of services to individuals who are developmentally disabled. Federal Formula funds were appropriately used to supplement existing State programs in order to expand the provision of services to individuals not presently served within those programs. The augmentation of State programs is an appropriate and even a mandated activity for the use of Federal Formula funds.

Associations were used as a resource in providing many services. Many State associations and local associations operate programs for individuals who are developmentally disabled. Associations are especially active in providing alternative living arrangements such as group homes, respite care and alternative living placement programs. Associations are also actively involved in providing sheltered workshop experiences and employment programs for individuals who are developmentally disabled. Many of the public awareness programs were implemented by associations at the State and local level through funding from funds provided by the Federal Formula Grant appropriation. State and local Associations of Retarded Citizens, United Cerebral Palsy Associations, Epilepsy Associations, and the National Society for Autistic Children were the primary associations used in the provision of service activities and programs in the three fiscal years of this report.

Table 19 shows the service providers used for service activities and programs funded by Federal Formula funds in FY '78, FY '79, and FY '80. There were a total of 838 projects funded, amounting to \$22,425,185 of Federal Formula Grant funds in FY '78. Non-profit organizations received 47.8% of the funds, or \$10,716,626. Associations and State Governments received an identical percentage of the funds in FY '78. Associations received \$4,796,223, or 21.4%, of the funds for a total of 190 service activities and programs. State Governments received \$4,794,690, or 21.4%, to implement 132 different service activities and programs during FY '78. Universities in the various States received 9.4% of the Federal Formula funds used for service activities through which they conducted 82 different individual service activities or projects.

There were 942 service activities and programs conducted in FY '79, using a total of \$25,810,044 of Federal Formula Grant funds. Almost half of these funds, 49.9%, were used to fund non-profit organizations which conducted 487 separate service activities and projects involving a total of \$12,892,324. State Governments were employed as resources with a total of \$5,332,808, or 20.7% of the service dollars in FY '79 to conduct 163 different service activities and programs. Associations were involved in

217 different service activities and programs in FY '79 requiring 19.6% of the service dollars, or \$5,066,620. Universities conducted 75 individual service activities and programs involving \$2,518,292, or 9.8% of the amount of Federal Formula funds used for service activities in FY '79.

TABLE 11-19. AMOUNT, PERCENT AND NUMBER OF PROJECTS BY SERVICE PROVIDERS USED FOR ALL SERVICE ACTIVITIES AND PROGRAMS FUNDED BY FEDERAL FORMULA GRANT FUNDS FOR FISCAL YEARS '78, '79, AND '80

Service Provider	Fiscal '78			Fiscal '79			Fiscal '80		
	No. of Proj.	Amount	%	No. of Proj.	Amount	%	No. of Proj.	Amount	%
Non-Profit Organizations	434	\$10,716,626	47.8	487	\$12,892,324	49.9	533	\$17,769,119	54.0
Universities	82	2,117,646	9.4	75	2,518,292	9.8	84	2,978,310	9.1
State Governments	132	4,794,690	21.4	163	5,332,808	20.7	152	6,444,537	19.6
Associations	190	4,796,223	21.4	217	5,066,620	19.6	188	5,692,463	17.3
Total	838	\$22,425,185	100	942	\$25,810,044	100	957	\$32,884,429	100

In FY '80, there was a total of \$32,884,429 expended by the 54 States and Territories participating in the Developmental Disabilities Program for service activities and programs. This amount funded a total of 957 individual service activities and projects. Non-profit organizations implemented 533 individual service activities and projects involving 54% of the funds, for a total of \$17,769,119. State Governments were involved in 152 of the programs requiring 19.6% of the funds, or a total of \$6,444,537. Associations received funds to conduct 188 individual service activities and programs requiring 17.3% of the service funds, or a total of \$5,692,463. Universities implemented 84 of the service activities and projects in FY '80. These 84 service projects involved 9.1% of the service dollars, or \$2,978,310.

There was apparently little change in the selection of service providers for service activities and programs between FY '78 and FY '79 and FY '80. Table 20 contains a comparison of the percentage of change in service providers used in FY '79 and FY '80 compared to those used in FY '78 for the service activities by the several States and Territories participating in the DD Program in the three fiscal years.

TABLE II-20. COMPARISON OF THE PERCENTAGE OF CHANGE IN SERVICE PROVIDERS USED IN FY '79 AND FY '80 COMPARED TO THOSE USED IN FY '78 FOR SERVICE ACTIVITIES AND PROGRAMS FUNDED WITH FEDERAL FORMULA FUNDS

Service providers	Percent for FY '78	Change in FY '79 from FY '78	Change in FY '80 from FY '78
Non-Profit Organizations	47.8	+ 2.1	+ 6.2
Universities	9.4	+ .4	- .3
State Governments	21.4	- .7	- 1.8
Associations	21.4	- 1.8	- 4.1

As can be seen, in FY '78, 47.8% of the Federal Formula funds used for service activities was provided to non-profit organizations to implement service activities and programs. In FY '79, there was a 2.1% increase in the percent of funds provided to non-profit organizations for service initiatives, and in FY '80 there was an increase of 6.2% in the percentage of funds provided to non-profit organizations for service initiatives.

As was pointed out in the section entitled Services Provided of this section of the report, there was an increase in the number of service activities and programs and the percentage of money used for activities in the four service areas identified in PL 95-602 in FY '80, and non-profit organizations are the major provider of these types of services in most of the States. Therefore, the increase of 6.2% in the percentage of monies provided to non-profit organizations is consistent with the increase in activities involving the four priority service areas.

Universities received 9.4% of the funds in FY '78 and experienced a four-tenths of one percent increase to 9.8% in FY '79 from the FY '78 level. In FY '80, the universities' percentage decreased three-tenths of one percent, which is not a significant statistical decrease, and therefore the universities remained the same in the percentage of funding over the three year period as the selected service provider for service activities among the various States.

State Governments, which in some States are the major service provider of services for individuals that are developmentally

disabled, received 21.4% of the funds in FY '78. There was a decrease of seven-tenths of one percent in FY '79 compared to the percentage received in FY '78, and a decrease of 1.8% in FY '80 from the FY '78 level. This decrease of less than 2% is not a significant decrease in percentage since the increase in number of dollars involved in FY '80 was significantly more than that in FY '78. State Governments still experienced an increase in dollar funding in service initiatives funded by Federal Formula Grant funds during FY '80 over that in FY '78.

Associations experienced the largest decrease in FY '80 of any of the service providers over the FY '78 level. In FY '78, the associations received 21.4% of the Federal Formula Grant funds involved in service initiatives. In FY '79, there was a decrease of 1.8%, which is not a significant decrease, and in FY '80, there was a decrease of 4.1% under the level of the FY '78 percentage of funding. This decrease is primarily caused by the emphasis put on the four priority service areas and the lack of emphasis on public awareness and on programs which affect the entire developmental disabilities population of a State. A majority of the programs which were operated by the State associations were for programs that affected the particular disability group of the association on a statewide basis, such as those in public awareness. In FY '80, as has been reported, the emphasis shifted to an emphasis on the four priority service areas, and therefore the programs in public awareness and other programs such as training received less emphasis, and therefore the decrease in this type of service activity.

However, the service providers were essentially the same throughout the three fiscal years. There is no significant change in the selection of service providers for service initiatives in FY '79 and FY '80 from those selected in FY '78. Apparently there is little impact on the service providers by the change in definition which is in PL 95-602 from the definition of developmental disabilities contained in PL 94-103. The service providers that served the severely involved developmentally disabled individuals in FY '78 still provided those services in FY '80. There was some shift in service providers to additional non-profit organizations, primarily in the area of alternative living arrangements and non-vocational social development programs. However, the shift was not as great as the change in the disability groups served, as we have recorded in the foregoing section of this paper. It is assumed that the service providers of service activities and programs provide services to individuals that have three or more functional disabilities regardless of the cause of those disabilities. As has been recorded, over 60% of the individuals are disabled because of mental retardation, who have been served through the Developmental Disabilities Program in FY '80, and many of the service providers which were selected for service initiatives and programs provide services for mentally retarded individuals and individuals who have similar types of service needs.

IMPACT OF DEFINITION

The Federal Basic Formula fund is the largest single appropriation component of the DD Program, amounting to almost 70% of the total appropriation for FY '80. Because of the magnitude of funding for this component of the program, it is important that expenditures and comparisons between the three fiscal years be carefully examined for signs of significant shift in patterns of expenditures.

Table 21 shows a comparison of the expenditures of Federal Formula Grant funds for planning and administration and for services by the Councils and Administrative Agencies in each of the three fiscal years.

TABLE II-21. AMOUNT AND PERCENT OF FEDERAL FORMULA GRANT FUNDS EXPENDED FOR PLANNING AND ADMINISTRATION AND FOR SERVICES IN FISCAL YEARS '78, '79, AND '80 BY STATES AND TERRITORIES PARTICIPATING IN THE DD PROGRAM

Fiscal Year	Total appropriation		Planning/Administration		Services	
	Amount	%	Amount	%	Amount	%
Fiscal '78	\$30,058,000	100	\$ 7,632,815	25.4	\$22,425,185	74.6
Fiscal '79	35,331,000	100	9,520,956	26.9	25,810,044	73.1
Fiscal '80	43,180,000	100	10,295,161	23.8	32,884,439	76.2

The information on Table 21 shows that although there was significant increase in the appropriation level of Federal Formula Grant funds between FY '78 and FY '80, there was little change in the percent of the appropriation used for services in the three years. The percent of Federal Formula funds used for services remained almost 75% during each of the three years. Therefore, the change in definition of developmental disabilities in PL 94-103 to the definition in PL 95-602 apparently had little impact on the percent of Federal Formula dollars used for services by the DD community.

Table 22 contains a comparison of the change in percentage of Federal Formula funds used for service activities and programs in the four priority service areas, other direct service areas, and support service areas in FY '79 and FY '80 from the percent expended in each area of service in FY '78.

TABLE II-22. COMPARISON OF PERCENT OF CHANGE OF FEDERAL FORMULA FUNDS USED FOR SERVICE ACTIVITIES AND PROGRAMS IN THE FOUR PRIORITY SERVICE AREAS, OTHER DIRECT SERVICE PROGRAMS, AND SUPPORT SERVICES IN FY '79 AND FY '80 FROM THE PERCENT OF FUNDS USED IN FY '78

Category of program	Percent expended in FY '78	Percent of change in FY '79 from FY '78	Percent of change in FY '80 from FY '78
Four Priority Service Areas	69.9	+ 2.1	+ 9.5
Other Direct Service Areas	21.7	- .1	- 6.7
Support Services	8.4	- 2.0	- 2.8

The information on Table 22 indicates that there was almost a 10% shift in the funding pattern in the utilization of Federal Formula monies from FY '78 to FY '80. The shift occurred in the increased emphasis on the four priority service areas. Almost 70% of the funds expended for services in FY '78 was for activities and programs in the four priority areas of service. In FY '80, the percentage of funds expended for programs increased to almost 80% of the service dollar expenditure.

There was a 6.7% decrease in the percent of funds devoted to other direct service activities, and a 2.8% decrease in the funds expended for support services in FY '80 from the percent expended for these activities in FY '78.

The impact of the change in the law to emphasize the four priority service areas in PL 95-602 is probably responsible in the funding pattern change rather than the change in the definition. The change in definition probably did not cause this shift in the funding pattern. However, the change is a factual event and must be recorded as part of this report since it did occur in the three year report period.

Table 23 shows the change in percent of individuals who are disabled because of mental retardation, cerebral palsy, epilepsy, and autism and individuals who are disabled because of causes other than the four listed served by the DD Program in FY '79 and FY '80 compared to the percent of individuals served in FY '78.

TABLE II-23. PERCENT AND PERCENT OF CHANGE OF INDIVIDUALS WHO ARE DISABLED BY MR, CP, E AND A AND INDIVIDUALS DISABLED FOR OTHER CAUSES SERVED BY THE DD PROGRAM AS MEASURED BY MAGNITUDE OF EXPENDITURE OF FEDERAL FORMULA FUNDS IN FY '79 AND FY '80 COMPARED TO THE PERCENT OF FUNDS EXPENDED IN FY '78

Disability groups	Percent served in FY '78	Percent served in FY '79	Percent of change in FY '79 from FY '78	Percent served in FY '80	Percent of change in FY '79 from FY '78
MR-CP-E-A	98.4	95.8	- 2.6	88.2	- 10.2
Other	1.6	4.2	+ 2.6	11.8	+ 10.2

The information on Table 23 shows that in FY '78, almost all individuals served through Federal Formula funds were disabled because of mental retardation, cerebral palsy, epilepsy, or autism. Only 1.6% of the individuals served with Federal Formula funds were disabled because of causes other than those listed.

In FY '79, there was an increase of 2.6% of individuals served who were disabled by causes other than mental retardation, epilepsy, autism, or cerebral palsy.

In FY '80, the largest increase in the service population of individuals who were disabled for "other" causes occurred. The population of individuals who were disabled because of other causes now consisted of 11.8% of the total population served through Federal Formula Grant funds.

It may be stated as a statement of fact that the change in definition of developmental disabilities caused an increase in the percentage of individuals served by the DD Program who were disabled for causes other than mental retardation, epilepsy, cerebral palsy, or autism. The increase in the service population was approximately 10% during the first two years of application of the definition of developmental disabilities contained in PL 95-602.

Table 24 shows the percent of change in the category of service providers selected by State Councils/Administrative Agencies to provide services for the individuals who are developmentally disabled in FY '79 and FY '80 compared to the percent selected in FY '78.

TABLE II-24. PERCENT AND PERCENT OF CHANGE IN PERCENT OF CATEGORY OF SERVICE PROVIDER USED TO IMPLEMENT SERVICE INITIATIVES WITH FEDERAL FORMULA GRANT FUNDS IN FY '79 AND FY '80 COMPARED TO PERCENT OF FUNDS EXPENDED IN FY '78

Category of Service Provider	Percent served in FY '78	Percent served in FY '79	Percent of change in FY '79 from FY '78	Percent served in FY '80	Percent of change in FY '80 from FY '78
Non-Profit Organiz.	47.8	49.9	+ 2.1	54.0	+ 6.2
Universities	9.4	9.8	+ .4	9.1	- .3
State Governments	21.4	20.7	- .7	19.6	- 1.8
Associations	21.4	19.6	- 1.8	17.3	- 4.1

Information presented on Table 24 indicates that the change in service providers over the three year period was not significant. The decrease in the utilization of associations in FY '80 was caused more by the shift in service activities to the four priority areas of service rather than the change in definition of developmental disabilities, as already has been detailed in this report.

The impact of the implementation of the definition of developmental disabilities contained in PL 95-602 has been to reduce the estimated DD population and to change the disability groups served by approximately 10%.

The inclusion of the four priority areas for funding emphasis has caused approximately a 10% increase in the percentage of Federal Formula funds devoted to service activities in these four priority areas of service in the first two years of the implementation of PL 95-602.

ASSESSMENT OF QUALITY

PL 95-602 requires that "an assessment, evaluation and comparison of services provided to persons with developmental disabilities" be included in the mandated report.

There are three ways in which the assessment of quality for activities and projects funded by Federal Formula Grant funds may be achieved. The three ways are:

1. Determine the amount of Federal Formula funds which went into the effort to develop and implement standards for services to individuals with developmental disabilities for each of the three years included in the report;
2. Compare the service providers used to implement service activities and programs for each of the three fiscal years; and
3. Examine the number of programs and activities which operated under national and State standards to determine any change in the quality of program offered individuals who were developmentally disabled between FY '78 and FY '80.

There is a category of service projects entitled standards/needs assessment listed in several sections of this report. The developmental disabilities community is very conscious of developing standards and implementing standards for service activities and programs. At the present time, each of the States and Territories is working diligently in developing a comprehensive evaluation system which complies with the requirements of PL 95-602, Section 110.

The DD community expended 2.6% of the total Formula Grant funds for service activities in the development of standards and needs assessment in FY '78. This percent amounted to a total dollar figure of \$581,916 of the Federal Formula Grant appropriation.

In FY '79, the amount of dollars expended for standards and needs assessment remained constant to the FY '78 level, exceeding the half million dollar amount. In FY '79, there was \$530,267 expended for this purpose.

The level of funds expended for the development of standards and needs assessment dropped just over 30% from the FY '78 level in FY '80. There was a total of \$395,827 expended for this purpose in FY '80.

It is apparent that the development and implementation of standards is important since some amount of funds was devoted to the purpose each of the fiscal years. However, there was a decrease in the magnitude of Federal resources expended for the purpose in FY '80 from the FY '78 level.

A comparison of service providers selected to implement the service activities and programs has already been made in this report. It was determined that the same service providers or similar service providers were used for each of the three fiscal years.

It is assumed that if the same or similar service providers were used to implement service activities in FY '79 and FY '80 as were used in FY '78, then the quality of services remained the same or increased in quality. It may be argued that if a service provider has additional years of experience working with individuals who are developmentally disabled, then the quality of service should increase as a result of the experience. However, it is unlikely that the quality of service will decline when the same or similar service providers are employed.

Finally, a majority of the States reported that the service providers used for service activities and programs operated under national and State standards of service for individuals who are developmentally disabled.

Table 25 contains a display of the type of standards under which States reported that some, if not all, of their services operated in their States. The number of projects which operated under national standards actually increased in FY '79 and FY '80 over the number of projects operating under national standards in FY '78. Therefore, it can be concluded that there was an increase in the quality of services provided individuals who were developmentally disabled in FY '79 and FY '80 compared to the quality of services provided in FY '78.

Eleven States indicated that all projects and service activities were operated under State standards, which included licensing activities, fire and safety codes, and other regulatory compliance components such as ratio of staff to clients, professional level of staff, and health standards.

Nine States operated programs under the nationally recognized AC/MRDD. These standards are the standards prepared by the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons. The base funding for the organization comes from Section 145 of PL 95-602 and it has been funded through a Grant of National Significance for several years.

Eight States operate programs under the JCAH standards. The JCAH are the standards put forth by the Joint Commission on Accreditation of Hospitals in Chicago, Illinois.

**TABLE II-25. STANDARDS FOR SERVICE ACTIVITIES AND PROGRAMS
INCLUDING NUMBER OF STATES AND PERCENT OF STATES USING THE
IDENTIFIED STANDARDS**

Standards	Number of States	Percent of States
State Standards	11	20
AC/MRDD	9	17
JCAH	8	15
CARF	5	9
ICF/MR	4	7
IHP	3	6
JCAH and ICF/MR	3	6
ICF/MR and State Standards	3	6
CARF and ICF/MR	3	6
JCAH and AC/MRDD	2	3
CARF and ICF/MR and AC/MRDD	2	3
JCAH and ICF/MR and State Standards	1	2
Total	54	100

Five States reported operating programs under the CARF standards. The CARF standards are those issued by the Commission on Accreditation of Rehabilitation Facilities in Tucson, Arizona.

There were four States which reported operating Federally financed service programs according to ICF/MR standards. ICF/MR are regulator standards put forth by the Social Security Commission for Intermediate Care Facilities for Mental Retardation.

There were three States which indicated that their standards of service were compliance with the development of an Individual Habilitation Plan for each of the individuals involved in a service program. The IHP is developed in accordance with Section 112 of PL 95-602.

There were fourteen States which reported using a combination of standards for their service activities and programs for individuals who are developmentally disabled.

It must also be pointed out that the DD Councils/Administrative Agencies present assurances in each State Plan that programs will be operated in compliance with "standards prescribed by the Secretary in regulations." Specifically, PL 95-602 requires that:

(5)(A)(i) The plan must provide that services furnished, and the facilities in which they are furnished, under the plan for persons with developmental disabilities will be in accordance with standards prescribed by the Secretary in regulations.

(ii) The plan must provide satisfactory assurances that buildings used in connection with the delivery of services assisted under the plan will meet standards adopted pursuant to the Act of August 12, 1968 (42 U.S.C. 4151-4157) (known as the Architectural Barriers Act of 1968).

(B) The plan must provide that services are provided in an individualized manner consistent with the requirements of section 112 (relating to habilitation plans).

(C) The plan must contain or be supported by assurances satisfactory to the Secretary that the human rights of all persons with developmental disabilities (especially those persons without familial protection) who are receiving treatment, services, or habilitation under programs assisted under this title will be protected consistent with section 111 (relating to rights of the developmentally disabled).

PL 95-602, Sec. 133

It may be concluded from the evidence presented that the quality of services provided through Federal Formula funds to individuals with developmental disabilities remained constant or improved from the period of October 1, 1977 to September 30, 1980. There is nothing in the review of project and program information which would indicate that the quality of service deteriorated during this period of time.

SECTION III

PROTECTION AND ADVOCACY PROGRAM

EXECUTIVE SUMMARY

INDIVIDUALS SERVED

MATERIALS DEVELOPED

TRAINING ACTIVITIES

ORGANIZATIONS

Type

Staff

FISCAL RESOURCES

IMPACT OF THE DEFINITION

SERVICES TO THE DEVELOPMENTALLY DISABLED

EXECUTIVE SUMMARY

The passage of PL 94-103 ushered into the developmental disabilities community a dynamic new program which was to be called Protection and Advocacy for Individuals with Developmental Disabilities. This new program is designed to address the needs and furnish relief for those individuals who need the assistance of specialized programs.

Section 113 of PL 94-103 stated that:

"(a) The Secretary shall require as a condition to a State receiving an allotment under Part (c) for fiscal year ending before October 1, 1977 that the State provide the Secretary satisfactory assurances that not later than that date (1) the State will have in effect a system to protect and advocate the rights of persons with developmental disabilities, and (2) such system will (A) have the authority to pursue legal, administrative and other appropriate remedies to insure the protection of the rights of such persons who are receiving treatment, services, or habilitation within the State, and (B) be independent of any State agency which provides treatment, services, or habilitation to persons with developmental disabilities. The Secretary may not make an allotment under part (a) to a State for a fiscal year beginning after September 30, 1977 unless the State has in effect the system described in the preceding sentences."

The above inclusion in PL 94-103 was received with mixed feelings throughout the developmental disabilities program community. On the one hand, many Developmental Disabilities State Planning Councils had been operating as advocates at the local and State level for a number of years. Also, many of the voluntary associations such as the local and State Associations for Retarded Citizens, the local chapters of United Cerebral Palsy Association, the local chapters of the Epilepsy Society, and the Society for Autistic Persons had been performing the tasks generally envisioned to be the tasks of the yet unidentified Protection and Advocacy agency within the State.

Each State developed a task force or committee usually contained within the Developmental Disabilities State Planning Council to develop a plan for the Protection and Advocacy Program within that State. The planning effort took approximately 18 months and was plagued with the usual problems of planning and establishing a new entity. The planning phase

consisted of long debates as to what this Protection and Advocacy Program must contain, its meaning, function, and activity. Also, the fact that the minimum allotment States would only receive \$20,000 for the operation of their Protection and Advocacy Program limited the scope of the program without reducing the statewide mandate which appeared in the guidelines.

PL 95-602 contained Section 1.13 with little change in the mandate. Section 113 of PL 95-602 continues to require a State to have in place a system of Protection and Advocacy in order to participate in the basic formula grant component of the Developmental Disabilities Program.

It is a tribute to the developmental disabilities community that each State and Territory in the United States had in place through an approved plan a system of Protection and Advocacy on or before October 1, 1977. The Protection and Advocacy agency could be placed in one of three organizational structures in order to comply with the mandates of the law. The three possible placements are:

1. State agency;
2. Existing non-profit corporation;
3. New non-profit corporation.

There is no universally agreed upon best placement of the P&A agency at this point in time. However, as is shown in this report, 32 P&A agencies are presently located in new non-profit, private corporations. The term "new" is used in this context to denote those corporations that were established specifically for the Protection and Advocacy Program.

There are four basic activities which a P&A agency involves itself in at the State and local level. These four activities are:

1. The advocating for individuals with developmental disabilities to secure appropriate programs and services to which these individuals are entitled and/or need at the time of need;
2. To develop and dispense materials and information which describes the Protection and Advocacy activity, agency, and the services, rules, regulations and laws which affect the individuals who are developmentally disabled within the State;
3. To conduct training activities to service providers, the individuals who are developmentally disabled (consumers), and professionals such as educators, attorneys, and physicians as to the rights, entitlements and skills of advocacy;

4. To participate in the drafting of and pursuit of legislation, regulations, and guidelines which will facilitate individuals who are developmentally disabled to participate as free and unrestricted individuals in society.

Each of the fifty-four Protection and Advocacy Programs operating in the United States achieves the above activities with various degrees of emphasis depending on the particular philosophy which has evolved in the specific State and the specific needs of individuals with developmental disabilities which were considered to be most critical by the planners of the Protection and Advocacy system.

The following statistical and narrative report will demonstrate that there is a multitude of models of Protection and Advocacy systems functioning within the United States. Each of the models demonstrates a particular philosophy of Protection and Advocacy and extends that philosophy into an implementation process which achieves the desired ends for which the mandate was created.

The information contained in the report describes through statistics, narrative and listings the first three activities of the Protection and Advocacy system. That is, there is a display and discussion of all cases of the 54 Protection and Advocacy Programs throughout the country. There also is a listing of major program materials which have been developed by the Protection and Advocacy Programs, and a listing of the training activities which are conducted by the programs.

Legislative activity, although a critical component in some of the P&A systems, has not been addressed in this report. The reason for the omission of this component is that the legislative activity was found to be specific to each State and unique to each program. The information was not easily summarized and tended to lose its identity when summarized to fit within the confines of the report. Therefore, the legislative activity of P&A Programs, although important and a major component in some programs, has not been included.

This report does contain a comprehensive description of the more than 68,000 individuals served in the first three years of the Protection and Advocacy Program in the United States. The report also includes a general statement describing important legal actions both as part of administrative procedure and/or court actions taken by Protection and Advocacy Programs. The report does contain a listing of major materials developed, training activities, and a description of the type of organization and staff of the Protection and Advocacy organizations throughout the country.

Most importantly, the report contains a description of and listing of the funding sources of Protection and Advocacy throughout the country. This display of fiscal resources indicates that the original seed money of \$3,000,000 provided by the Federal Government for FY '78 for Protection and Advocacy has grown not only because of the increase to \$7.5 million for FY '80 by the Federal Government, but also because of the significant contribution of State Governments in support of the Protection and Advocacy agencies within their States. It is significant that the seed money from the Federal Government has served as a catalyst to attract additional resources, grants, private monies and state monies so that the program can effectively serve individuals with developmental disabilities and the protection of their rights and securing their program entitlements at the point of need.

The information in this report demonstrates the dynamic and universal activity of Protection and Advocacy throughout the United States. It also underscores the fact that a large contingency of individuals with developmental disabilities have been positively served by this unique three year old which has demonstrated maturity beyond conception within its first three years of operation.

The Protection and Advocacy activity in most States is no longer an experience but truly a service which is well received and dynamically involved in the inter-relationship of service delivery to individuals at the local and State level. The evidence within the report demonstrates unequivocally that Protection and Advocacy has developed a character by which individuals, organizations, and service providers are brought together for the betterment of individuals with developmental disabilities. The Protection and Advocacy Program, in cooperation with the other elements, and in some cases single handedly, has allowed thousands of individuals who are developmentally disabled to live in a less restrictive environment, to secure an appropriate education, and to enjoy to the limits of their physical and mental capabilities activities within society that they had not heretofore realized prior to the development of the Protection and Advocacy activity within their State.

INDIVIDUALS SERVED

There have been many activities in which the Protection and Advocacy agencies have intervened in protecting the personal rights of individuals who are developmentally disabled. The following is a listing of examples of those activities in which the Protection and Advocacy agencies have aided the individuals to maintain their rights:

- Caused to have established a protective service for an adult who was mentally retarded
- Caused to have the regulations changed by which the State determined incompetency
- Upheld the prohibition of the use of aversion stimuli in programming
- Secured indefinite support from the father for an adult who was mentally retarded in a divorce case
- Pleaded for the children to be returned to parents who are handicapped which had been taken away
- Placed an abandoned baby who had Downs Syndrome
- Reinstated a child taken away from its multiple-handicapped mother
- Defined the meaning of "adult" for purposes of the requirement for sterilization without consent

No less important are the examples of the activities of Protection and Advocacy agencies in the social activities of individuals who are developmentally disabled. Examples of activities in the social areas of concern are as follows:

- Allowed handicapped youth to compete for Boy Scout merit badges
- Obtained a compensation from an airline which refused to transport an adult who is mentally retarded
- Secured a change in driver's license requirements for individuals with epilepsy

Living arrangements are important to each individual in our society. To have determination and options about where one lives in our society is a fundamental freedom of our

society. Unfortunately, society has many times created restrictive laws and implemented programs which prohibit some individuals from having the freedom of choice to live where they desire. Protection and Advocacy has been instrumental in allowing individuals who are developmentally disabled to increase their options and obtain choices in their living arrangements. The following are examples of some of the activities in which Protection and Advocacy agencies have been engaged in securing new freedom for living arrangements:

- Demonstrated that a nursing home was an inappropriate institutionalization
- Gained the right to an option for community placement for residents of a State institution. Required that out-of-state placement be reviewed prior to making such placements
- Gained a policy that required a mandatory hearing prior to revocation of community placement
- Challenged the voluntary admission policy of the State hospital
- Gained reversal of a zoning ruling that a group home was a public nuisance
- Gained a statewide zoning law which prevented discrimination on the county and local level
- Challenged the procedure of involuntary admission to the State mental retardation institution
- Got the State to close an unlicensed institution and secured community placement for residents

The right to earn a living is a fundamental right in our society. Although our society compensates for the less fortunate, the seriously limited, and the special populations in providing programs and economic benefits, most individuals would like the opportunity to be able to be economically self-sufficient. Protection and Advocacy agencies increasingly have been involved with individuals in gaining rescission of laws which are restrictive in the opportunity for employment. Some of the specific examples in this area in which the Protection and Advocacy agencies have been involved are as follows:

- Re-employment of a deaf-mute who was discharged from employment
- Re-employment of a person who was epileptic to a job with an airline

- The overturn of the denial of employment of an individual whose epilepsy was medically controlled

With passage of PL 94-142 there have been many special education entitlements provided by Federal Law which have not been translated at the local school district for individuals who are developmentally disabled. Twenty-seven percent by actual count, of the cases of Protection and Advocacy during its first three years of existence have been in the area of education. These cases vary from individuals receiving no education to individuals who receive an appropriate education. It is important to note that most of the cases in which Protection and Advocacy has been involved are cases of an individual and that individual's right and opportunity for an appropriate education. The following is a listing of examples of some of the practices which have been confronted by Protection and Advocacy agencies on behalf of individuals who are developmentally disabled in the area of education:

- Secured a limit on the number of days a handicapped child can be expelled without evaluation and a hearing
- Established that the local school district was fiscally responsible for the cost of educating an emotionally disturbed child
- Received the decision that the lack of resources is not a defense in providing an appropriate education program for an individual who is developmentally disabled
- Received a prohibition against the transfer of multiple-handicapped youths to an inaccessible school facility
- Established that the burden of proof for educational placement rationale rests with the school district
- Secured the provision of occupational therapy and physical therapy within the school program for individuals who are developmentally disabled
- Secured a twelve month education program for individuals who are developmentally disabled who otherwise would suffer from regression during a three month vacation
- Secured the provision of home and care funded by the school district for a severely involved individual

- Secured educational programs for individuals who are developmentally disabled housed in a nursing home
- Secured speech therapy for medically eligible 3-5 year olds
- Received the decision that the State institution was an inappropriate setting for education because it is a segregated facility

Protection and Advocacy agencies are also involved in securing financial entitlements for individuals who are developmentally disabled. Some of the Protection and Advocacy agencies have secured standing in court to represent individuals who are developmentally disabled. Other Protection and Advocacy agencies have sought accessible public transportation for individuals who are developmentally disabled as well as addressing the other social, psychological, economic barriers that prevent this population from free access and movement throughout society. As one reviews the statistics of over 68,000 individuals who have contacted or been contacted by Protection and Advocacy agencies within the last three years, one must call to mind that this is a population that needs assistance. It is a population that needs assistance throughout their lifetime. It is a population that is best helped through the efforts of individuals, citizen advocates, and interested society at the local level and through individual advocates. The Protection and Advocacy system provides that mechanism which allows representation of the individuals as they are confused, confronted, and sometimes denied access to services and developmental skills during their growth and mature years.

Table 1 shows the number of cases for FY '78, FY '79, and FY '80 displayed by age, disability, geographical area, request, informant, problem area, and intervention for Protection and Advocacy agencies in the United States. The table shows that during the first three fiscal years, 68,792 were served. In all cases in this report a case and an individual are interchangeable. The statistics were compiled on the unduplicated count of individuals served by the Protection and Advocacy agencies in each State. This summary table provides the reader with a national picture of the activity of Protection and Advocacy in the United States.

The age of the clients of P&A agencies during the first three years has been about equally distributed between children and adults. Five percent of the clients have been below the age of 5 years. Forty-two percent have been between 5 and 21 years of age. Forty-two percent have been between 22 and 64 years of age. One percent have been over 65 years of age.

TABLE III-1. NUMBER OF CASES FOR FY '78, FY '79, AND FY '80 DISPLAYED IN PERCENT BY AGE, DISABILITY, GEOGRAPHICAL AREA, REQUEST, INFORMANT, PROBLEM AREA, AND INTERVENTION FOR PROTECTION AND ADVOCACY AGENCIES BY HIS REGIONS

Region	I	II	III	IV	V	VI	VII	VIII	IX	X	Y O T
NO. OF CASES											
FY78	977	1511	1064	1496	3616	990	204	1634	1271	1718	14501
FY79	2259	2011	1846	2069	5980	1553	551	1555	5213	3987	27018
FY80	3022	2754	3356	2347	5549	1039	342	1493	3756	3815	27273
Total	6258	6276	6280	5912	14945	3582	1097	4662	10240	9520	68792
% BY AGE											
0-4	5	6	5	6	4	8	7	7	6	6	5
5-21	35	45	48	60	37	44	34	54	36	38	42
22-64	44	30	42	33	52	35	25	33	43	41	42
65+	0	0	0	0	1	0	0	0	2	2	1
Unreported	16	19	5	1	6	13	34	6	13	13	10
Total	100	100	100	100	100	100	100	100	100	100	100
% BY DD											
MR	45	50	38	44	62	40	26	52	39	40	47
CP	10	5	6	11	7	8	11	8	9	6	8
CF	12	9	5	7	6	9	8	11	7	5	8
Autism	4	3	2	5	2	3	3	3	4	3	3
Dyslexia	2	4	6	6	0	1	3	2	3	1	2
Neurological	0	0	1	1	2	1	1	1	2	3	1
Learning Dis.	2	2	13	2	2	3	0	2	3	3	3
Eul Diag	2	0	2	4	4	1	0	4	2	2	3
Aphasic	0	0	0	0	0	0	0	0	0	0	0
Other	17	25	24	19	11	34	12	15	20	32	20
Unreported	6	2	3	1	4	0	56	2	11	5	3
Total	100	100	100	100	100	100	100	100	100	100	100
% BY GEOG. AREA											
Urban	25	50	40	38	42	44	35	46	42	49	42
Suburban	21	19	18	20	16	10	7	4	21	7	16
Rural	26	24	24	31	16	28	31	35	16	33	24
Out-Of-State	1	1	1	3	1	0	1	2	1	1	1
Institution	17	5	15	7	25	12	3	16	6	3	12
Other	1	1	1	1	0	1	1	1	2	0	1
Unreported	9	0	1	0	0	5	22	2	12	7	4
Total	100	100	100	100	100	100	100	100	100	100	100
% BY REQUEST											
Family	32	47	48	46	32	54	26	36	32	36	38
Friend	3	4	4	6	5	4	5	6	6	7	5
Consumer	14	14	12	8	7	7	15	13	22	26	14
Serv.Prov.	31	24	28	30	46	18	28	22	21	22	29
Adv.Prov.	3	6	1	4	5	2	0	5	2	4	4
Other	8	5	5	5	5	15	4	12	4	3	5
Unreported	9	0	2	1	0	0	22	6	13	8	5
Total	100	100	100	100	100	100	100	100	100	100	100
% BY INFORMANT											
TV	2	2	3	2	1	1	0	1	3	2	2
Radio	2	2	2	2	2	1	0	3	2	1	2
Newspaper	8	4	6	4	7	2	2	24	7	2	6
Posters	2	6	3	1	1	1	9	0	3	2	2
Serv.Prov.	37	32	20	36	36	39	18	26	21	29	31
Counselor	1	5	5	1	3	3	1	4	3	11	4
Friend	8	3	14	10	6	15	4	8	9	7	9
Cons.Adv.	11	7	10	13	7	9	7	4	18	6	10
P&A Publ.	1	1	9	5	16	27	6	5	11	5	9
Other	6	3	14	19	13	2	21	12	6	5	10
Unreported	20	35	4	3	6	0	38	13	17	30	15
Total	100	100	100	100	100	100	100	100	100	100	100
% BY TYPE SER.											
EDUCATION	24	30	41	38	17	44	19	31	24	20	27
Employment	10	3	12	9	5	6	12	6	7	8	8
Transport	1	1	0	0	1	2	0	0	1	1	1
Medical	5	9	6	9	4	3	4	3	3	7	5
Financial	14	10	10	10	9	5	9	20	11	20	12
Housing	2	1	0	2	1	1	3	1	4	9	3
Criminal	0	0	0	0	0	0	0	1	1	0	0
Arch.Barriers	1	0	0	0	0	0	0	0	0	0	0
Abuse/Neglect	5	6	4	5	6	3	3	2	4	3	4
Rehabilitation	1	1	2	0	1	1	0	1	1	2	1
Incap/Living	17	16	14	14	14	19	3	7	3	6	12
Consumer	0	0	0	0	0	1	0	0	8	1	1
Support Serv.	0	0	0	0	1	2	0	0	3	3	1
Guardianship	0	0	2	1	1	8	0	1	2	2	2
Other	22	18	8	12	37	5	13	27	21	13	21
Unreported	0	0	1	0	3	0	25	0	3	3	2
Total	100	100	100	100	100	100	100	100	100	100	100
% BY INTERV.											
Information	34	29	31	32	40	45	65	44	40	47	39
Counseling	7	0	8	6	8	6	1	5	7	7	6
Negotiation	15	14	14	21	5	6	5	19	13	12	12
Admins.Rem.	9	9	9	9	2	7	4	7	3	3	6
Legal	2	3	6	4	2	1	0	5	1	1	2
Withdrawal	1	0	0	0	1	0	0	1	1	1	1
Referral	13	17	13	9	13	18	3	12	16	15	13
Other	19	28	19	17	29	17	22	6	17	14	20
Unreported	0	0	0	0	0	0	0	1	2	0	1
Total	100	100	100	100	100	100	100	100	100	100	100

Forty-seven percent of the clients of P&A agencies the first three years were mentally retarded. Twenty percent of the 68,792 clients were multiply handicapped. Of this percent of multiply handicapped, mental retardation was one of the handicaps for at least 50% of the clients. All of the dual diagnosis individuals were also mentally retarded. Therefore, mental retardation was the handicap for sixty percent of the clients, or for 41,000 individuals.

Eight percent of the clients were cerebral palsied and an equal number were epileptic. Three percent, or 2,100 individuals who sought P&A services the first three years, were autistic. Two percent were dyslexic and one percent were affected by neurological disorders. Three percent of the clients were hearing disabled and three percent were both mentally retarded and mentally ill.

The impact of the application in the change in definition of developmental disabilities from PL 94-103 to PL 95-602 on the clientele of the P&A agencies from FY '78 to FY '79 and FY '80 is described in a later section of this report.

The Protection and Advocacy agencies continue to serve a cross section of the population. Forty-two percent of the clients were from urban areas, sixteen percent from suburban areas, and twenty-four percent from rural areas. One percent, or 651 clients, were from out-of-state in the first three years.

The P&A agencies continue to be responsive to providing services for individuals in institutions. The P&A agencies represented 7,144 individuals in institutions in the first three years of operation. This number represented 12 percent of the total clients served.

It is interesting to note that 38 percent of the requests for services came from the family of the individual. Twenty-nine percent of the individuals were sent to Protection and Advocacy agencies by service providers. It is interesting to notice the cooperation between service providers and Protection and Advocacy in the provision of information and services for individuals who are developmentally disabled. Fourteen percent of the individuals represented came to Protection and Advocacy agencies on their own, five percent were recommended by a friend, and five percent recommended by others. "Others" category included citizen advocate groups, judges, lawyers, criminal justice system, counselors and other professionals involved with individuals who are developmentally disabled.

One of the questions that is frequently asked in any business is, "How did you find out about our service?" The Protection and Advocacy agencies are under the mandate to be

statewide and to make their services available statewide. Early in the program, the Bureau of Developmental Disabilities gave each of the Protection and Advocacy programs a \$3,500 grant for a toll-free telephone line within each of the States so that the P&A office would be accessible to any individual wanting their service during the first year of operation. The Protection and Advocacy agencies also had a series of public service announcements, radio spots, TV spots, and general advertising during the first three years of experience. The question can be asked if this type of advertising aided in the knowledge of individuals about Protection and Advocacy and the contact of the agencies. It is interesting to note that media - TV, radio, newspapers, and posters, are responsible for 12 percent of the contacts to P&A agencies.

Thirty-one percent of the individuals found out about the Protection and Advocacy agency through the service provider, which conforms well to the fact that 29 percent of the individuals indicated that they were referred by the service provider. Nine percent of the individuals served were told about Protection and Advocacy by a friend, 10 percent by consumer advocates, 4 percent by counselors. There was a variety of other people who told the consumer about the services of Protection and Advocacy. Word-of-mouth is still the most effective way to penetrate the developmental disabilities community. Ten percent of the individuals found out about the agency from the P&A agency's own publicity campaign.

Twenty-seven percent, or 18,900 of the P&A agencies' cases the first three years, were concerned with education problems. The next highest category was problems concerned with inappropriate placement, which accounted for 12 percent of the problems. Financial problems also accounted for 12 percent of the problems handled by the P&A agencies in the first three years.

Eight percent, or almost 5,500 cases, were concerned with employment problems. Five percent of the problems were medically related problems. Four percent, or almost 3,000 cases, were concerned with abuse and neglect of the individuals.

The variety of cases are dispersed over a wide variety of problems encountered by the handicapped. The percent of education cases is down from 31 percent of cases in the first two years to 27 percent of the cases in the first three years.

It is interesting to carefully review the type of services provided in the first three years of Protection and Advocacy in the United States. Thirty-nine percent of the cases were information only cases. Six percent of the cases required counseling and twelve percent required negotiations. Six percent, or 4,700 cases, required administrative procedures to bring to resolution. Two percent of the cases required legal remedies including court

action. An analysis of the statistics indicates that only 1,320 of the 68,000 served by Protection and Advocacy during the first three years required court intervention in order to solve the problem.

The fact that only 2 percent of all the cases handled by Protection and Advocacy agencies in the first three years required court intervention is an indication that society, programs, and individuals are able to work cooperatively to meet the needs of individuals who are developmentally disabled. The fact that very few of the cases required court opinion speaks well of society's desire to provide adequate programming and services for individuals that are developmentally disabled. Also, the fact that 2 percent of the cases required litigation speaks well of the skill of the individuals who staff the Protection and Advocacy agencies in their ability to obtain appropriate programming and appropriate services without enjoining court action to secure the desirable outcome.

The statistics would indicate that the fear that constant court intervention would be necessary and used by the Protection and Advocacy system was immensely overstated. There are times when court action is appropriate to decide on the program and fiscal responsibility for a particular section and segment of social programming. It is not always a negative factor to allow a court to render a decision. Also, there are times that an impasse requires the deliberation of the judicial body. However, the fact that Protection and Advocacy has used the legal redress judiciously underscores the maturity that this unique and dynamic system has attained in its first three years of operation.

The P&A systems used referrals to other agencies and programs for 14 percent of the cases. It is important to note that in 60% of the cases in which individuals came to the Protection and Advocacy agency services were provided beyond information only. It is important to understand this statistic in light of the limited resources and staffs that have been provided for the population which the mandate requires be served by the Protection and Advocacy agency.

MATERIALS DEVELOPED

There has been a great amount of instructional materials developed by the Protection and Advocacy agencies in the first three years of existence. It was apparent from the beginning that the Protection and Advocacy agency would have to find its place within the service community and to identify its purpose in its initial year of operation. In order to facilitate the identification of purpose, most of the P&A agencies developed an agency brochure which described its function, services, and how to access its services. In some cases these agency brochures also contained information as to the philosophical position of a Protection and Advocacy agency.

As the Protection and Advocacy agency matured, additional materials were needed in order to develop informational and instructional guides on a variety of subjects for individuals with developmental disabilities, their parents and/or guardians. Figure 1 contains the materials by subject matter that were developed by three or more of the Protection and Advocacy agencies in the several States.

The legal and/or human rights of individuals who are developmentally disabled is a topic of materials which are as large as 200 pages and as small as a 4 page pamphlet, which were produced by 24 different Protection and Advocacy agencies. Next in volume is material on the educational rights of individuals who are developmentally disabled, which were produced by 23 P&A agencies. Primarily, these materials focused on rules and regulations and entitlements under PL 94-142. In many cases, these materials also contained instructional procedures for completing an IEP and what to do and how to request a due process hearing.

There were 19 Protection and Advocacy agencies which produced training materials on how to be an advocate. Several of the models of Protection and Advocacy which had been implemented throughout the United States require the training of citizen advocates at the local level. The training materials produced by the P&A Agencies were primarily aimed at training citizen advocates, and in some cases professional individuals to be advocates for individuals with developmental disabilities.

There are 18 P&A agencies which write monthly, bi-monthly or quarterly newsletters. These newsletters have a variety of editorial philosophies and a magnitude which is reflective of that editorial philosophy. Distribution of these newsletters is wide and they are used as educational aids in many States for the transmission of specific program knowledge.

The commonality of materials development declines rapidly, as is shown in Figure 1. There are four Protection and Advocacy agencies which have developed materials on the implementation of Section 504, an additional four that have developed materials on financial entitlements of individuals that are developmentally disabled, and eight Protection and Advocacy agencies have developed manuals describing the services for individuals who are developmentally disabled in the State.

Materials development has been an important component of the Protection and Advocacy Program. Most of the materials have developed out of specific repetitive questions asked by individuals interested in services in the programs for individuals who are developmentally disabled.

Subject

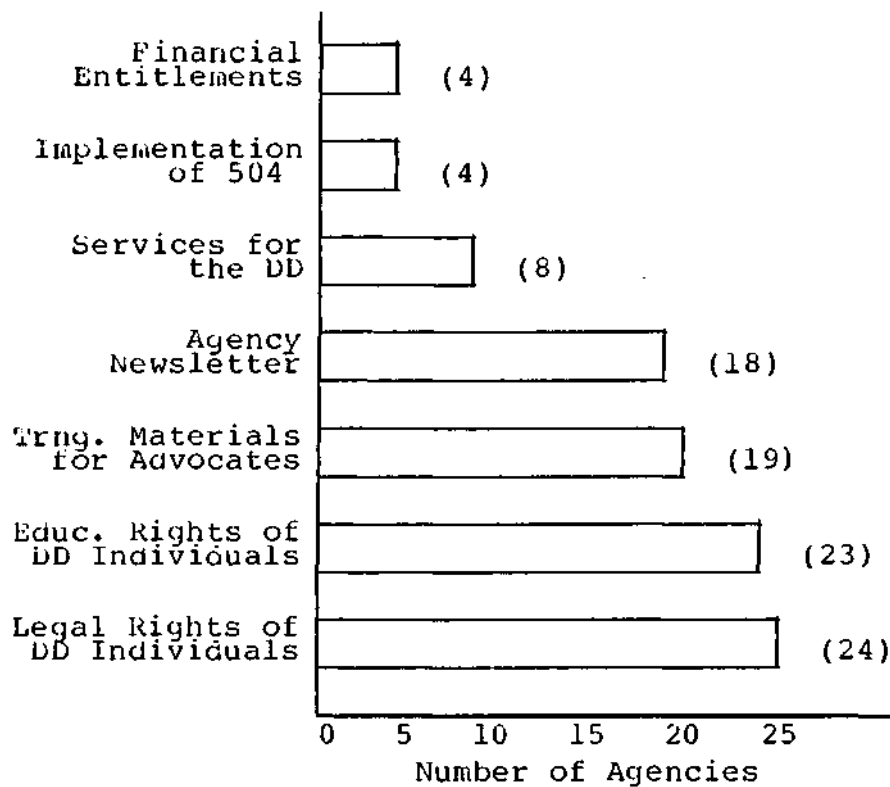


Figure III-1. Materials by Subject Matter Developed by Protection and Advocacy Agencies in the First Three Years

TRAINING ACTIVITIES

Training activities are an activity of most of the Protection and Advocacy agencies throughout the United States. Training is defined as providing workshops, seminars and other formal educational experiences for a specific group of individuals communicating a specific body of information. The topics of the seminars and workshops vary from State to State and program to program depending on the philosophy of the Protection and Advocacy Program and the particular model of Protection and Advocacy services instituted within the State.

The most popular training program is the development of advocacy skills and instruction in the rights and entitlements of individuals with developmental disabilities. This type of training activity is conducted by a majority of the Protection and Advocacy agencies in the United States. It is carried out from a few hour workshop to a month long, intensive in-service training activity. There are several programs that focus on self-advocacy and programs that focus on becoming a volunteer advocate and working with an individual who is developmentally disabled.

The second most popular type of training provided by the Protection and Advocacy agencies throughout the country is the training of professionals. This training takes two forms in its implementation. One form is to inform the professionals of rules and regulations under Federal and State Law which apply to the individuals who are developmentally disabled with whom they work. The other is to assist the professional in learning how to work with the developmentally disabled, and in some cases provide professional representation for them. There are a few programs which provide training to attorneys in the specific nuances of representing individuals who are developmentally disabled.

Most Protection and Advocacy agencies provide speakers and make presentations to any and all groups requesting such presentations. The Protection and Advocacy Program is unusually responsive to opportunities to tell their story and in most cases is very appreciative of the opportunity to speak in behalf of the developmentally disabled population within the State. Training and public presentation is one of the ways in which the message of the Protection and Advocacy agency is being communicated and thereby assisting in the attainment of its mission.

ORGANIZATIONS

Type

Each State had the opportunity to select the placement of their Protection and Advocacy agency during the planning period in FY '77. There were three options as to the location of the State Protection and advocacy agency. These three options were:

1. Within the administrative structure of the State
2. Within an existing non-profit organization
3. Establishing a new non-profit organization

There were some restrictions as to the placement of the Protection and Advocacy agency which centered around the fact that the Protection and Advocacy agency could not be placed in a situation where it would be subject to a conflict of interest. This meant that the Protection and Advocacy agency could not be placed in the same administrative organization as the provider of services to individuals with developmental disabilities. This restriction eliminated the possibility of placing the Protection and Advocacy agency in the same governmental structures as the nine Federally assisted programs, or the location of the Developmental Disabilities State Planning Council, and the Administrative Agency.

The mandate of Section 113 of PL 94-103 and PL 95-602 required that the Protection and Advocacy agency also have the power to seek legal redress on behalf of individuals with developmental disabilities. This mandate eliminated from consideration many State placements because few Departments within the Administrative structure of State Governments have the legislative authority to bring legal action against the State. Therefore, the selection of the placement of the Protection and Advocacy agency within the State became a question of considerable magnitude during the planning phase. However, by October 1, 1977 all problems of placement had been resolved and the results of those resolutions are contained in Figure 2, which shows a comparison of the placement of Protection and Advocacy agencies within each of the 54 States and Territories between the placement in FY '80 and in FY '81.

Nine States selected to originally place the Protection and Advocacy agency with existing organizations. These organizations had a variety of purposes depending upon the State. The organizations ranged from an Association of Retarded Citizens, which was a non-service provider, to the State Bar Association. Sixteen of the States originally placed the

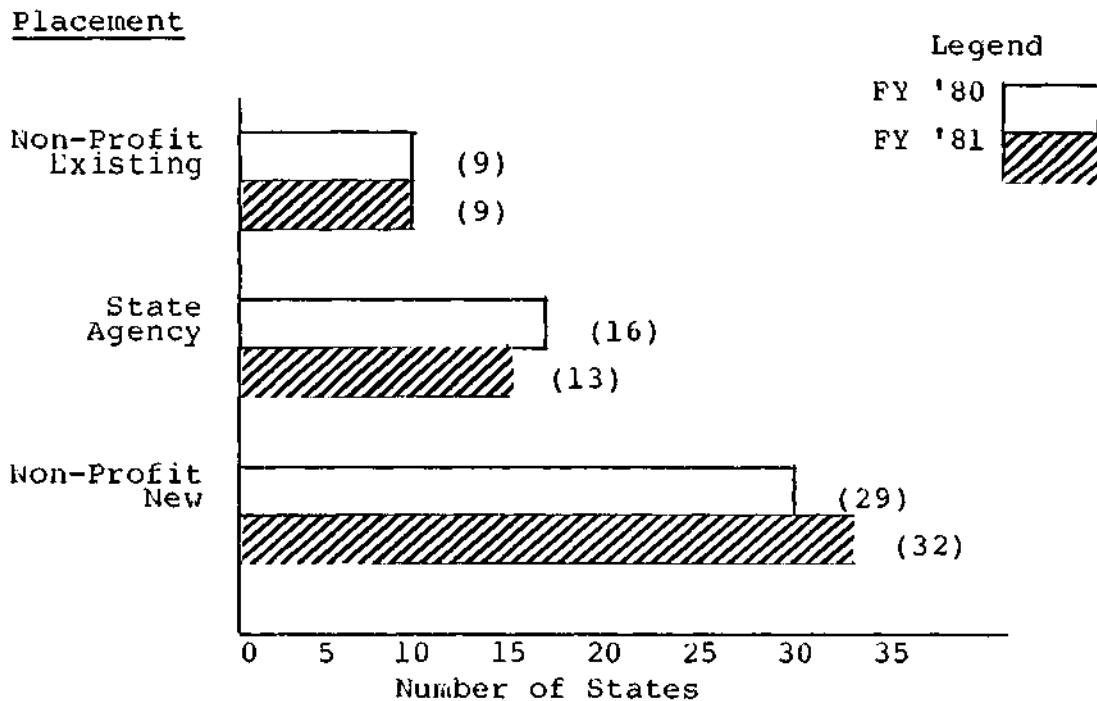


Figure III-2. Comparison of the Placement of Protection and Advocacy Agency Within the State Between FY '80 and FY '81

Protection and Advocacy agency within the State Government. There are a variety of placements among the States within the Administrative arm of State Government including, but not limited to, the Governor's Office, the Department of Consumer Affairs, and the Department of the State Advocate.

The majority, 29 States, provided new non-profit corporations as the placement organization for Protection and Advocacy within the State in FY '78. These new non-profit organizations were 501(c)(3) corporations especially set up to house the Protection and Advocacy Program within that State. The Board of Directors of these corporations are appointed by the Governor, elected by the constituency, and/or appointed by voluntary associations within the State. There is no uniformity of the appointment of the Board of Directors to a corporation which administers the Protection and Advocacy Programs across the 29 States. There is no uniformity as to the numbers of individuals who serve on the Boards, nor the structure. However, there is a uniformity as to the dedication and effective operation of the program.

There were only three placement changes in FY '80. These three placement changes were that three P&A agencies left State Government and are now placed in new non-profit corporations which were especially created for this purpose. . Therefore, at the beginning of FY '81 there are thirty-two agencies placed in non-profit corporations especially created for the purpose of operating a State P&A agency. There are thirteen agencies placed in State Government and nine agencies are still operated by non-profit agencies which existed prior to the implementation of Section 113 of the DD Act.

Staff

There are at present a total of 588 individuals employed in the 54 Protection and Advocacy agencies. This number represents an increase of 60 individuals during the last year of operation. Table 2 shows the number and percent of staff for Protection and Advocacy agencies in the United States at the beginning of FY '81.

There are 440 professionals employed in P&A agencies and 148 clericals so employed. Ninety-two percent of the professionals are full-time employees and eight percent are part-time workers. Eighty-eight percent of the clerical personnel are employed full-time and twelve percent are employed part-time. The ratio of clerical personnel to professional employees is 1 to 3.

TABLE III-2. NUMBER AND PERCENT OF STAFF FOR PROTECTION AND ADVOCACY AGENCIES IN THE UNITED STATES BY CLASSIFICATION

Classification	Total		Full Time		Part-Time	
	No.	%	No.	%	No.	%
Professional	440	100	404	92	36	8
Clerical	148	100	130	88	18	12
Total	588	100	534	91	54	9

Figure 3 shows a comparison of the number of staff members which P&A agencies had in FY '80 and the number of staff members which the 54 P&A agencies have in FY '81. The average number of staff members per P&A agency has increased from 10 in FY '80 to 11 in FY '81.

There are two P&A agencies which have two staff members. This is a decrease of three programs from FY '80. There are now fourteen programs which have 3-5 staff members, an increase of two from FY '80. There are ten programs which have 6-8 staff members, and nine programs which have between 9-11 staff members. Eight programs still have 12-14 staff members. There are four programs which now have between 15-17 staff members, which is an increase of three programs from FY '80 staffing patterns. There is one program which has between 18-20 staff members. There are six programs which have twenty-one or more employees for FY '81.

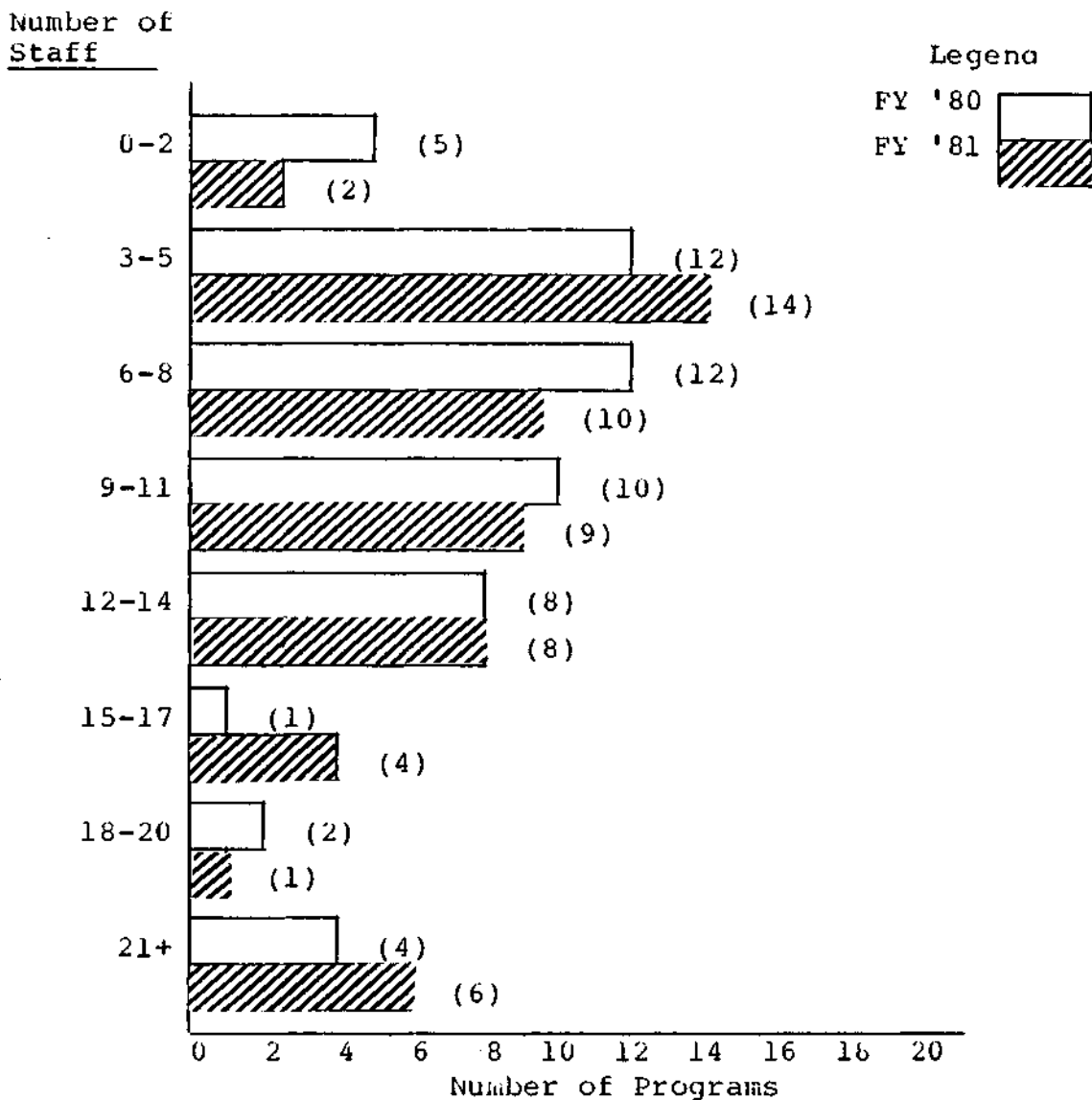


Figure III-3. Comparison of the Number of Staff Members of Protection and Advocacy Agencies in the United States Between FY '80 and FY '81

Table 3 shows a comparison of professionals by job classification employed by P&A agencies in FY '80 and FY '81 and percentage of change for each classification.

The number of professional staff has increased a total of forty-eight, or twelve percent from FY '80 to FY '81. The staffing pattern has changed to reflect the emphasis which the P&A agencies are putting on advocacy and client/case activity.

There has been a ninety-two percent increase in the number of professional advocates used in the P&A programs. There are presently 184 employees who are identified as advocates compared to 96 in FY '80. There has been a fifteen percent increase in attorneys. There were 68 in FY '80 and there are 78 reported at the beginning of FY '81. The combination of professional advocates and attorneys account for 60% of the total professional workforce in the P&A agency network. There has been a decrease in the number of project directors, coordinators and community organizers. The P&A agencies are using professional staffing patterns to focus on the client and client related problems as they carry out the legal mandate.

It should be added that the fifty-four executive directors are often attorneys and/or advocates and maintain caseloads. In at least two P&A agencies, the executive director is the only professional staff person employed.

TABLE III-3. COMPARISON OF PROFESSIONALS BY JOB CLASSIFICATIONS EMPLOYED BY P&A AGENCIES IN FY '80 AND FY '81 AND PERCENTAGE OF CHANGE FOR EACH CLASSIFICATION

Job classification	Employed in FY'80	Employed in FY'81	Percent of change
Professional Advocate	96	184	+ 92
Attorney	68	78	+ 15
Executive Director	54	54	0
Community Organizer	42	9	- 79
Paralegal	28	29	+ 4
Professional	17	19	+ 12
Project Director	15	4	- 73
Trainer	11	13	+ 18
Law Intern	10	9	- 10
Coordinator	10	4	- 60
Field Representative	10	1	- 90
Assistant Director	7	6	- 14
Education Specialist	6	6	0
Inf. & Ref. Specialist	6	3	- 50
Public Relations	5	10	+ 50
Resource Developer	5	5	0
Program Developer	2	6	+ 200
Total	392	440	+ 12

Table 4 shows a comparison of clerical positions by job classification for P&A agencies in FY '80 and FY '81 and percentage of change for each classification.

The clerical staff has increased by nine percent in FY '81 over the FY '80 level. The significant increase was in the clerical or typist classification. There was a decrease in the number of bookkeepers employed by the P&A agencies. There are a total of 148 individuals employed in clerical positions by the P&A agencies for FY '81.

TABLE III-4. COMPARISON OF CLERICAL POSITIONS BY JOB CLASSIFICATIONS FOR P&A AGENCIES IN FY '80 AND FY '81 AND PERCENTAGE OF CHANGE FOR EACH CLASSIFICATION

Job classification	Employed in FY'80	Employed in FY'81	Percent of change
Secretary	57	58	+ 2
Clerical	31	40	+ 23
Administrative Asst.	29	31	+ 7
Bookkeeper	18	15	- 16
Receptionist	1	4	+ 300
Total	136	148	+ 9

FISCAL RESOURCES

Protection and Advocacy is one of the four components of the Developmental Disabilities Act. The four components of the Developmental Disabilities Act are the Protection and Advocacy Program in Section 113, the Basic Formula Grant Program in Section 132, the University Affiliated Facilities Program in Section 121, and the Special Projects Program in Section 145.

The Protection and Advocacy Program was funded at the level of \$3,000,000 in FY '78. In FY '79, because the minimum allotment to any State regardless of size was raised from \$20,000 to \$50,000, the appropriation rose to \$3.8 million. In FY '80 and FY '81 the appropriation for Protection and Advocacy was \$7.5 million.

It is interesting to note, as can be seen from perusing the information on Table 3, that there has been a significant increase in supplementary funding to the Protection and Advocacy systems over the last four years. There has been an 18% increase in the supplementary funding in FY '81 from the FY '80 level.

In FY '78 the total amount of money expended for Protection and Advocacy in the United States was \$5,341,171. Of this money, \$2,120,652 was from supplemental sources other than the basic Federal money coming from Section 113 of the law. In FY '79 there was a total of \$8,134,789 spent for Protection and Advocacy in the country. The supplementary amount was almost twice that which it had been in FY '78. The supplementary amount in FY '79 was \$4,365,010. It is interesting to note that the supplementary amount exceeded the basic funding amount from Section 113 in FY '79.

In FY '80 a total of \$11,856,663 was budgeted for Protection and Advocacy. Of this amount, \$4,442,719, or 37%, was from sources other than the basic support supplied by Section 113 of PL 95-602. In FY '81 a total of \$12,636,729 is budgeted for Protection and Advocacy. This amount represents a 6.6% increase in the total budget for P&A. The entire increase in P&A funds is in supplementary sources. Supplementary funds increased \$785,219, or 18% in FY '81 over the FY '80 amount.

TABLE III-5. COMPARISON OF FUNDING LEVELS OF PROTECTION AND ADVOCACY IN THE UNITED STATES FOR FY'78, FY'79, FY'80, AND FY'81

Funding Category	FY '78 \$	FY '79 \$	FY '80 \$	FY '81 \$
Basic Funding	3,220,519	3,769,779	7,413,944	7,408,754
Supplementary Fund.	2,120,652	4,365,010	4,442,719	5,227,975
Total	5,341,171	8,134,789	11,856,663	12,636,729

Table 6 displays the total resources for Protection and Advocacy in the United States for FY '78, FY '79, FY '80, and FY '81 source of funds. It is important to note that in FY '78 the Federal dollars paid for 60 percent of the activity in Protection and Advocacy. The DD Council, through its Formula Grant Program, supplied 17 percent of the monies for Protection and Advocacy. Specific grants from other sources than PL 94-103 paid for 9 percent of the program. The State contribution in FY '78 for Protection and Advocacy was 6 percent. The CETA program, where some Protection and Advocacy Programs generate their additional staff requirements, accounted for 5 percent of the funding in FY '78. Title XX provided 2 percent, and carryover planning money which was a part of the payment by the Federal Government to develop the Protection and Advocacy accounted for 1 percent of the fiscal resources used for FY '78 activity.

In FY '79 the Federal allotment under Section 113 was down 14 percent to 46 percent of the resources used for Protection and Advocacy in the United States. Fourteen percent of the resources for Protection and Advocacy came from the DD Council through its Formula Grant Program. Specific grants again contributed 9 percent. However, in FY '79, 18 percent of the resources for Protection and Advocacy came from State general funds, which is a growth of almost 12 percent, but in real dollars it is \$1,200,000 additional monies for Protection and Advocacy. CETA in FY '79 contributed 4 percent of the monies which indicated a real dollar increase of \$100,000 for that year over FY '78. Title XX produced 3 percent of the operating budget and contractors' contributions to program operations contributed 4 percent. One percent of the monies came from private funding sources and 1 percent from miscellaneous funding sources.

In FY '80 the Federal allotment under Section 113 accounted for 63% of all expenditures. The Federal amount under Section 113 was increased \$3,644,166, or 97%, over the FY '79 amount. Seven percent of the resources of P&A agencies came from DD Councils. There was a decrease of approximately a quarter of a million dollars in resources from this source in FY '80. State general funds contributed 18% of the P&A resources in FY '80. This percent represented a \$646,180 increase from the FY '79 contribution. CETA contributed \$385,683 to the program. This amount was an increase of 18% over the FY '79 level. Title XX funds were 50% less in FY '80 over the amount received in FY '79. The amount received from contributors and donations was down in FY '80 compared to the amount received in FY '79. VISTA as a resource contributed one percent of the P&A budget in FY '80.

**TABLE III-6. TOTAL RESOURCES FOR PROTECTION AND ADVOCACY IN THE UNITED STATES FOR
FY '78, FY '79, FY '80, AND FY '81 BY SOURCE OF FUNDS**

Source	FY '78		FY '79		FY '80		FY '81	
	\$ Amount	%	\$ Amount	%	\$ Amount	%	\$ Amount	%
P&A Sec. 113	3,220,519	60	3,769,779	46	7,413,944	63	7,408,754	59
DD Council Part C	894,691	17	1,130,651	14	876,161	7	1,141,544	9
Grants/Contracts	473,490	9	711,589	9	617,708	5	455,770	4
State	296,204	6	1,497,395	18	2,143,575	18	2,682,842	21
CETA	244,676	5	326,613	4	385,683	3	346,803	3
Title XX	83,945	2	248,000	3	126,000	1	233,000	2
Planning Money	76,907	1	36,196	-	-	-	-	-
Contractors	-	-	297,526	4	175,589	1	175,589	1
Private	24,875	-	58,996	1	23,000	.5	74,099	.6
Miscellaneous	19,864	-	30,790	1	31,438	.5	57,100	.4
VISTA	6,000	-	18,328	-	62,800	1	31,228	-
WIN	-	-	8,926	-	765	-	-	-
United Way	-	-	-	-	-	-	30,000	-
Total	5,341,171	100	8,134,789	100	11,856,663	100	12,636,729	100

There appears to be a 6.6% increase in the budget for the P&A agencies in FY '81. Since this report is written in the first quarter of FY '81 the budgets appear as projected budgets which, in some cases, await action by State Legislatures and a variety of grant cycles.

The amount of Federal funds under Section 113 of PL 95-602 will account for 59% of the resources. The amount is the same amount as in FY '80 but the percent is less due to the 18% increase in supplementary funds.

Resources from the DD Councils are at the highest level in the four year history of the program. The DD Councils account for 9% of the funding of P&A systems of 1.1 million dollars. The level of grants and contracts has declined in FY '81 to the \$400,000 level of FY '78.

State general funds have increased again in FY '81. The FY '81 level from State general funds is almost 2.7 million dollars. This represents an increase of \$500,000 when compared to FY '80.

The amount to be received from CETA remains at the FY '80 level while the amount to be received from Title XX will increase 85% over the FY '80 level. Private donations are at a four year high of almost \$75,000. VISTA funding has decreased by 50% of its FY '80 level in FY '81. However, the amount is made up by one P&A agency receiving \$30,000 from United Way.

In summary, the resources for P&A continue to grow from the 5.3 million dollar program in FY '78 to the 12.6 million dollar program in FY '81. P&A agencies have consistently attracted 40% of their resources from alternative funding sources other than the basic support received from Section 113 of PL 95-602.

Table 7 shows the number of Protection and Advocacy agencies receiving monies from supplementary sources in addition to those funds received from Section 113.

The number of P&A agencies receiving funds from DD Councils increased by three from FY '80 to FY '81. The number of P&A agencies which are receiving State funds increased by five in FY '81 from 15 in FY '80 to 20 in FY '81.

There are two more agencies participating in the CETA program in FY '81 than there were in FY '80. One more agency has tapped Title XX funds, bringing this source of funding to four P&A programs. There are three agencies using VISTA personnel and no agencies using WIN resources in FY '81. One agency received a grant from United Way.

TABLE III-7. NUMBER OF PROTECTION AND ADVOCACY AGENCIES RECEIVING FUNDS FROM SUPPLEMENTARY FUNDING SOURCES FOR PROTECTION AND ADVOCACY IN THE UNITED STATES FOR FY '78, FY '79, FY '80, AND FY '81

Source of Additional Funding	FY '78 No. of States	FY '79 No. of States	FY '80 No. of States	FY '81 No. of States
DD Councils	26	24	19	22
Grants/Contracts	8	9	11	8
State Support	8	16	15	20
CETA	7	8	8	10
Title XX	2	4	3	4
VISTA	1	2	2	3
WIN	0	1	1	0
United Way	0	0	0	1

In summary, it can be seen from this report that the Protection and Advocacy Program is a viable program which contributes a valuable service to individuals who are developmentally disabled. The program has managed to generate almost 50% of its resources outside of its basic formula grant.

The program, as has been shown in this report, is serving the most severely involved of the disabled in our country. The clientele of the P&A agencies is increasingly becoming the multiply handicapped who have no slot in the service system. The DD Program in total is more and more addressing the service, social and psychological needs of the severely and profoundly developmentally disabled in this country.

The Protection and Advocacy agencies are working diligently to place the individuals for whom regulations must be rewritten, program activities expanded, and attitudes changed in order to allow them maximum participation in a free society. Five hundred plus individuals who staff P&A agencies work diligently to obtain additional resources, tell the P&A story throughout the State, and provide thoughtful and considered representation to each individual in need of service.

IMPACT OF THE DEFINITION

The application of the definition of developmental disabilities contained in PL 95-602 apparently has had some effect on the clientele of the Protection and Advocacy Agencies. The effect is an increase in the number of individuals who are not mentally retarded, cerebral palsied, epileptic, or autistic receiving P&A services. However, the total number of individuals who are mentally retarded receiving P&A services has not significantly decreased in either FY '79 or FY '80.

Table 8 contains the number and percent of individuals served by Protection and Advocacy Agencies in FY '78, FY '79, and FY '80 by cause of disability. The table also shows the percent of cases attributable to each cause of disability for each of the three fiscal years.

TABLE III-8. NUMBER AND PERCENT OF INDIVIDUALS SERVED BY PROTECTION AND ADVOCACY AGENCIES BY CAUSE OF DISABILITY FOR FY '78, FY '79, AND FY '80

Cause of disability	Fiscal '78		Fiscal '79		Fiscal '80	
	Number	%	Number	%	Number	%
Mental Retardation ¹	9,542	65.8	16,265	60.2	14,073	51.6
Cerebral Palsy	1,218	8.4	1,756	6.5	2,236	8.2
Epilepsy	1,377	9.5	1,513	5.6	2,209	8.1
Autism	464	3.2	865	3.2	927	3.4
Multiply Handicapped ²	1,290	8.9	3,755	13.9	2,155	7.9
Other	610	4.2	2,864	10.6	5,673	20.8
Total	14,501	100	27,018	100	27,273	100

¹ Includes multiply handicapped, of which one handicap is mental retardation.

² Non-mentally retarded, cerebral palsied, epileptic, or autistic.

The first year of P&A, FY '78, there were a total of 14,501 individuals served, of which 65.8%, or 9,542, were mentally retarded. Of the total served, 1,218 were cerebral palsied, 1,377 were epileptic, and 464 were autistic. There were 1,290 multiply handicapped non-mentally retarded served and 610 individuals with other than the disabilities listed served during FY '78.

During the second year of operation, FY '79, the P&A program served a total of 27,018 individuals, of which 60.2%, or 16,265, were mentally retarded. Although the percentage of cases involving mentally retarded individuals was lower in FY '79 when compared with FY '78 statistics, the number of mentally retarded served increased a total of 6,723 from the prior year.

One thousand seven hundred fifty-six individuals with cerebral palsy were served in FY '79, an increase of 538 over the number served in FY '78. The individuals with cerebral palsy accounted for 6.5% of all individuals served during FY '79.

The number of individuals with epilepsy who were served in FY '79 increased by 136 over the number served in FY '78. The percent of individuals with epilepsy was only 5.6% of the cases in FY '79, where it had been 9.5% in FY '78.

The number of individuals who were autistic served in FY '79 was 865, which is an increase of 401 from FY '78. Individuals with autism accounted for the identical percentage of cases in both FY '78 and FY '79.

The number of non-mentally retarded multiply handicapped increased in FY '79, 2,465 over the number so disabled served in FY '78. There were 3,755 multiply handicapped individuals served in FY '79, which represents 13.9% of the clients for that year.

There were 2,864 individuals served with handicaps other than those listed, which represented 10.6% of the cases in FY '79. 'Other' handicaps included, but were not limited to, individuals with learning disabilities, deafness, blindness, cystic fibrosis, spina bifida, muscular dystrophy, osteogenesis imperfecta, and individuals who were physically handicapped.

The increase of individuals with other handicaps who were served by P&A Agencies could originate from factors other than the change in the Federal definition of developmental disabilities. Many States, sixteen, received State monies for the operation of the P&A program. Eligibility criteria for handicapped persons were changed in some States with the provision of State monies for Protection and Advocacy. The State contribution to P&A increased \$1.2 million in FY '79 from FY '78. Some States required their P&A Agencies to serve all handicapped.

The numbers of individuals served by P&A Agencies in FY '80 was 27,273. Of this number, 51.6% of the individuals served were mentally retarded. There were 2,236 individuals with cerebral palsy served in FY '80, which represented 8.2% of the total clientele. Individuals with epilepsy represented 8.1% of the clientele, and 3.4% of those served were individuals with autism. The total number of non-mentally retarded multiply handicapped served went down in FY '80 when compared with FY '79 statistics. However, the individuals in the category of 'other' served in FY '80 increased significantly.

Table 9 shows the percent of change for each category of individuals served by P&A Agencies in FY '79 and FY '80 using FY '78 as the base year.

TABLE III-9. COMPARISON OF PERCENTAGE OF INDIVIDUALS SHOWN BY CAUSE OF DISABILITIES SERVED BY P&A AGENCIES IN FY '79 AND FY '80 WITH THOSE SERVED IN FY '78

Cause of disability	Fiscal '78	Fiscal '79 ¹	Fiscal '80 ²
	% Control year	% Experimental year	% Experimental year
Mental Retardation	100	+ 70.5	+ 43.5
Cerebral Palsy	100	+ 44.2	+ 78.6
Epilepsy	100	+ 9.9	+ 56.1
Autism	100	+ 86.4	+ 94.4
Multiply Handicapped	100	+ 191.1	+ 62.5
Other	100	+ 369.5	+ 804.4
Total	100	+ 86.3	+ 82.9

¹ Compared to number served in FY '78.

² Compared to number served in FY '78.

It is apparent from the information presented in Table 9 that individuals with multiple handicaps and other handicaps besides mental retardation, cerebral palsy, epilepsy, and autism accounted for a significantly larger percentage of the 86% increase in individuals served in FY '79.

The figures for FY '80 indicate that the individuals with other handicaps represented an 800% growth when compared with FY '78 statistics, while the total number of individuals served increased by only 82.9%.

Table 10 shows the changes in individuals served who were mentally retarded, cerebral palsied, epileptic, and autistic and all other individuals served by P&A Agencies for FY '78, FY '79, and FY '80.

One could conclude from the information shown in Table 10 that the impact of the definition of developmental disabilities in PL 95-602 was to shift the clientele of the P&A system approximately 15% from individuals with mental retardation, cerebral

palsy, epilepsy or autism to individuals with other types of handicapping conditions. However, it is not known what part State requirements in those States which received State funds played in the shift of P&A clientele over FY '79 and FY '80. It is assumed for the purposes of this report that the definition in PL 95-602 was the major factor in the shift of clientele.

TABLE III-10. PERCENTAGE OF INDIVIDUALS WHO ARE MENTALLY RETARDED, CEREBRAL PALSID, EPILEPTIC AND AUTISTIC AND ALL OTHER INDIVIDUALS SERVED BY P&A AGENCIES FOR FY '78, FY '79, AND FY '80

Category of disability	FY '78 %	FY '79 %	FY '80 %
MR - CP - E - A	86.9	75.5	71.3
All others	13.1	24.5	28.7
Total	100	100	100

SERVICES TO THE DEVELOPMENTALLY DISABLED

PL 95-602 requires that "an assessment, evaluation and comparison of services provided to persons with developmental disabilities" be included in the mandated report.

It is difficult to assess and evaluate the quality of services provided by the P&A Agencies. Evaluation can take the form of client satisfaction, efficiency of operation, number of individuals served, magnitude of services provided, or a host of other evaluative indicators which would provide assessment data.

However, Protection and Advocacy Agencies are responsive to individuals at the point of need. The fact that over 68,000 individuals have been served in a three year period is significant.

The types of services provided have not changed significantly over the three year period. Cases concerned with education problems represented only 27% of all cases in FY '78, whereas this problem area represented 31% in FY '79. The percent of cases dealing with problems in employment, fiscal entitlements, inappropriate living arrangements, and medical entitlements remained consistent over the first three years of P&A.

There has not been a significant change in the type of services provided by the P&A Agencies. Only 2% of all cases handled by P&A Agencies have required legal intervention, which means 98% have been solved outside of legal action.

Twelve percent of all cases handled by P&A Agencies have been for individuals in institutions, which demonstrates good access to institutions. This percentage has remained constant over the three year period.

The fact that all fifty-four programs survived the first three years without crib deaths and administrative accidents speaks well of the program.

The Administration on Developmental Disabilities is working toward finalizing standards for P&A Agencies and has supported the program with technical assistance during the first three years.

In summary, examination of the P&A report shows that the services provided by the P&A Agencies are consistent with the legislative mandate, programs are in place in each of the 54 States and Territories, and statistical evidence indicates a growth in number of individuals served in each of the three years in which P&A's have been in existence.

SECTION IV

SPECIAL PROJECTS

LEGISLATIVE MANDATE

APPROPRIATIONS

DISTRIBUTION OF RESOURCES

PROJECTS FUNDED

SERVICE PROVIDERS

IMPACT OF THE DEFINITION

SERVICES TO THE DEVELOPMENTALLY DISABLED

LEGISLATIVE MANDATE

Grants of National Significance and Special Projects have been part of the Developmental Disabilities Program since its inception. Grants of National Significance and Special Projects are funded under Part D of PL 95-602, Title V. Part D, entitled Special Project Grants, contains the following:

- (a) The Secretary may make project grants to public or nonprofit private entities for--
- (1) demonstration (and research and evaluation in connection therewith) for establishing programs which hold promise of expanding or otherwise improving services (particularly priority services) to persons with developmental disabilities (especially those who are disadvantaged or multihandicapped); and
 - (2) demonstration (and research, training, and evaluation in connection therewith) for establishing programs which hold promise of expanding or otherwise improving protection and advocacy services related to the State protection and advocacy system (described in Section 113).
- (b) Grants provided under subsection (a) shall include grants for--
- (1) public awareness and public education programs to assist in the elimination of social, attitudinal, and environmental barriers confronted by persons with developmental disabilities;
 - (2) coordinating and using all available community resources in meeting the needs of persons with developmental disabilities (especially those from disadvantaged backgrounds);
 - (3) demonstration of the provisions of services to persons with developmental disabilities who are also disadvantaged because of their economic status;
 - (4) technical assistance relating to services and facilities for persons with developmental disabilities, including assistance in State and local planning or administration respecting such services and facilities;
 - (5) training of specialized personnel needed for the provision of services for persons with developmental disabilities or for research directly related to such training;
 - (6) developing or demonstrating new or improved techniques for the provision of services to persons with developmental disabilities (including model integrated service projects);
 - (7) gathering and disseminating information relating to developmental disabilities;

(8) improving the quality of services provided in
and the administration of programs for such persons;
and

(9) developing or demonstrating innovative methods
to attract and retain professionals to serve in rural
areas in the habilitation of persons with develop-
mental disabilities

PL 95-602, Title V, Sec.145

For each of the three fiscal years covered by this report, the Bureau of Developmental Disabilities printed an announcement of intention to make grants in certain priority areas which were consistent with the eleven areas of activities designated in Parts a and b of Section 145.

The introduction to the announcement appeared in the Federal Register on Monday, August 18, 1980. This announcement was for the Special Project Grant Program - Projects of National Significance in Developmental Disabilities.

OFFICE OF HUMAN DEVELOPMENT SERVICES

[Program Announcement No. 13631.8011

Special Project *Grant Program* - Projects of National
Significance in Developmental Disabilities

AGENCY: Office of Human Development Services, DHHS

SUBJECT: Announcement of availability of grant funds for the special project
Grant Program - Projects of National Significance in Developmental Disabilities

SUMMARY: The Administration on Developmental Disabilities (ADD) announces that applications will be accepted for grants under the Special Project Grant Program - Projects of National Significance authorized by Title I, Section 145 of the Developmentally Disabled Assistance and Bill of Rights Act, Pub.L.95-602, 142 U.S.C. 60011. Regulations applicable to this program include the Administration on Developmental Disabilities general regulations, 45 CFR Part 1385, and the regulations governing Discretionary Grant Programs [45 CFR Part 13871.

DATE: Closing date for receipt of applications is September 5, 1980.

Scope of this Announcement

This program announcement covers only projects of national significance authorized under the Special Project Grants Program of the Developmentally Disabled Assistance and Bill of Rights Act, Pub.L.95-602, and encompasses only those projects that relate to the Developmental Disabilities Protection and Advocacy Systems.

Program Purpose

The Special Projects Grant Program, as authorized in Section 145(a) of Pub.L.95-602, enables the Administration on Developmental Disabilities to award grants for a variety of purposes, among which are:

1. To demonstrate how to establish programs which will expand or improve services to developmentally disabled persons
2. To increase public awareness and public education programs
3. To demonstrate services for economically disadvantaged developmentally disabled persons
4. To gather and disseminate information.

For the purposes of this program announcement, these projects must:

- (1) Be designed to have a direct impact on Developmental Disabilities State Protection and Advocacy systems throughout the country; and
- (2) Involve activities to be conducted in a number of sites in various parts of the country as part of a unified program.

Program Goal and Objective

All States and Territories participating in the Basic State Formula Grant Program have systems designed to protect and advocate for the rights of persons with developmental disabilities. Staff of Protection and Advocacy Systems must deal with a wide variety of programs and issues, including legal matters on behalf of the developmentally disabled persons whom they serve. Many of the systems need information in the most expeditious manner possible on relevant laws, court decisions, as well as guidance on legal matters in order to protect their clients' rights to services.

The purpose of these projects is to provide back-up specialized knowledge, legal expertise, and support to State Protection and Advocacy Systems that will enhance and strengthen their capabilities to engage in outreach to minority, institutionalized, geographically isolated and other hard-to-reach persons with developmental disabilities. Specifically, the objectives for these projects are:

1. To provide State Protection and Advocacy Systems with the necessary legal and technical information that will assist them in assuring the rights of institutionalized, minority and other under-served and under-involved persons with developmental disabilities; and

2. To provide technical information to State Protection and Advocacy systems to enable them to overcome obstacles to reaching underserved, traditionally separated, and isolated persons with developmental disabilities.

Eligible Applicants

Applications may be made by public or private non-profit organizations experienced in the provision of legal services and which have particular expertise in areas relevant to the rights of developmentally disabled persons. Applicants must have legal and technical expertise specifically related to the civil rights of institutionalized developmentally disabled persons as well as the rights of developmentally disabled members of racial and ethnic minority groups affirmed in Title VI of the Civil Rights Act.

APPROPRIATIONS

As has been reported in Section I of this report, the Special Projects component of the Developmental Disabilities Program has almost ceased to exist because of the drastic cutback in appropriations. The cutback of appropriations in the area of Special Projects was unfortunate both in magnitude and timing. The severe cutback of appropriations in FY '80 limited the amount of assistance at the national and regional levels which could be provided to the DD community in the implementation of the definition in PL 95-602 and the understanding of the four priority service areas. The lack of appropriation also limited the amount of assistance which could be provided in the development of the comprehensive evaluation plan in accordance with Section 110 of PL 95-602. Without the Special Projects, the DD Program has not the flexibility and resources to provide the technical assistance, model programming, and regional and national demonstration necessary at a time of massive program change. Therefore, the deappropriation of Special Projects in FY '80 and FY '81 was unfortunate in light of program needs.

The reduction of funds provided for the Special Projects is illustrated by the appropriations provided for Special Projects for FY '78, FY '79, and FY '80. Table 1 shows the amount of appropriation provided for Special Projects in each of the three fiscal years.

TABLE IV-1. AMOUNT OF APPROPRIATION AND PERCENT OF CHANGE FROM FY '78 FOR SPECIAL PROJECTS FOR FY '78, FY '79, AND FY '80

Category of Special Projects	Appropriation for FY '78	Percent	Appropriation for FY '79	Percent of Change	Appropriation for FY '80	Percent of Change
Project Grants	\$13,801,000	100	\$ 3,001,000	- 78	\$1,977,000	- 86
Projects of Nat'l Sig.	4,695,000	100	9,187,000	+ 95	2,399,000	- 49
Special Studies	500,000	100	0	-100	0	-100
Program Evaluations	571,000	100	385,000	- 33	380,000	- 33
Total	\$19,567,000	100	\$12,573,000	- 35	\$4,756,000	- 76

It is apparent from appropriation levels over the three year period that all phases of Special Projects have been virtually eliminated from the Developmental Disabilities Program. There was an overall reduction of 35% in FY '79 and an overall reduction from FY '78 of 76% in FY '80. The level of funding was reduced from \$19.5 million in FY '78 to \$4.7 million in FY '80.

The various categories of Special Projects were almost equally reduced over the three year period with the exception of the Projects of National Significance in FY '79.

Project grants were usually distributed and supervised at the regional level. The administrative structure of Developmental Disabilities provides for ten Regional Directors of Developmental Disabilities. A Regional Director is placed in each of the ten Health and Human Services regions.

The Central Office of the Administration on Developmental Disabilities and its forerunner would have published in the Federal Register the announcement and Request for Proposal for Special Project grants. The Regional Directors would receive the proposals, supervise the peer review process, and have the regional grants personnel award the grant. The Regional Director of Developmental Disabilities would then supervise the implementation and operation of the project to its conclusion.

As is evident from the information presented in Table 1, the amount of funds appropriated for project grants was reduced 78% in FY '79 from the FY '78 level, and reduced 86% in FY '80 from its FY '78 level. As any program specialist can verify, this magnitude of reduction over a twenty-four month period eliminates the program resources and research capabilities.

Projects of National Significance were projects which attempted to provide model programs having universal application and provide technical assistance from a national perspective. The Projects of National Significance were successful in performing this mandate, which is readily seen from the comprehensive nature of this report to Congress.

Projects of National Significance funded the design and implementation of the comprehensive planning system used by all of the DD State Planning Councils and Administrative Agencies. Without this uniform process of planning, coordinated program data from each of the States and Territories would have been unattainable.

Also, the telecommunications system in place throughout the University Affiliated Facilities was the result of a Project of National Significance. The report on the UAF's contained in Section V of this report uses the data from the UAF telecommunications system. The coordinated UAF data would have been unattainable without the Projects of National Significance.

Appropriations for Projects of National Significance were increased 95% in FY '79 from the FY '78 level. However, as is demonstrated later in this report, much of these funds had to be used for second and third year commitments made under FY '78 project grants which had potential of being national demonstration projects. The FY '80 level of Projects of National Significance was reduced 49% from its FY '78 level.

There was only one special study during the three year period covered by this report. The special study was the definition study. The result of this study was to change the definition of developmental disabilities from the one in PL 94-103 to the current definition contained in PL 95-602. The contents of both of these definitions appear in Section I of this report.

Program evaluation received much attention in FY '80 with the requirement to implement Section 110 of PL 95-602, Part V. However, funding for program evaluation has been cut 33%, both in FY '79 and FY '80 from the FY '78 level.

Special Projects, when adequately funded in FY '78, relied on a variety of resources to provide the demonstration, advocacy, technical assistance, and applied research mandated in Section 145 of PL 95-602. The following accounting of projects and resources used for Special Projects in FY '78, FY '79, and FY '80 demonstrates conscious stewardship on the part of the Administration on Developmental Disabilities and its forerunner to make the Special Projects work for the benefit of the individuals with developmental disabilities by efficiently and effectively developing model and demonstration programs, strengthening the State Planning Councils and Administrative Agencies, and researching problematic areas in an effort to find solutions.

DISTRIBUTION OF RESOURCES

The Special Project monies were distributed throughout the developmental disabilities system through national and regional grants. Table 2 shows the distribution of the Special Project monies according to regions and national offices. The Projects of National Significance have been included on this table due to utilization of some of these funds in FY '79 for Special Projects.

TABLE IV-2. DISTRIBUTION OF SPECIAL PROJECT MONIES FOR FY '78, FY '79, AND FY '80 BY REGIONS AND NATIONAL OFFICE

Administration area	FY '78		FY '79		FY '80	
	Amount	%	Amount	%	Amount	%
Central Office ¹	\$5,766,000	29.5	\$7,279,792 ²	57.9	\$2,779,000	58.4
Region I	535,732	2.7	382,121	3.0	211,761	4.5
Region II	1,730,838	8.8	781,869	6.2	189,595	4.0
Region III	1,708,927	8.7	876,322	7.0	212,687	4.5
Region IV	1,795,679	9.2	722,378	5.7	220,334	4.6
Region V	2,555,355	13.1	818,497	6.5	180,000	3.8
Region VI	1,653,386	8.4	395,863	3.2	185,049	3.9
Region VII	1,123,891	5.7	286,396	2.3	195,000	4.1
Region VIII	481,864	2.5	289,133	2.3	164,393	3.5
Region IX	915,211	4.8	431,523	3.4	213,984	4.5
Region X	1,300,117	6.6	309,106	2.5	204,197	4.2
Total Region	\$13,801,000	70.5	\$5,293,208 ³	42.1	\$1,977,000	41.6
Total Special Projects	\$19,567,000	100	\$12,573,000	100	\$4,756,000	100

¹ Totals include amounts funded for special studies and evaluation efforts.

² Does not include the \$2,292,208 which was used for Special Projects.

³ Includes \$2,292,208 of Projects of National Significance money used for continuation of Special Projects.

The information presented on Table 2 shows just over 70% of the Special Projects monies were used for Special Projects at the regional level and almost 30% of the monies were used for Projects of National Significance in FY '78. There was a total of \$13.8 million expended for Special Projects at the regional level in FY '78 and just over \$5.8 million expended on Projects of National Significance.

In FY '79, almost 58% of the Special Project monies were expended for Projects of National Significance. The 58% does not include almost 18% of the monies of Projects of National Significance used for Special Projects at the regional level. A total of 42% of the Special Projects monies were used for Special Projects at the regional level. A total of \$7.2 million was expended for Projects of National Significance in FY '79. A total of almost \$5.3 million was expended for Special Projects at the regional level in FY '79.

In FY '80, the distribution of Special Project funds almost paralleled that of FY '79. Fifty-eight percent of the Special Project funds were expended for Projects of National Significance. Almost 42% of the Special Project funds were expended for Special Projects at the regional level. There was a total of just over \$2.7 million expended for Projects of National Significance in FY '80. There was a total of just over \$1.9 million expended for Special Projects during the same year.

PROJECTS FUNDED

The legislative mandate for Special Projects contained in Section 145 of PL 95-602 requires attention be paid to specific areas and activities of the Developmental Disabilities Program. The specific areas identified in Part A of Section 145 are the priority service areas and advocacy services. There are four priority service areas identified in PL 95-602 which are to be emphasized by the DD Program. These four priority areas are:

1. Case Management Services
2. Child Development Services
3. Alternative Community Living Arrangements
4. Nonvocational Social Development Services

There are several areas and activities identified in Part B of Section 145 for which attention is to be paid through the funding of Special Projects. The areas and activities so identified are:

Public Awareness
Coordination of Services
Demonstration Projects
Technical Assistance
Training
Model Programs
Information Dissemination
Improving Quality of Services
Projects for Special Groups

In order to document the areas in which projects were funded for Projects of National Significance and Special Projects, all projects for FY '78, FY '79, and FY '80 have been grouped under topical headings which closely parallel those identified in Section 145 of PL 95-602. The topical headings which are used for this part of the report are as follows:

1. Child Development
2. Case Management
3. Alternative Living Arrangements
4. Nonvocational Social Development
5. Technical Assistance
6. Training
7. Employment/Vocational Development
8. Advocacy
9. Programs for Special Groups
10. Standards/Needs Assessment
11. Public Awareness
12. Council Activity

Table 3 shows the number of projects, percent of resources, and the amount of money expended for Projects of National Significance in each of the three fiscal years.

There were a total of 69 individual Projects of National Significance funded during the three fiscal years. The projects on Table 3 have been recorded as one year projects, separate for each fiscal year, although many of the projects are funded for two or three years. However, for the purposes of comparing expenditures between fiscal years it is assumed that each project is a one year project.

In FY '78, 20% of the Projects of National Significance monies were for technical assistance. Almost 17% was expended for alternative living arrangements and 15% for advocacy. Nearly 14% was expended for nonvocational social development. Programs for special groups accounted for just under 12% of expenditures. Just under 8% was expended for training. Child development, standards/needs assessment, and public awareness each received 5% of the funding in FY '78.

TABLE IV-3. AMOUNT AND PERCENT OF RESOURCES AND NUMBER OF PROJECTS OF NATIONAL SIGNIFICANCE BY TOPICAL HEADINGS FOR FY '78, FY '79, AND FY '80

Project Topic	Fiscal '78			Fiscal '79			Fiscal '80		
	No. of Proj.	Amount	%	No. of Proj.	Amount	%	No. of Proj.	Amount	%
Child Development	2	\$ 300,000	5.2	4	\$ 593,829	8.2	2	\$ 108,561	3.9
Case Management	0	0	0	2	593,881	8.2	0	0	0
Alternative Liv. Arrg.	7	970,519	16.8	7	1,089,682	15.0	4	266,189	9.6
Nonvoc. Social Devel.	5	787,557	13.7	0	0	0	1	100,000	3.6
Technical Assistance	6	1,152,059	20.0	2	790,000	10.9	2	550,000	19.8
Training	2	442,682	7.7	7	765,733	10.5	5	369,455	13.3
Employment/Voc. Devel.	0	0	0	0	0	0	0	0	0
Advocacy	6	851,055	14.8	5	1,062,924	14.6	7	768,720	27.7
Pro. for Special Groups	7	680,323	11.8	3	526,702	7.2	2	320,000	11.5
Standards/Needs Asses.	2	273,935	4.8	1	275,110	3.8	1	296,075	10.6
Public Awareness	3	307,870	5.2	2	82,106	1.1	0	0	0
Council Activities	0	0	0	1	1,499,825	20.5	0	0	0
Total	40	\$5,766,000	100	34	\$7,279,792	100	24	\$2,779,000	100

Just over 50% of the expenditures for Projects of National Significance in FY '78 went to the four priority areas and advocacy or the activities identified in Part a of Section 145 of PL 95-602.

In FY '79, Council activities received 20.5% of the funds from Projects of National Significance. This was the funding of the UAF telecommunications project already referred to in this report.

Almost 15% of the project funds were used for advocacy and 15% were used for projects in alternative living arrangements. Just over 10% of the funds was used for technical assistance and just over 10% was used for training. There was an equal amount used for child development and for case management. Just over 7% was used to fund projects for programs for special groups. Nearly 4% was used for the developing of standards. Public awareness received 1% of the funds in FY '79.

In FY '79, 46% of the National Significance monies was expended in the four priority areas of service and advocacy. These are the activities identified in Part a of Section 145 of PL 95-602.

In FY '80, almost 28% of the Projects of National Significance monies was spent for advocacy. Nearly 20% of the money was expended for technical assistance. Over 13% of the money was expended for training, and almost 12% was expended for projects for special groups. Over 10% of the monies was expended to develop standards for the services provided for individuals who are developmentally disabled. Nearly 10% was expended for projects in alternative living arrangements. Just over 3% of the funds was used for two projects in child development and just over 3% was used for one project in nonvocational social development in FY '80.

In FY '80, nearly 45% of the Projects of National Significance monies was expended for projects in the four priority areas and advocacy. These are the activities which are listed in Part a of Section 145 of PL 95-602.

Figure 1 shows the percent of Projects of National Significance by topical headings for the three fiscal years of '78, '79, and '80. There was a total of \$15.8 million expended for Projects of National Significance during the three years.

Seventeen percent of the National Significance project funds was used to develop and aid the advocacy program for the Developmental Disabilities Program during the three fiscal years of '78, '79, and '80.

The next largest category of projects was technical assistance for which 15.7% of the resources was used. These projects were used to aid DD Councils/Administrative Agencies to implement the DD Program and aid in the development of staff and service providers.

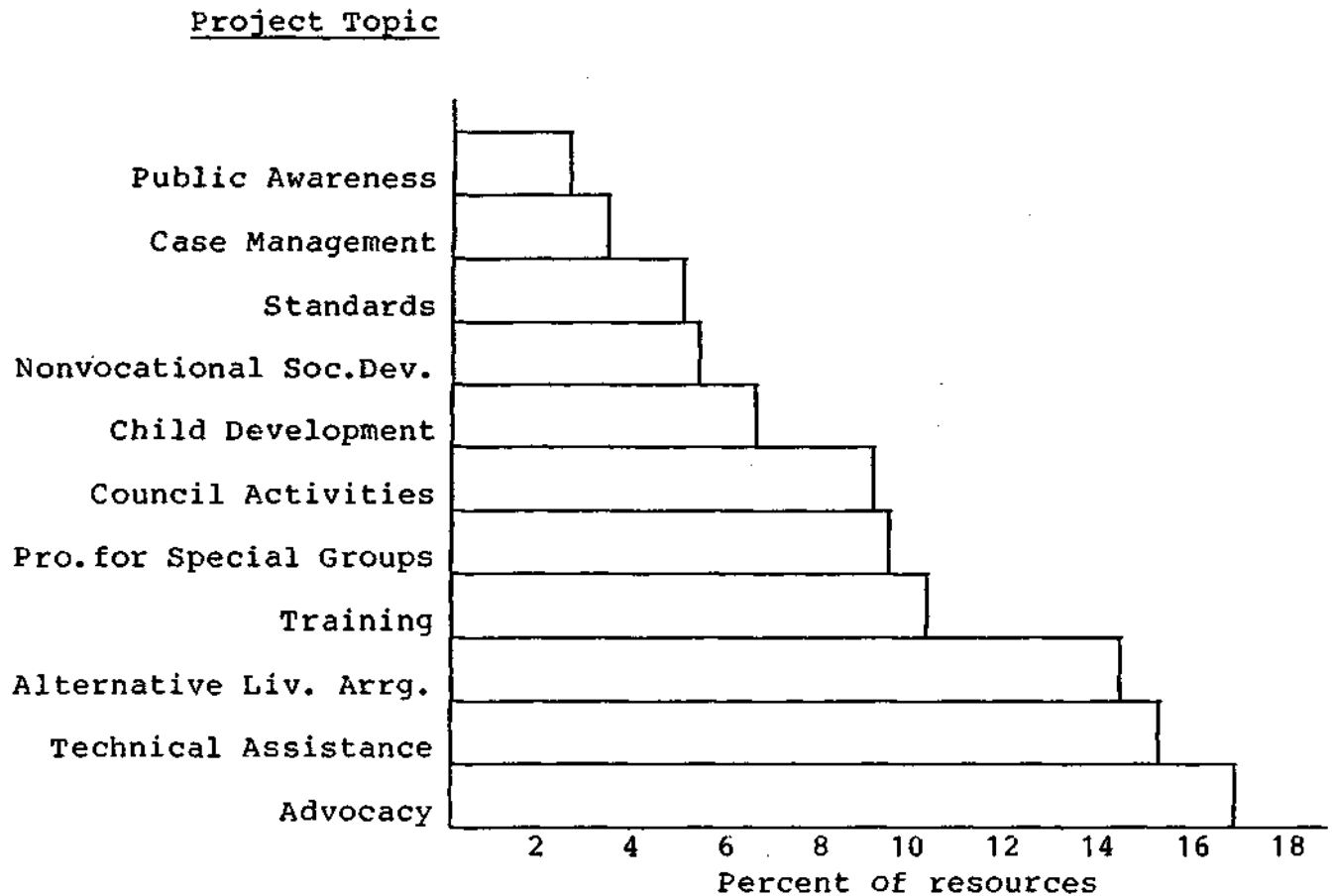


Figure IV-1. Percent of Resources Used for Projects of National Significance by Project Topic for the Three Fiscal Years '78, '79, and '80

Nearly 15% of the resources was used for projects in alternative living arrangements. Several of the projects funded under this topic were in deinstitutionalization, which was the emphasis of the DD Program in FY '78.

Ten percent of the resources was used to fund training projects. The development of Council staff, Council membership, interdisciplinary training and specialized personnel were included in training projects funded during the three years.

There was 9.6% of the resources used for programs for special groups. These projects included projects for the aged, programs for delivery of services in rural areas and projects for minority groups.

There was 9.5% of the resources used to develop the telecommunications system for the University Affiliated Facilities.

Just over 6% of the Projects of National Significance monies was used for projects in child development. Projects in this area included prevention, genetics, preschool, and demonstration projects in early intervention.

Nearly 6% of the monies was used for projects under non-vocational social development, including coordination of services, dental programs, and social adjustment programs.

The Administration on Developmental Disabilities has expended just over 5% of its resources to develop and implement national standards for service providers who provide institutional care and alternative community living arrangements. As a result of this expenditure, national standards for services provided to individuals who are developmentally disabled exist.

Almost 4% of the resources was expended for projects in case management. Public awareness projects accounted for 2.5% of the expenditures during the three year period.

There was nearly equal distribution of expenditures between those activities identified in Part a of Section 145 of PL 95-602 and those activities identified in Part b of the same section. There was a total of 47.4%, or \$7,492,917 expended for projects in the four priority areas and advocacy during the three year period. There was a total of 52.6%, or \$8,331,875 expended for projects under headings identified in Part b during the three year period from October 1, 1977 through September 30, 1980.

Table 4 shows the number of projects, percent of resources, and the amount of money expended for Special Projects in each of three fiscal years. The Special Projects were funded by regional offices of the Developmental Disabilities Administration, as previously explained.

There were 210 individual Special Projects funded in Fiscal Years '78, '79, and '80. The projects in Table 4 have been recorded as one year projects, separate for each fiscal year, although many of the projects are funded for two or three years. Many of the projects identified in FY '78 are continuation years of projects originally funded in FY '76 and FY '77. However, for the purposes of comparing expenditures between fiscal years, it is assumed that each project is a one year project.

In FY '78 there was \$13.8 million expended for Special Projects. Over 18% of this amount was expended for employment and vocational development projects. There were 40 such projects funded in that year. FY '78 projects were funded under PL 94-103 and not subject to the four priority areas as in FY '79 and FY '80 under PL 95-602.

TABLE IV-4. AMOUNT AND PERCENT OF RESOURCES AND NUMBER OF SPECIAL PROJECTS BY TOPICAL HEADINGS FOR FY '78, FY '79, AND FY '80

Project Topic	Fiscal '78			Fiscal '79			Fiscal '80		
	No. of Proj.	Amount	%	No. of Proj.	Amount	%	No. of Proj.	Amount	%
Child Development	5	\$ 212,979	1.6	0	\$ 0	0	0	\$ 0	0
Case Management	5	350,720	2.6	4	250,779	4.7	3	160,775	8.1
Alternative Liv. Arrg.	17	1,676,339	12.2	2	151,857	2.9	1	35,000	1.8
Nonvoc. Social Devel.	41	2,514,665	18.3	23	1,433,213	27.1	10	440,930	22.3
Technical Assistance	26	2,476,032	17.9	14	1,422,064	26.9	8	576,936	29.2
Training	23	1,481,473	10.7	8	560,688	10.6	4	158,859	8.0
Employment/Voc. Devel.	40	2,545,567	18.4	1	70,681	1.3	0	0	0
Advocacy	11	869,196	6.3	7	509,148	9.6	3	277,850	14.1
Pro. for Special Groups	10	652,567	4.7	8	582,679	11.0	6	245,288	12.4
Standards/Needs Asses.	3	310,088	2.2	0	0	0	0	0	0
Public Awareness	9	541,090	3.9	5	312,099	5.9	2	81,362	4.1
Council Activities	3	170,284	1.2	0	0	0	0	0	0
Total	193	\$13,801,000	100	72	\$5,293,208	100	37	\$1,977,000	100

There was over 18% of the Special Project monies expended for nonvocational social development projects. These projects involved dental services, offenders programs, recreation, and coordination of services within the community.

Just under 18% of the Special Projects monies was spent for regional technical assistance projects in FY '78. Over 10% of the Special Projects money was devoted to training projects at the regional, state and local levels. Over 12% of the funds was used for alternative living arrangement projects in FY '78.

Six percent of the monies was used for advocacy projects in the regions. The rest of the funds were used to fund projects in child development, case management, programs for special groups, needs assessment, and public awareness in FY '78.

There was \$5,293,208 expended for 72 Special Projects in FY '79. There is a change in emphasis from projects funded in FY '79 when compared to those funded in FY '78. Changes occurred in Special Projects funded in FY '79 because of the passage of PL 95-602. The four priority areas of service are included in the law and advocacy was in its second year of implementation.

Over 27% of the Special Project monies was expended in non-vocational social development projects. Also, 27% of the funds was expended for technical assistance projects which aided Councils in implementing the new legislation, understand the change in definition, and maintain the system of comprehensive planning in FY '79.

Almost 11% of the funds was used for training programs, many of which were started in FY '78 and continued in FY '79. Eleven percent of the funds was used for programs for Special Projects including programs in rural areas and programs for minority and poverty groups. Almost 10% of the funds was used to assist advocacy programs at the state and local level. Projects were also funded for public awareness, case management, and alternative living arrangements in FY '79.

Less than \$2 million was expended for 37 Special Projects in FY '80. The average size of each grant was reduced from over \$70,000 in FY '79 to just over \$50,000 in FY '80. The same areas of activities were emphasized in FY '80 as in FY '79. Most of the projects in FY '80 were continuations of projects originally funded in FY '78 and FY '79.

Nearly 30% of the FY '80 funds was used for technical assistance and over 22% was used for projects in the nonvocational social development service area. Fourteen percent was used for advocacy programs and assistance to advocacy programs. Over 12% was used for programs for special groups. Eight percent was used for child development projects. Eight percent was used for projects in training programs. Public awareness and alternative living arrangements were also funded with FY '80 funds.

The impact of PL 95-602, Title V can be seen in areas of Special Project grants funded in FY '79 and FY '80. In FY '78, 41% of the Special Project funds was used for projects in the four priority areas of service and advocacy. In FY '79, these areas of funding utilized over 44% of the funds, and in FY '80 over 46% of the funds was expended in these areas.

Figure 2 shows the percent of Special Projects by topical headings for the three fiscal years of '78, '79, and '80. There was a total of \$21 million expended for Special Projects during the three years.

Just over 21% of the Special Project funds was used for technical assistance during the three year period between

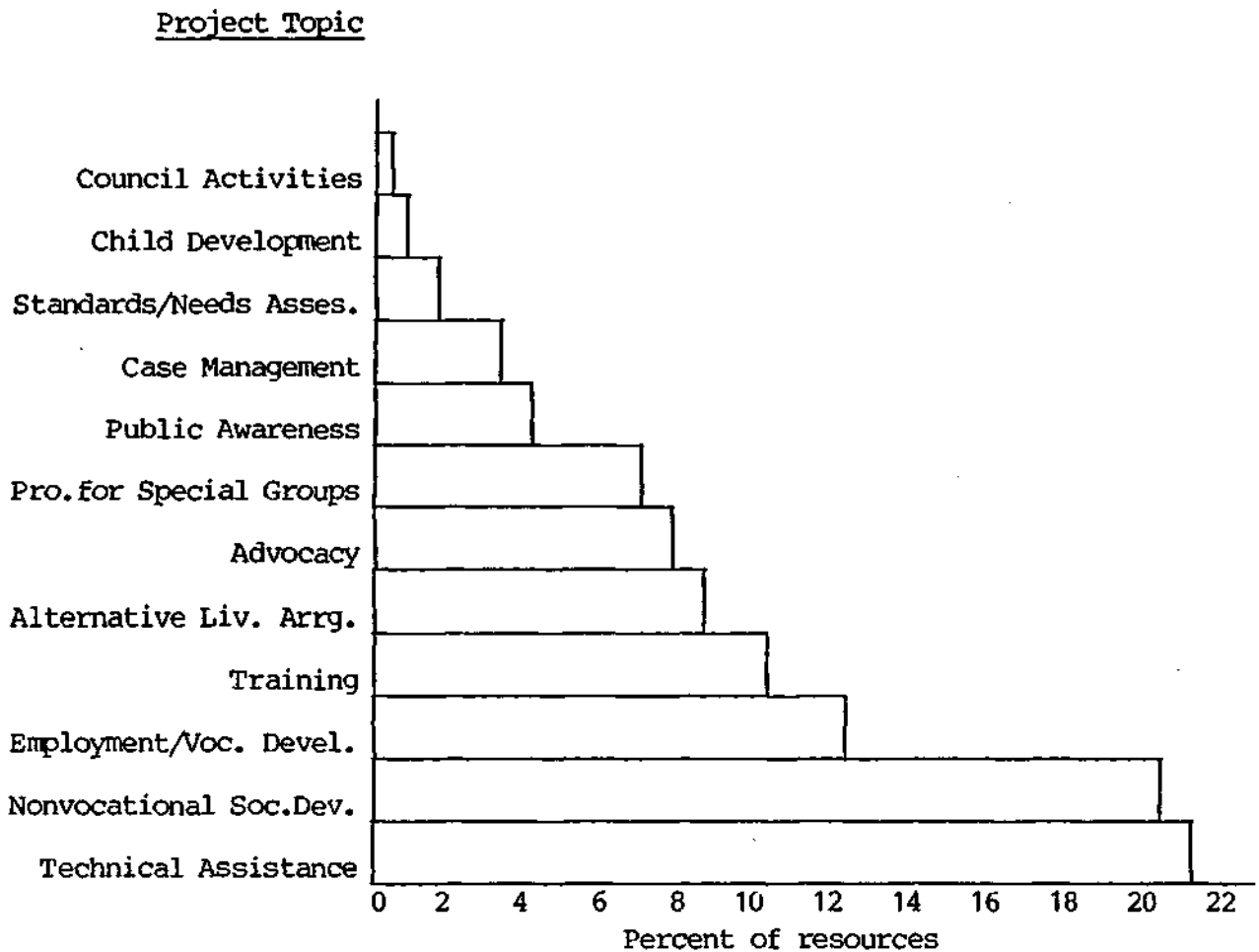


Figure IV-2. Percent of Resources Used for Special Projects by Project Topics for the Three Fiscal Years '78, '79, and '80

October 1, 1977 and September 30, 1980. Over 20% was used for projects in the area of nonvocational social development at the state and local level. Just over 12% of the Special Project funds was used for employment and vocational development projects. Training projects received over 10% of the funds during the three year period.

Special Projects in the area of alternative living arrangements required 8.8% of the funds over three years and advocacy projects used just under 8% of the funds. Seven percent of the funds was used for programs for special groups.

Public awareness projects accounted for 4.4% of the funds. Case management accounted for 3.6% of the funds and 1.6% was

expended for needs assessment. Child development projects used 1% of the funds.

The total amount for Special Projects and Projects of National Significance during the three year period was \$36,896,000. Figure 3 shows the percent of all Special Projects by topical headings for the period between October 1, 1977 and September 30, 1980.

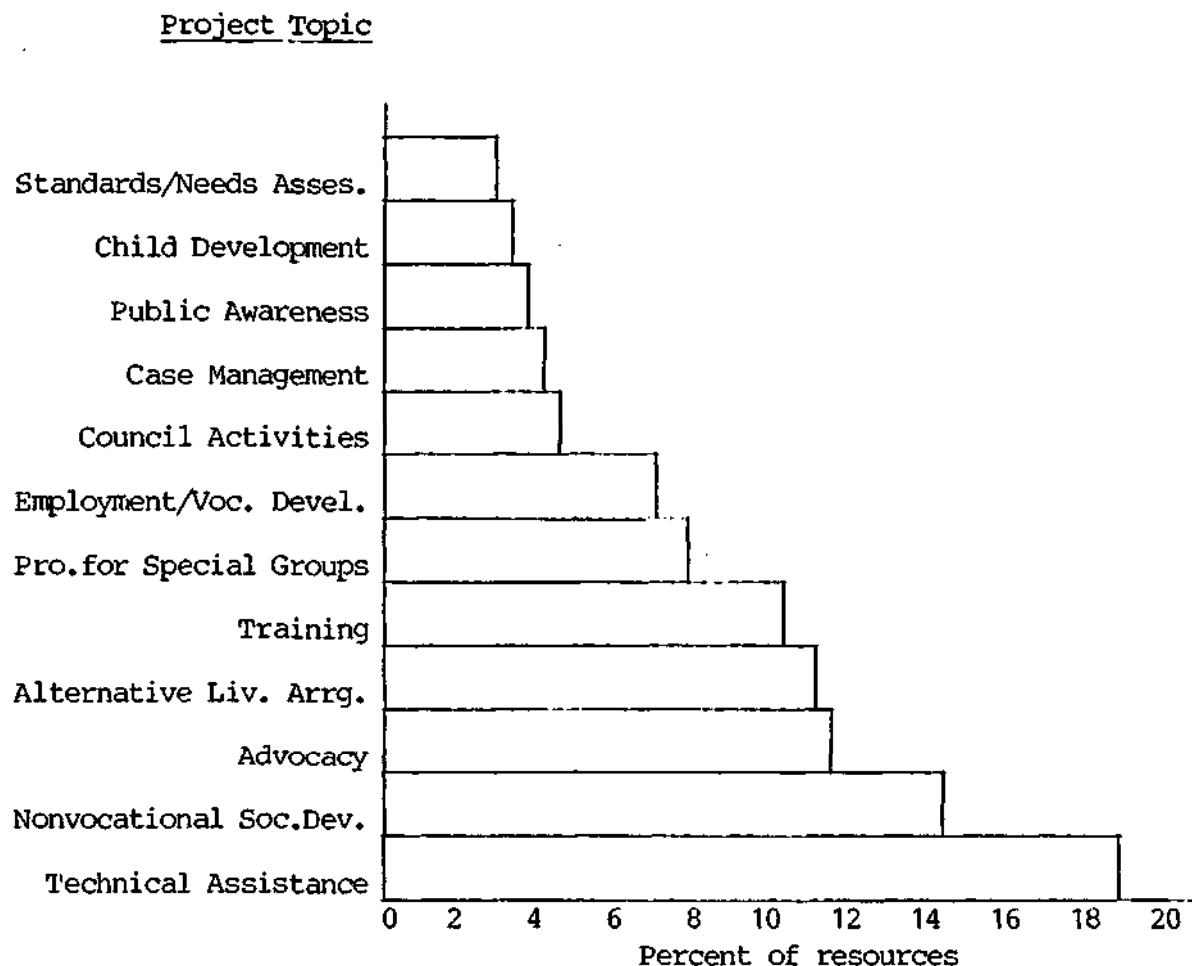


Figure IV-3. Percent of Resources Used by Special Projects and Projects of National Significance for the Three Fiscal Years '78, '79, and '80

During the three year period, almost 19% of Section 145 monies was used for technical assistance. Technical assistance projects were funded at just over \$6.9 million. These projects aided Councils in implementation of programs, developed and

maintained the comprehensive planning process, and improved the quality of services for individuals who are developmentally disabled.

Just over \$5 million of Section 145 monies was used to fund projects in the area of nonvocational social development service. There were a variety of projects funded at the national, regional, state and local levels which aided individuals who are developmentally disabled and created model programs for imitation by service providers.

Nearly 12% of the Section 145 monies was used to aid in implementation of the advocacy program in the three year period. The \$4.3 million was used for technical assistance to advocacy programs, national and regional conferences, and legal assistance in the three year period.

Over 11% of the Section 145 monies was used to fund alternative community living projects. Nearly \$4.2 million was used for this purpose. These projects help establish model programs and demonstration projects for establishing alternative community living arrangements.

Over 10% of the Section 145 funds was used for training programs. The nearly \$3.8 million was used to train personnel, professionals, para-professionals, and volunteers in information, techniques and skills related to the developmentally disabled.

Programs for special groups such as the aged, minority groups, and programs for rural areas accounted for just over 8% of the expenditures of Section 145 funds, or \$3 million.

Programs for employment and vocational development of individuals were funded with 7% of the Section 145 monies. The \$2.6 million was expended in Special Projects in FY '78 prior to the passage of PL 95-602 and the change of emphasis and program focus.

Projects related to Council activities and a project to establish the UAF telecommunications system required 4.5% of Section 145 monies. This percent of the funds accounted for just over \$1.6 million.

Projects in case management were funded at the \$1.3 million level in the three year period, which represented 3.7% of the Section 145 funds. Projects in child development were funded at the \$1.2 million level, and represented 3.3% of the funds.

Public awareness projects used 3.6% of the funds, or just over \$1.3 million. Projects to establish national standards and needs assessment programs were funded with 3% of the funds, or just over \$1.1 million in the three year period encompassing FY '78, FY '79, and FY '80.

SERVICE PROVIDERS

The initial instructions in Section 145 of PL 95-602 allow the Secretary to make "project grants to public or non-profit private entities." A variety of service providers were used for the Grants of National Significance and Special Projects during the three year period. The service providers can be classified in four categories. The four categories of service providers used are:

1. Non-profit organizations
2. Universities
3. State Governments
4. Associations

Non-profit organizations were used for their specialized services and knowledge in providing services to individuals who are developmentally disabled. The majority of non-profit organizations used for Projects of National Significance and Special Projects were service providers who specialized in providing specific services.

Universities were used as service providers for Projects of National Significance and Special Projects. University Affiliated Facilities provided assistance in performing many of the national projects and Special Projects at the regional, state and local levels. Non-UAF universities were also used as resources of Special Projects during the three year period.

Projects of National Significance and Special Projects were also conducted by State Governments. Departments of Human Resources and Departments of Mental Retardation were recipients of several Grants of National Significance.

Associations were used as a resource for conducting Projects of National Significance and Special Projects. National, state and local Associations of Retarded Citizens were recipients of grants for Special Projects. The United Cerebral Palsy Associations at all levels were also used as sources, as were the Epilepsy Associations. Other associations were also used as sources for Projects of National Significance and Special Projects during FY '78, FY '79, and FY '80.

Table 5 shows the service providers used for the Projects of National Significance in FY '78, FY '79, and FY '80.

Universities were used as providers for 44% of the Projects of National Significance in FY '78. Universities received 16 grants which totaled \$2,535,433 in FY '78. Non-profit organizations received 28% of the Projects of National Significance in

TABLE IV-5. AMOUNT, PERCENT AND NUMBER OF PROJECTS BY SERVICE PROVIDERS USED FOR GRANTS OF NATIONAL SIGNIFICANCE FOR FISCAL YEARS '78, '79, AND '80

Service Provider	Fiscal '78			Fiscal '79			Fiscal '80		
	No. of Proj.	Amount	%	No. of Proj.	Amount	%	No. of Proj.	Amount	%
Non-Profit Organizations	13	\$1,626,296	28.2	10	\$2,095,191	28.8	8	\$1,239,795	44.6
Universities	16	2,535,433	44.0	17	4,363,639	59.9	11	930,426	33.5
State Governments	2	566,864	9.8	0	0	0	1	100,000	3.6
Associations	9	1,037,407	18.0	7	820,962	11.3	4	508,779	18.3
Total	40	\$5,766,000	100	34	\$7,279,792	100	24	\$2,779,000	100

FY '78. There were 13 grants awarded to non-profit organizations, for a total of \$1,626,296. Eighteen projects were awarded to associations, for a total of \$1,037,407. Almost 10% of the Grants of National Significance were awarded to State Governments, for a total of \$566,804 in two grants in FY '78.

Universities were the recipients of 17 Grants of National Significance in FY '79, for a total of \$4,363,639. This represented almost 60% of the total Grants of National Significance in FY '79. More than \$3 million of these grants were awarded to University Affiliated Facilities.

Ten Grants of National Significance were awarded to non-profit organizations for \$2,095,191 in FY '79. This represented nearly 29% of the Grants of National Significance awarded in FY '79. Associations were used as service providers for seven Projects of National Significance in FY '79. Associations received a total of \$820,962, or just over 11% of the grants in FY '79. No grants were awarded to State Governments in FY '79.

Eight projects were awarded to non-profit organizations in FY '80 for a total of \$1,239,795, which was almost 45% of the awards made for Grants of National Significance. Just over 33% of the awards was made to universities in FY '80 under Grants of National Significance. This amounted to \$930,426 of the FY '80 appropriation. Over 18% of the projects was awarded to associations, for a total amount of \$508,779. One grant was awarded to a State Government in the amount of \$100,000 in FY '80.

Figure 4 shows the percent of the grants of National Significance for each of the four categories of service providers used for the three year period from October 1, 1977 through September 30, 1980.

There was a total of \$15,824,792 appropriated for Grants of National Significance in the three year period. Nearly 50%, \$7.8 million, was awarded to universities. Just over 31%, \$4.9 million, was awarded to non-profit organizations. Fifteen percent, \$2.3 million, was awarded to associations for Grants of National Significance. Just over 4%, \$.6 million, was awarded to State Governments in the three year period.

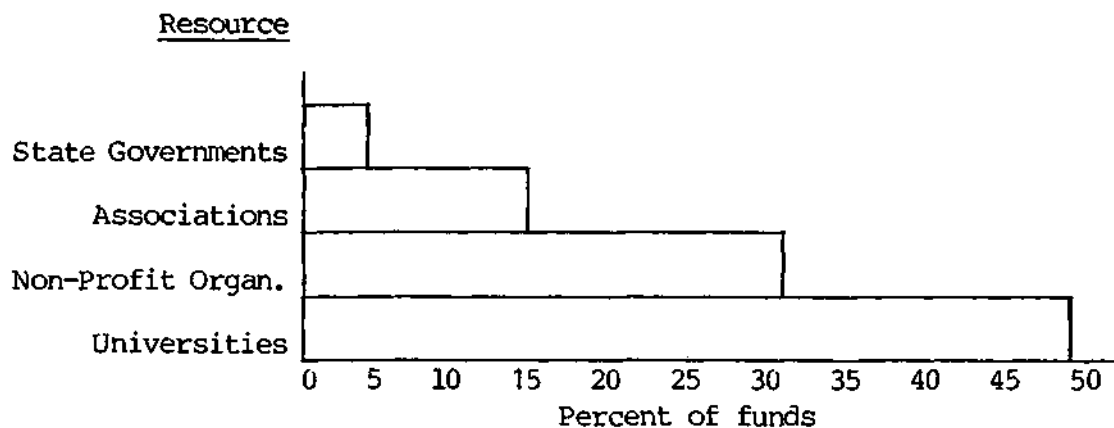


Figure IV-4. Percent of Funds Used by Projects of National Significance by Service Providers Used for the Fiscal Years '78, '79, and '80

Table 6 shows service providers used for the Special Projects for Fiscal Years '78, '79, and '80. The Special Projects were projects awarded at the regional level for activities conducted at the regional, state or local level.

A total of \$13,801,000 was awarded for Special Projects in FY '78. Nearly 40% of the Special Projects were conducted by non-profit organizations, indicating the service nature of several projects conducted at the local level. There was \$5.4 million awarded to non-profit organizations in FY '78.

Just over 33% of the Special Project grants were awarded to universities in FY '78. The universities received a total of \$4.6 million during this year. Just over \$2 million of Special

TABLE IV-6. NUMBER OF PROJECTS AND AMOUNT OF FUNDING FOR EACH CATEGORY OF SERVICE PROVIDER OF SPECIAL PROJECTS IN FY '78, FY '79, AND FY '80

Service Provider	Fiscal '78			Fiscal '79			Fiscal '80		
	No. of Proj.	Amount	%	No. of Proj.	Amount	%	No. of Proj.	Amount	%
Non-Profit Organizations	76	\$ 5,421,745	39.3	30	\$2,247,936	42.5	16	\$ 824,074	41.7
Universities	57	4,615,557	33.4	25	1,754,168	33.1	14	804,318	40.7
State Governments	31	2,093,753	15.2	11	702,336	13.3	6	309,986	15.7
Associations	29	1,669,945	12.1	7	588,768	11.1	1	38,622	1.9
Total	193	\$13,801,000	100	73	\$5,293,208	100	37	\$1,977,000	100

Project grants was awarded to State Governments, which represented 15% of the appropriations. Associations were awarded 12% of the Special Projects in FY '78 in the amount of \$1.6 million.

The percent of distribution of Special Project funds of the \$5.2 million in FY '79 mirrored that of the distribution in FY '78 in respect to service providers used. Just over 42% was awarded to non-profit organizations in the amount of \$2.2 million. Just over 33% was awarded to universities. Thirteen percent of the Special Project funds for FY '79 was awarded to State Governments, while 11% was used by associations for the conduct of Special Projects in FY '79.

In FY '80, just under \$2 million was appropriated for Special Projects. Forty-one percent went to non-profit organizations and 40% went to universities. Nearly 16% went to State Governments and almost 2% was awarded to associations.

Figure 5 shows the percent of Special Project grant funds for each of the four categories of service providers used for the three year period from October 1, 1977 through September 30, 1980.

There was a total of \$21,071,208 appropriated for Special Projects for the three year period. Forty percent, or \$8,493,755, was provided for projects operated by non-profit organizations. Thirty-four percent, or \$7,174,043, was awarded to universities to conduct Special Projects. Just under 15%, or \$3,106,075, was provided to State Governments for the conduct of Special Projects

and 10.9%, or \$2,297,335, was appropriated to associations for the conduct of Special Projects in the three year period.

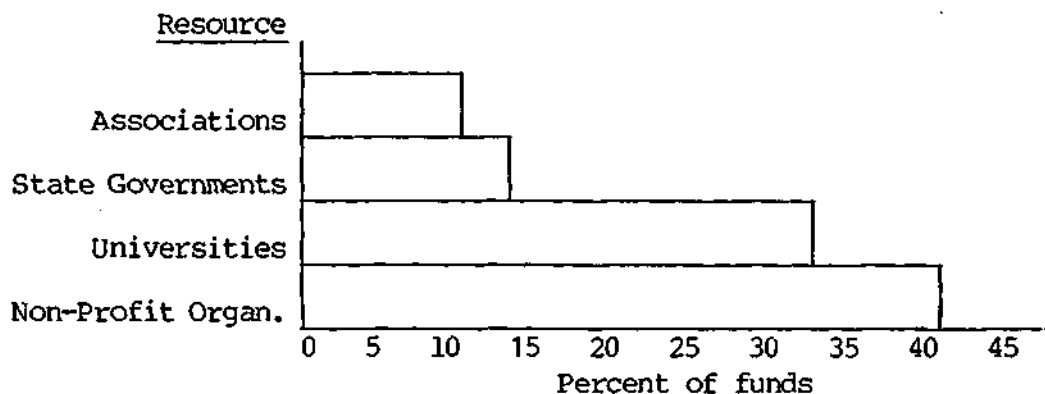


Figure IV-5. Percent of Funds Used by Special Projects by Category of Service Providers Used for the Fiscal Years '78, '79, and '80

Figure 6 shows the percent of Section 145 projects for each of the four categories of service providers used for the fiscal years encompassed by FY '78, FY '79, and FY '80.

There was a total of \$36,896,000 appropriated for all projects funded under Section 145 during the three fiscal years. Forty percent of the appropriation was provided to universities. Thirty-six percent was provided to non-profit organizations. Twelve percent was used for associations to conduct Special Projects. Ten percent was provided to State Governments with the opportunity to conduct Special Projects during the three year period.

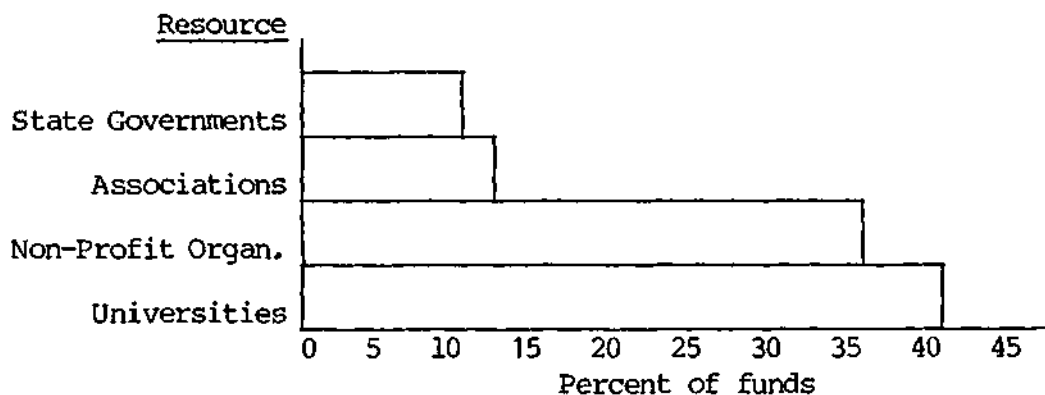


Figure IV-6. Percent of Funds of Section 145 Special Project Funds for Each of the Categories of Service Providers Used for the Three Year Period of Fiscal Years '78, '79, and '80

The cutback in appropriations for Special Projects has significantly reduced the resources available to the Developmental Disabilities Program and individuals with developmental disabilities.

One significant loss as a result of the cutback is the resource of national, state and local associations which usually stay on the cutting edge of the needs of the handicapped and the gaps in the service network. Parents groups and grass root advocacy groups are the first to try innovative programs for the benefit of the disabled.

Also lost to the DD Program with cutback in appropriation of Special Project funds are the specific research and model programs conducted and developed by the universities.

The DD Program is not the same dynamic and innovative program without significant Special Projects and technical assistance. The program has little flexibility without adequate funds for Section 145 projects.

IMPACT OF THE DEFINITION

The Special Projects funded with Section 145 monies can be divided into five groups in order to assess the impact of the definition of developmental disabilities in PL 95-602 when compared with the definition in PL 94-103. The five groups of projects are:

1. Projects affecting DD community
2. Advocacy projects
3. Projects for employment/vocational development
4. Telecommunications projects
5. Projects in four priority areas/special groups

Each of the 400 Special Projects funded within the three year period of this report was assigned to one of the five categories. Actually, there were 262 individual projects funded during the three years, but 138 of the 262 Special Projects were extended for a second and, in some cases, third year. For the purposes of this report, each project has been assumed to be a one year project, therefore the report contains information on the 400 Special Projects. The target population and number of individuals served has been analyzed in order to be responsive to the report requirements contained in PL 95-602.

The Special Projects assigned to group 1 are all projects involving technical assistance, public awareness, training, standards/needs assessment, and Council activities. Table 7 contains the amount and percent of resources expended in each of these areas of activity.

TABLE IV-7. AMOUNT AND PERCENT OF FUNDS USED FOR SPECIAL PROJECTS AFFECTING THE ENTIRE DD COMMUNITY FUNDED IN FY '78, FY '79, AND FY '80 BY AREA OF ACTIVITY

Area of activity	FY '78		FY '79		FY '80	
	Amount	%	Amount	%	Amount	%
Technical Assistance	\$3,628,091	50.7	\$2,212,064	52.6	\$1,126,936	55.4
Public Awareness	848,960	11.9	394,205	9.4	81,362	4.0
Training	1,924,155	26.9	1,326,421	31.5	528,314	26.0
Standards	584,023	8.1	275,110	6.5	296,075	14.6
Council Activities	170,284	2.4	0	0	0	0
Total	\$7,155,513	100	\$4,207,800	100	\$2,032,687	100

It is assumed that all Special Projects in group one affect the entire DD community and therefore their effect on specific populations of developmentally disabled is distributed according to the DD population as presented in Section I of this report. The magnitude of service according to disability groups is contained in Table 8.

TABLE IV-8. AMOUNT AND PERCENT OF SPECIAL PROJECT FUNDS WHICH AFFECTED THE ENTIRE DD COMMUNITY BY DISABILITY GROUPS FOR FISCAL YEARS '78, '79, AND '80

Disability group	FY '78		FY '79		FY '80	
	Amount	%	Amount	%	Amount	%
Mental Retardation	\$4,686,861	65.5	\$2,705,615	64.3	\$1,113,912	54.8
Cerebral Palsy	672,618	9.4	513,352	12.2	290,674	14.3
Epilepsy	1,559,901	21.8	828,937	19.7	353,687	17.4
Autism	107,334	1.5	63,117	1.5	32,523	1.6
Other	128,799	1.8	96,779	2.3	241,891	11.9
Total	\$7,155,513	100	\$4,207,800	100	\$2,032,687	100

In FY '78, almost \$4.7 million of Special Project money in the first category affected individuals who were mentally retarded. Nearly \$700,000 affected individuals who were cerebral palsied, \$1.5 million affected individuals with epilepsy, just over \$100,000 affected individuals with autism, and just over \$100,000 affected individuals with other handicapping conditions.

In FY '79, \$2.7 million of Special Project monies affected individuals who were mentally retarded, just over \$500,000 affected individuals with cerebral palsy, and over \$800,000 affected individuals who were epileptic. Just over \$63,000 affected the autistic, and \$96,000 affected individuals with handicapping conditions other than those listed.

In FY '80, just over \$1.1 million of Special Project monies affected individuals who were mentally retarded, and almost \$300,000 affected individuals who were cerebral palsied. In the same year, just over \$350,000 affected individuals who were epileptic and \$32,000 affected individuals who were autistic. Nearly a quarter of a million dollars was spent on individuals with other handicaps in FY '80 in the first category of Special Project funding.

The percent of Special Project monies spent for advocacy and support of advocacy increases each of the three fiscal years encompassed by this report. In FY '78, \$1,720,251 of Special Project monies was so spent, which represented 8.8% of the appropriation. In FY '79, the amount spent for advocacy was \$1,572,072, or 12.5% of the appropriation. In FY '80, 22% of the appropriation was spent for advocacy, which represented \$1,046,570.

Table 9 shows the magnitude of services provided by Special Project monies in the area of advocacy for Fiscal Years '78, '79, and '80.

TABLE IV-9. AMOUNT AND PERCENT OF SPECIAL PROJECT FUNDS USED FOR ADVOCACY BY DISABILITY GROUPS FOR FY '78, FY '79, AND FY '80

Disability group	FY '78		FY '79		FY '80	
	Amount	%	Amount	%	Amount	%
Mental Retardation	\$1,131,925	65.8	\$ 946,387	60.2	\$ 540,030	51.6
Cerebral Palsy	144,502	8.4	102,185	6.5	85,818	8.2
Epilepsy	163,424	9.5	88,037	5.6	84,773	8.1
Autism	55,048	3.2	50,306	3.2	35,584	3.4
Other	225,352	13.1	385,157	24.5	300,365	28.7
Total	\$1,720,251	100	\$1,572,072	100	\$1,046,570	100

In FY '78, 65.8%, or \$1,131,925, of the Special Project funds expended for advocacy benefited individuals who were mentally retarded. The individuals with cerebral palsy were benefited by \$144,502, or 8.4%, of the funds in advocacy projects. There was 9.5% of the funds, or \$163,424, expended for individuals with epilepsy, and just over \$55,000 for the autistic. Other handicapped were assisted with 13.1% of the funds, or \$225,352 in FY '78.

In FY '79, \$946,387, or 60.2%, of Special Project monies in advocacy were used to benefit the mentally retarded. There was 6.5% of the funds, or \$102,185, used for the cerebral palsied, and 5.6%, or \$88,037, used for individuals with epilepsy. There was 3.2% of the funds, amounting to \$50,306, used for the autistic in FY '79. Nearly one-fourth of the Special Project funds used for advocacy went for individuals with handicaps other than those listed.

In FY '80, just over 50%, or \$540,000, was used to benefit the mentally retarded. Almost the identical amount of 8% went to both the individuals with cerebral palsy and the individuals with epilepsy. The autistic received the benefit of 3.4%, or \$35,584. The other handicapping conditions received the benefit of \$300,365, or 28.7% of the funds.

There were several Special Projects funded in the area of employment and vocational development in FY '78. Most of these projects went toward funded programs in sheltered workshops designed for individuals who were mentally retarded. The amount funded for this purpose in FY '78 was \$2,545,567, or 13% of the funds appropriated for Special Projects in FY '78.

Employment and vocational development were not categories for which Special Project funds were used in FY '79 and FY '80. The reason for the decrease and omission of Special Project funds being used in these areas in FY '79 and FY '80 was that the priority service areas of PL 95-602 omit these categories. The Special Project funds were primarily used in the four priority areas, advocacy, training and technical assistance in the Fiscal Years '79 and '80.

The omission of the category of employment and vocational development in FY '79 and FY '80 as a category of funding is more a change in the emphasis of the 1978 amendments to the DD law rather than the definition of developmental disabilities in PL 95-602. Therefore, the Special Project monies used for this category have been omitted from the summary impact statement at the end of this section of the report.

There was \$1,499,825 of Special Project monies expended for the UAF telecommunications system. As can be seen from the section of the report which describes the UAF activities, this data retrieval system is most helpful. The distribution of this money according to disabilities is approximately 55% for the mentally retarded, 9% for the cerebral palsied and epileptic, and 3% for the autistic. About 24% of the money is distributed to handicaps other than the ones listed. Therefore, of the amount expended for the telecommunications system, \$824,904 is designated for individuals who are mentally retarded, \$134,984 each for the cerebral palsied and for individuals with epilepsy, and \$45,000 for the autistic. There is \$359,953 assigned to individuals with handicaps other than the ones listed.

There was a total of \$8,143,669 Special Project funds used for projects in the four priority service areas and projects for special groups in FY '78 which involved a total of 204,897 individuals who were developmentally disabled, as shown in Table 10. Seventy-nine percent of these individuals were mentally retarded, 3.3% were cerebral palsied, 12% were epileptic, and 1.5% were autistic.

TABLE IV-10. NUMBER AND PERCENT OF INDIVIDUALS SERVED AND AMOUNT AND PERCENT OF SPECIAL PROJECT FUNDS EXPENDED FOR PROJECTS IN THE FOUR PRIORITY SERVICE AREAS OF CASE MANAGEMENT, CHILD DEVELOPMENT, ALTERNATIVE LIVING ARRANGEMENTS, AND NONVOCATIONAL SOCIAL DEVELOPMENT AND PROJECTS FOR SPECIAL GROUPS

Disability group	FY '78				FY '79				FY '80			
	Number	%	Amount	%	Number	%	Amount	%	Number	%	Amount	%
Mental Retardation	161,923	79.0	\$6,165,800	75.7	112,624	73.2	\$3,687,173	70.6	53,503	54.1	\$1,031,198	61.5
Cerebral Palsy	6,636	3.3	578,795	7.1	6,498	4.2	438,700	8.4	13,550	13.7	211,269	12.6
Epilepsy	24,674	12.0	1,072,024	13.2	24,193	15.7	558,820	10.7	14,934	15.1	258,218	15.4
Autism	3,048	1.5	236,408	2.9	2,905	1.9	141,010	2.7	1,716	1.8	53,656	3.2
Other	8,616	4.2	90,642	1.1	7,736	5.0	396,919	7.6	15,197	15.3	122,402	7.3
Total	204,897	100	\$8,143,669	100	153,956	100	\$5,222,622	100	98,900	100	\$1,676,743	100

There was a total of \$5,222,622 Special Project funds used for projects in the four priority service areas and projects for special groups in FY '79 which involved a total of 153,956 individuals who were developmentally disabled. Just over 73% of these individuals were mentally retarded, over 4% were cerebral palsied, 15.7% were epileptic, and 1.9% were autistic. Five percent were handicapped because of conditions other than those listed.

There was a total of \$1,676,743 Special Project funds used for projects in the four priority service areas and projects for special groups in FY '80 which involved 98,900 individuals who were developmentally disabled. Just over 54% were mentally retarded, 13% were cerebral palsied, 15.1% were epileptic, and 1.8% were autistic. There were 15.3% who were handicapped because of conditions other than those listed.

Table 11 contains a comparison of utilization of Special Project funds distributed by disability groups for the three fiscal years of this report with the exception of those funds distributed for employment and vocational development for the reasons heretofore stated.

There was a total of \$17,019,433 Special Project funds spent on projects other than employment in FY '78. Just over 70% of this amount was expended for individuals who were mentally retarded, 8.2% for the cerebral palsied, 16.4% for the epileptic, and 2.4% for the autistic.

In FY '79, there was a total of \$12,502,919 expended for Special Projects with the exception of that which was spent for employment. Of this amount, 65.3% was spent for individuals

who were mentally retarded, 9.5% for the cerebral palsied, 12.9% for the epileptic, and 2.4% for the autistic. Just under 10% was expended for projects for handicapped individuals other than those listed.

TABLE IV-11. SPECIAL PROJECT FUNDS EXPENDED DISTRIBUTED BY DISABILITY GROUPS FOR FISCAL YEARS '78, '79, AND '80

Disability group	FY '78		FY '79		FY '80	
	Amount	%	Amount	%	Amount	%
Mental Retardation	\$11,984,586	70.4	\$ 8,164,079	65.3	\$2,685,141	56.5
Cerebral Palsy	1,395,915	8.2	1,189,821	9.5	587,761	12.3
Epilepsy	2,795,349	16.4	1,610,778	12.9	696,678	14.6
Autism	398,790	2.4	299,433	2.4	121,763	2.6
Other	444,793	2.6	1,238,808	9.9	664,657	14.0
Total	\$17,019,433	100	\$12,502,919	100	\$4,756,000	100

In FY '80, \$4,756,000 was expended on all Special Projects. Individuals who were mentally retarded were involved in 56.5% of the projects, cerebral palsied in 12.3% of the projects, epileptic in 14.6% of the projects, and autistic in 2.6% of the projects. 'Other' handicapping conditions received 14% of the expenditures.

Table 12 contains the comparison of the percent of expenditures between FY '78, the control year, and FY '79 and FY '80, the two experimental years, in relation to the expenditures of Special Project monies funded under Section 145 of PL 94-103 in FY '78 and PL 95-602 in FY '79 and FY '80 by disability groups.

TABLE IV-12. COMPARISON OF THE PERCENTAGE OF EXPENDITURES OF SPECIAL PROJECT MONIES BETWEEN FY '78 AND FY '79 AND FY '80 BY DISABILITY GROUPS

Disability group	FY '78	FY '79	FY '80
	Percent	Percent of change	Percent of change
Mental Retardation	70.4	- 5.1	- 13.9
Cerebral Palsy	8.2	+ 1.3	+ 4.1
Epilepsy	16.4	- 3.5	- 1.8
Autism	2.4	0	+ .2
Other	2.6	+ 7.3	+ 11.4

The apparent effect of applying the definition of developmental disabilities in PL 95-602 on the magnitude of Special Project funding is a 13.9% decrease in the percent used for individuals with mental retardation and a 11.4% increase in the amount of money expended for individuals with handicaps caused by other than mental retardation, cerebral palsy, epilepsy or autism.

Table 13 contains a comparison of the numbers of individuals involved in Special Projects by disability between FY '78 and FY '79 and FY '80.

TABLE IV-13. COMPARISON OF THE NUMBER OF INDIVIDUALS INVOLVED IN SPECIAL PROJECTS BETWEEN FY '78 AND FY '79 AND FY '80 BY DISABILITY GROUPS

Disability group	FY '78	FY '79	FY '80
	Percent	Percent of change	Percent of change
Mental Retardation	79.0	- 5.8	- 24.9
Cerebral Palsy	3.3	+ .9	+ 10.4
Epilepsy	12.0	+ 3.7	+ 3.1
Autism	1.5	+ .4	+ .3
Other	4.2	+ .8	+ 11.1

The apparent effect of applying the definition of developmental disabilities in PL 95-602 on the number of individuals involved in Special Projects is a decrease in the percent of individuals with mental retardation by almost 25% and an increase in the percent of individuals who are cerebral palsied, epileptic and autistic, and also an increase in the number of individuals with 'other' handicapping conditions by 11.1%.

SERVICES TO THE DEVELOPMENTALLY DISABLED

PL 95-602 requires that "an assessment, evaluation and comparison of services provided to persons with developmental disabilities" be included in the mandated report.

There are two ways in which an assessment, evaluation and comparison of services provided under Special Projects may be made. One way to evaluate services is to ascertain the amount of Special Project funding which went into developing standards and implementing standards for services for individuals who are developmentally disabled. Another way to assess, evaluate and compare services is to examine the service providers used to conduct the Special Projects in each of: the fiscal years of '78, '79, and '80 to determine any change in service providers.

It must be pointed out that Grants of National Significance and Special Projects are awarded through a comparative bid process in which peer review teams are used at the national and regional levels to rate each proposal. With this quality control process of grant awards in effect, it is assumed that the most qualified resource is used for each of the Special Projects funded.

Taking the first indicator of quality, information already presented shows that nearly 3% of the Special Project monies were expended for the development and implementation of standards in FY '78. In FY '79, 2.1% of the Special Project monies were used for this purpose. In FY '80, the amount of Special Project monies used for standards of service was 6.2%.

The one national project dedicated to the development of service standards for services to individuals who are developmentally disabled is the project conducted by the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons. There were other projects which trained ICF/MR evaluation teams at the regional and state levels.

An examination of the service providers used to conduct the Special Projects has been presented in an earlier section in this report. However, a further analysis of the service providers used shows that the same or nearly the same providers were used for Special Projects in each of the three fiscal years.

There were 20 different universities used to provide services in 29 different Projects of National Significance. Table 14 shows the universities that conducted Projects of National Significance in FY '78, FY '79, and FY '80.

There were 14 universities which were conducting national projects in FY '78. There were 15 universities conducting national projects in FY '79, of which six did not have national projects in FY '78. There were 10 universities conducting national projects

**TABLE IV-14. UNIVERSITIES WHICH CONDUCTED PROJECTS OF NATIONAL SIGNIFICANCE
IN FY '78, FY '79, AND FY '80**

University	Fiscal '78	Fiscal '79		Fiscal 80
	Number new projects	Number new projects	Number continued projects	Number continued projects
U. of North Carolina	1	1		1
U. of Michigan	1	1		1
U. of Arizona	1			
U. of Nebraska	1			
U. of Oregon	1	1		1
U. of Minnesota	2		1	1
U. of Alabama	2	1	1	1
U. of Colorado	1			
U. of Georgia	1			
Texas Tech U.	1	1		1
U. of Kansas	1			
New York U.	1	1		
U. of Maryland	1	1	1	2
U. of California		1		
Louisiana State U.	1		1	
UCLA		1		
U. of Washington		1		
Eastern Washington U.		1		1
Utah State U.		1		1
U. of Kentucky		1		1
Total	16	13	4	11

in FY '80. All projects in FY '80 are continuations, second or third year, of original projects funded in earlier years.

It should be noted that most of the universities listed on Table 14 are University Affiliated Facilities and conduct programs under the recently developed standards for the UAF's. The universities conducted 50% of the Projects of National Significance in the three year period.

Table 15 shows the non-profit organizations used to conduct Projects of National Significance during the three year period of FY '78, FY '79, and FY '80. There were 23 non-profit organizations used to conduct Projects of National Significance over the three year period. There were 13 organizations which conducted projects in FY '78, three projects continued in FY '79, and two of those projects continued in FY '80.

TABLE IV-15. NON-PROFIT ORGANIZATIONS WHICH CONDUCTED PROJECTS OF NATIONAL SIGNIFICANCE IN FY '78, FY '79, AND FY '80

Non-Profit organization	Fiscal '78	Fiscal '79		Fiscal '80	
	Number new projects	Number new projects	Number continued projects	Number new projects	Number continued projects
Joint Com. Accredit.	1				
New Dimensions	1				
EMC Institute	1				
J.F. Kennedy Found.	1				
No.Am.Ctr.Adoption	1				
People First Inc.	1				
E.K. Shriver Ctr.	1				
Rock Creek Found.	1				
Wheeler Clinic	1				
Nat'l Ctr.Law & Hand.	1		1		1
Harlem Val.Psy.Ctr.	1		1		
Public Int.Law Ctr.	1		1		1
Inches, Inc.	1				
J.F. Kennedy Inst.		1			
Milwood Heart Trng.		1			
Accreditation Council		1			1
Natl.Citiz.Part.Coun.		1			1
Urban Institute		1			
Devel.Ser. NW Kansas		1			1
Nat'l Coun.Soc.Welf.		1			
Legal Aid of W. MO				1	
Ment.Health Law Pro.				1	
Vinland Nat'l Ctr.				1	
Total	13	7	3	3	5

There were seven new projects started in FY '79 which were granted to organizations not used to conduct projects in FY '78. Three of the seven projects continued through FY '80. There were three new projects started in FY '80 granted to organizations which did not have grants in the prior years. However, it should be noted that many of these organizations had Special Projects at the regional and local levels prior to receiving Projects of National Significance grants.

There were two State Governments and one City Government which conducted Grants of National Significance. The two State Governments were used in FY '78. Projects were operated by the New York Department of Mental Hygiene and the Massachusetts Department of Mental Health. In FY '80, a project was awarded to the City of Los Angeles.

National and local associations have traditionally conducted Projects of National Significance. Table 16 shows the associations which conducted Projects of National Significance in FY '78, FY '79, and FY '80.

Table 16 shows the thirteen associations which conducted Projects of National Significance. Eight of the associations conducted projects funded in FY '78, of which two projects continued through FY '79 and one continued through FY '80. Five associations conducted new projects in FY '79, of which three were continued through FY '80. Four of the five associations used in FY '79 for new projects were different from those used in FY '78.

TABLE IV-16. ASSOCIATIONS WHICH CONDUCTED PROJECTS OF NATIONAL SIGNIFICANCE IN FY '78, FY '79, AND FY '80

Association	Fiscal '78	Fiscal '79		Fiscal 80
	Number new projects	Number new projects	Number continued projects	Number continued projects
Am.Assn.for Mental Deficiency	1			
Am.Assn. of UAP	1	1		
UCP of California	1			
Nat'l Assn. MRPD	1			
American Bar Assn.	2		1	
National ARC	1			
Nat'l Soc. Autistic Children	1			
Nat'l Assn. of Counties	1		1	1
Nat'l Home Care Council		1		
Assoc. Western Govs.		1		1
Oregon ARC		1		1
Mesa County ARC		1		1
Total	9	5	2	4

There were no changes in the service providers used to conduct the Special Projects in FY '79 and FY '80 from those used in FY '78 due to the fact that only continuation monies were made available to the Regional Offices in those two years. There were no new Special Projects funded at the regional level in FY '79 and FY '80.

In summary, the quality of Special Projects remained consistent throughout the three year period since similar service providers or the same service providers were used for the conduct of the projects and an effective peer review group process was used in selection of the service providers to receive awards.

SECTION V

UNIVERSITY AFFILIATED FACILITIES

EXECUTIVE SUMMARY

SERVICES OF UAF'S

DIRECT SERVICES

TRAINING

RESEARCH

FISCAL RESOURCES

EXECUTIVE SUMMARY

The mandate for University Affiliated Facilities has been Part B of the Developmental Disabilities Act since its initial passage in 1970. The mandated role of the UAF's has changed little over the first decade of service under the DD Act. The mandated role requires the UAF system to:

1. Provide direct client services;
2. Train personnel; and
3. Conduct applied research.

Section 121 of the Amendments to the Developmental Disabilities Act of PL 95-602, Part V describes the full range of activities required of the UAF system.

Sec. 121(a) From appropriations under Section 123, the Secretary shall make grants to university affiliated facilities to assist in the administration and operation of the activities described in Section 102(10).

(b) The Secretary may make one or more grants to a university affiliated facility receiving a grant under subsection (a) to support one or more of the following activities:

(1) Conducting a feasibility study of the ways in which it, singly or jointly with other university affiliated facilities which have received a grant under subsection (a), can establish and operate one or more satellite centers which would be located in areas not served by a university affiliated facility. Such a study shall be carried out in consultation with the State Planning Council for the State in which the facility is located and where the satellite center would be established.

(2) Assessing the need for trained personnel in providing assistance to persons with developmental disabilities.

(3) Provision of service-related training to practitioners providing services to persons with developmental disabilities.

(4) Conducting an applied research program designed to produce more efficient and effective methods (A) for the delivery of service to persons with developmental disabilities, and (B) for the training of professionals, para-professionals, and parents who provide these services.

PL 95-602, Title V, Sec.121(a)

The definition of a University Affiliated Facility is contained in Section 102 of PL 95-602. The definition is:

(10) 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.

(B) Demonstration of the provision of exemplary services relating to persons with developmental disabilities .

(C)(i) Dissemination of findings relating to the provision of services to persons with developmental disabilities, and (ii) providing researchers and government agencies sponsoring service-related research with information on the needs for further service-related research.

PL 95-602, Title V, Sec.102

There are 48 University Affiliated Facilities in the Association of University Affiliated Programs. There is at least one UAF in 32 of the 50 States. Four States, Georgia, Indiana, Massachusetts and Oregon, have two UAF's located in the State. Three States, California, Kansas and Ohio, have three UAF's; and New York has four UAF's. A complete list of the UAF's is contained in Appendix 1 of this report.

The University Affiliated Facilities provide general and specialized services in three complementary areas. UAF's provide a wide range of direct services for individuals who are developmentally disabled. The UAF's provide specialized instruction in a variety of disciplines to college students and non-college students including professionals, para-professionals, parents of individuals who are developmentally disabled, and individuals from the general public. UAF's also have students, mainly at the graduate level, who are specializing in order to provide services to individuals who are developmentally disabled. UAF's also conduct a wide variety of applied research developing model programs, new treatment methodologies, developing materials and providing training programs for practitioners in the field.

The following statistical and narrative report will demonstrate that the UAF's provide a magnitude of services. The report contains a display and discussion of the almost 24,000 individuals receiving direct service in 21 of the UAF's in FY '79. Statistical reports are provided containing the demographics of the clients, level of retardation, and medical classification of the individuals.

The report also contains statistical evidence that the UAF's conduct training programs, provide college level instruction for thousands of college and non-college students, and provide specialized training programs for all audiences. Almost 14,000 college students received eight hours or more instruction in 36 of the UAF's in FY '79. The report also shows that there were 350 students majoring in programs for the developmentally disabled in 18 UAF's in FY *79.

There were almost 100,000 non-university students involved in training programs in FY '79. Fifty-five percent of these trainees were professionals, seventeen percent para-professionals, and six percent parents of individuals who were developmentally disabled.

Nearly \$8.5 million, or 8% of the UAF's fiscal resources, are received to conduct applied research in a variety of areas. Research is carried on in employment, physical habilitation, genetics, early intervention, evaluation, and a variety of other areas. In FY '79, UAF's had 69 different research projects under contract from a variety of funding sources.

The combined annual budget of UAF's is in excess of \$100 million. These funds are obtained from a variety of sources including Maternal and Child Health, Developmental Disabilities, State general funds, Rehabilitation Services, university general funds, fees for service, Public Health, and Bureau of Education of the Handicapped.

The major portion of the funds for UAF's are obtained from grants and contracts. This fiscal resource accounts for 63% of the UAF's funds. Almost 22% of the funds come from the general funds of the university, while 12% of the funds are obtained from fees for service. Three percent of the resources come from in-kind match and contractors' contributions.

The University Affiliated Facilities Program is an important component of the DD Program. Not only providing direct services to individuals who are developmentally disabled, but this network of UAF's provides valuable interdisciplinary training and applied research.

The UAF Program receives only a small amount of funds from the DD Program. In FY '78, the UAF Program received \$6.5 million for basic support, in FY '79 the program received \$7.4 million in basic support, and \$7.0 million in FY '80 for the same purpose.

SERVICES OF UAF'S

The University Affiliated Facilities provide three general types of services. The three types of services are:

1. Direct client services
2. Training
3. Research

The three types of services are provided in eleven categories. Table 1 shows the areas in which services are provided for 44 of the UAF's. A key to the abbreviations used to identify the UAF's is found in Appendix 1 of this report.

The services provided by the UAF's are grouped in eleven categories. The eleven categories are:

1. General Support
2. Identification
3. Treatment
4. Education
5. Counseling Services
6. Family Support
7. Living Arrangements
8. Vocational Services
9. Recreation
10. Transportation
11. Indirect Services

The information on Table 1 shows that 43 of the 44 UAF's provide at least one service identified under the heading of general support. Most of the institutions provide coordination, information and referral, and follow-along services. Over fifty percent provide case finding services, while 41% provide personal advocacy. Twenty-seven percent provide protective services, and only three UAF's provide services in guardianship.

There are 43 UAF's which provide identification services. All 43 of these institutions provide evaluation services, while 42 provide diagnosis services and 38 provide screening services.

There are 42 UAF's which provide treatment services for individuals who are developmentally disabled. Thirty-nine of these provide speech services, 39 provide medical services, and 32 psychotherapy. There are 33 UAF's which supply physical therapy, 29 supply occupational therapy, and 26 provide dental services to the handicapped.

There are 40 UAF's which provide educational services to the developmentally disabled. Most, 39, of these institutions, provide pre-school education. Thirty-three of the UAF's provide

TABLE V-1. AREAS OF SERVICE PROVIDED BY UNIVERSITY AFFILIATED FACILITIES (Continued)

ROLE OF UNF	Institutions																										No.	g ¹
	A	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C		
1. Living Arrang.																												
Board & em. liv.																												
Group home care																												
Foster care																												
Sheltered care																												
Nursing home																												
Institution																												
8. Vocational Ser.																												
Evaluation																												
Teaching																												
Placement																												
Sheltered emp.																												
Activity center																												
Other emp. ser.																												
9. Recreation																												
Therapeutic																												
Leisure time																												
10. Transportation																												
11. Indirect Ser.																												
Planning coord.																												
Public educ.																												
Primary prev.																												
Basic res.																												
Manpower																												
Data																												
Funding																												
Architect. barrier																												

¹ Based on 44 UNF's.

school programs for the severely and profoundly handicapped, while 26 provide school programs for the mildly handicapped. Twenty-three of the UAF's provide special school programs. Only eight UAF's provide adult education programs for the disabled.

Forty-one of the UAF's provide counseling services for the disabled. Thirty-seven provide general counseling, and 29 provide crisis intervention services. Twenty-eight of the UAF's have genetic counseling services, and 16 provide family planning.

There are 41 UAF's which provide services in the area of family support. Thirty-nine of these institutions provide family education services. Thirty-seven of the institutions provide family training. Only three of the institutions provide in-home sitter services, six provide out-home respite care, and two UAF's provide homemaking services. One UAF provides out-home sitter service.

Only 13 UAF's provide services related to living arrangements. Eight of the UAF's provide institutional care. Five of the UAF's provide group home care, while two UAF's provide board and room living arrangements. Four UAF's provide foster care and three provide nursing home care. One UAF provides sheltered care.

There are 27 UAF's which provide vocational services for individuals who are disabled. Twenty-six of these institutions provide evaluation services. There are 16 UAF's which provide teaching services, 15 institutions provide placement services, and 10 provide sheltered employment. Seven of the UAF's have activity centers and seven provide other employment services.

There are 23 UAF's which provide recreation services to the developmentally disabled. Twenty-one of these institutions provide therapeutic recreation services and 18 provide leisure time recreation services.

There are six institutions which provide transportation services.

Forty-three of the UAF's provide indirect services. Forty of the universities provide manpower services and 38 provide public education. Thirty-six of the institutions provide planning coordination and 36 participate in basic research. Twenty-nine of the UAF's keep data and statistics in the disabilities area, while 24 of the organizations provide information on funding of programs. Twenty-seven of the UAF's conduct programs in primary prevention. Eleven have programs in overcoming architectural barriers.

Table 2 shows the activity provided for each of the services offered by the UAF's. The activity is categorized by client services, training, or research in the area of service. Some UAF's provide all three categories of activities for some services and other UAF's provide only one or two activities for a given service.

TABLE V-2. NUMBER AND PERCENT OF UAF'S PROVIDING CLIENT SERVICES, TRAINING, AND RESEARCH ACCORDING TO SERVICE AREAS

Type of service	Client services		Training		Research	
	No.	%	No.	%	No.	%
1. General						
1.1 Case Finding	29	66	20	45	2	5
1.2 Infor. & Referral	37	84	27	61	5	11
1.3 Coord. of Service	42	95	34	77	5	11
1.4 Follow-Along	37	84	31	70	5	11
1.5 Protective Ser.	11	25	4	9	0	0
1.6 Pers. Advocacy	17	39	15	34	0	0
1.7 Guardianship	3	7	2	5	0	0
2. Identification						
2.1 Screening	37	84	30	68	14	32
2.2 Diagnosis	41	93	36	82	14	32
2.3 Evaluation	42	95	37	84	16	36
3. Treatment						
3.1 Medical Service	37	84	29	66	10	23
3.2 Dental Service	25	57	22	50	5	11
3.3 Speech Therapy	36	82	36	82	8	18
3.4 Physical Therapy	30	68	27	61	3	7
3.5 Occup. Therapy	28	64	21	48	2	5
3.6 Psychotherapy	29	66	26	59	7	16
4. Education						
4.1 Pre-school	37	84	34	77	14	32
4.2 School Ser. Mild	23	52	22	50	6	14
4.3 School Ser. Severe	32	73	29	66	10	23
4.4 Adult Basic Educ.	7	15	5	11	2	5
4.5 Special School Ser.	22	50	20	45	7	16
5. Counseling						
5.1 General	36	82	30	68	3	7
5.2 Crisis	28	64	25	57	4	9
5.3 Family	15	34	11	25	0	0
5.4 Genetic	27	61	23	52	11	27
6. Family Support						
6.1 Education	38	86	35	80	6	14
6.2 Training	35	80	24	55	7	16
6.3 In-Home	2	5	2	5	0	0
6.4 Out-Home	1	2	0	0	0	0
6.5 Respite	4	9	3	7	0	0
6.6 Homemaker	1	2	2	5	0	0

TABLE V-2. NUMBER AND PERCENT OF UAF'S PROVIDING CLIENT SERVICES, TRAINING, AND RESEARCH ACCORDING TO SERVICE AREAS (Continued)

Type of service	Client services		Training		Research	
	No.	%	No.	%	No.	%
7. Living Arrangements						
7.1 Board	1	2	2	5	0	0
7.2 Group Home	4	9	3	7	0	0
7.3 Foster	2	5	3	7	0	0
7.4 Sheltered	1	2	0	0	0	0
7.5 Nursing	2	5	2	5	0	0
7.6 Institution	6	14	6	14	1	2
8. Vocational						
8.1 Evaluation	26	59	19	43	2	5
8.2 Teaching	16	36	11	25	2	5
8.3 Placement	15	34	10	23	1	2
8.4 Sheltered	9	20	5	11	2	5
8.5 Activity	6	14	3	7	1	2
8.6 Other	7	16	3	7	1	2
9. Recreation						
9.1 Therapy	21	48	14	32	1	2
9.2 Leisure	17	39	12	27	1	2
10. Transportation	6	14	2	5	0	0
11. Indirect Services						
11.1 Planning	35	80	21	48	4	9
11.2 Public	34	77	26	59	2	5
11.3 Primary	27	61	20	45	11	25
11.4 Basic Research	11	25	20	45	34	77
11.5 Manpower	22	50	36	82	11	25
11.6 Data	26	59	14	32	12	27
11.7 Funding	22	50	19	43	10	23
11.8 Arch. Barriers	10	23	7	16	6	14

Ninety-five percent of the UAF's coordinate services for individuals. Eighty-four percent provide individuals with information and referral and follow-along services, Sixty-six percent of the UAF's provide services to individuals in case finding, and 39% services in personal advocacy. One-fourth of the UAF's provide individuals protective services, and seven percent provide individuals guardianship services.

UAF's provide training in all services listed under the category of general services. Seventy-seven percent train in coordination of services and 70% train in follow-along services. Sixty-one percent train in information and referral services, 45% in case finding, 34% in personal advocacy, and 9% train in protective services. Five percent train in guardianship services.

UAF's conduct research in four services listed under general services. Eleven percent of the UAF's conduct research in information and referral, coordination of services and follow-along services. Five percent of the UAF's conduct research in case finding services.

Almost all the UAF's provide direct client identification services. Ninety-five percent provide evaluation services, 93% provide diagnosis services, and 84% provide screening services.

Most of the UAF's train in all identification services. Eighty-four percent train in evaluation, 82% train in diagnosis, and 68% train in screening services.

One-third of the UAF's conduct research in identification services. Thirty-six percent conduct research in evaluation, 32% in diagnosis services, and 32% in screening services.

UAF's provide client services in treatment services. Eighty-four percent provide medical treatment and 82% provide speech therapy. Sixty-eight percent provide physical therapy, 64% occupational therapy, and 66% provide psychotherapy. Fifty-seven percent of the UAF's provide dental services.

Over half of the UAF's train in treatment services. Eighty-two percent train in speech therapy, 61% in physical therapy, and 66% in medical services. Fifty-nine percent train in psychotherapy, 50% in dental services, and 48% in occupational therapy.

Some of the UAF's conduct research in treatment services. Twenty-three percent conduct research in medical services, 18% conduct research in speech therapy, and 16% in psychotherapy. Eleven percent conduct research in dental services, 7% in physical therapy, and 5% in occupational therapy.

Direct client services in education are provided by UAF's. Eighty-four percent provide pre-school services, 73% provide school services for the severely involved, and 52% provide school services for the mildly involved. One-half of the UAF's provide special school services for individuals who are developmentally disabled. Only fifteen percent of the UAF's provide adult basic education.

Nearly the same percentage of UAF's train in educational services as offer direct client educational services. Seventy-seven

percent train in preschool services, 66% train for education services for the severely involved, and 50% train for educational services for the mildly involved. Forty-five percent train for special school services, and 11% train for adult basic education programs.

One-third of the UAF's conduct research in preschool education. Twenty-three percent conduct research for severely involved and 14% for mildly involved. Sixteen percent of the UAF's conduct research for special school services. Only five percent of the UAF's conduct research in adult basic education.

UAF's provide direct counseling services. Eighty-two percent of the UAF's provide general counseling services. Sixty-four percent provide crisis intervention services, 61% provide genetic counseling services, and 34% provide family counseling services.

UAF's also provide training in the counseling service area. Sixty-eight percent train in general counseling, 57% train in crisis intervention, 52% train in genetic counseling, and one-fourth train in family counseling.

Twenty-seven percent of the UAF's conduct research in genetic counseling. Nine percent conduct research in crisis intervention, and 7% conduct research in general counseling. No UAF's conduct research in family counseling.

The majority of direct client services provided by the UAF's in family support is in the area of education and training. Eighty-six percent of the UAF's provide services in family education, and 80% in family training. Nine percent offer respite care, 5% in-home sitters, 2% out-home sitters, and 2% homemaker services.

Eighty percent of the UAF's provide training in family education, 55% provide training in family training, and 7% in respite care. Five percent provide training in in-home sitter service and 5% in homemaker service. No UAF's provide training in out-home sitter services.

Only two services under family support are under research by the UAF's. sixteen percent conduct research in family training and 14% in family education.

Few of the UAF's provide direct services in living arrangements. Fourteen percent provide institutional services, 9% group home services, .5% provide foster care service, and 5% provide nursing care service. Two percent provide board and room and 2% provide sheltered care.

Training in living arrangements is also provided by a few UAF's. Fourteen percent train in institutional services, 7% in foster care, and 7% in group home care. Five percent of the UAF's

train in nursing home care, and 5% train in board and room living. No UAF's train in sheltered care services.

There is only one, or 2% of the UAF's, which conduct research in living arrangements. This research is in the area of institutional service.

Direct client services are provided by UAF's in the area of vocational services. Fifty-nine percent provide evaluation services. Thirty-six percent provide teaching, 34% provide placement services, and 20% provide sheltered workshop services. Fourteen percent provide activity services, and 16% provide other vocational services.

Some of the UAF's are providing training in the area of vocational services. Forty-three percent of the UAF's train in evaluation services. Twenty-five percent train in teaching, and 23% in placement. Eleven percent of the UAF's train in sheltered workshop services, while 7% train in each of activity services and other services.

Research in vocational services is being conducted by two of the UAF's.

Forty-eight percent of the UAF's provide direct services in therapeutic recreation, and 39% in leisure time recreation.

Thirty-two percent of the UAF's provide training in therapeutic recreation, and 27% in leisure time recreation.

One UAF is conducting research in the area of recreation.

Most of the UAF's provide direct client services in indirect services. Eighty percent provide services in planning, 77% in public education, and 61% in primary prevention. Half of the UAF's provide manpower and funding services. Fifty-nine percent provide data management services, and 23% provide services in the removal of architectural barriers. One-fourth provide services in basic research.

The UAF's train in all services which are classified as indirect services. Eighty-two percent train in manpower development, 55% in public education, and 48% in planning. Forty-five percent of the UAF's provide training in primary prevention and in basic research. Forty-three percent provide training in funding, 16% in removal of architectural barriers, and 32% in data management.

Seventy-seven percent of the UAF's are conducting basic research for individuals who are developmentally disabled. One-fourth are conducting research in primary prevention, and one-fourth in manpower development. Twenty-seven are conducting research in data management, 23% in funding, and 14% in removal

of architectural barriers. Five percent are conducting research in public education, and 9% in planning.

Figure 1 shows the combination of client services, training and research activities for each of the services provided by the University Affiliated Facilities. As is apparent from the figure, most UAF's provide both direct client services and training for each of the services they provide. Several of the UAF's provide client services, training and research in the services they provide. Some of the UAF's provide only direct client services in service areas.

There are UAF's that provide only training in some service areas and only research in a few specific areas.

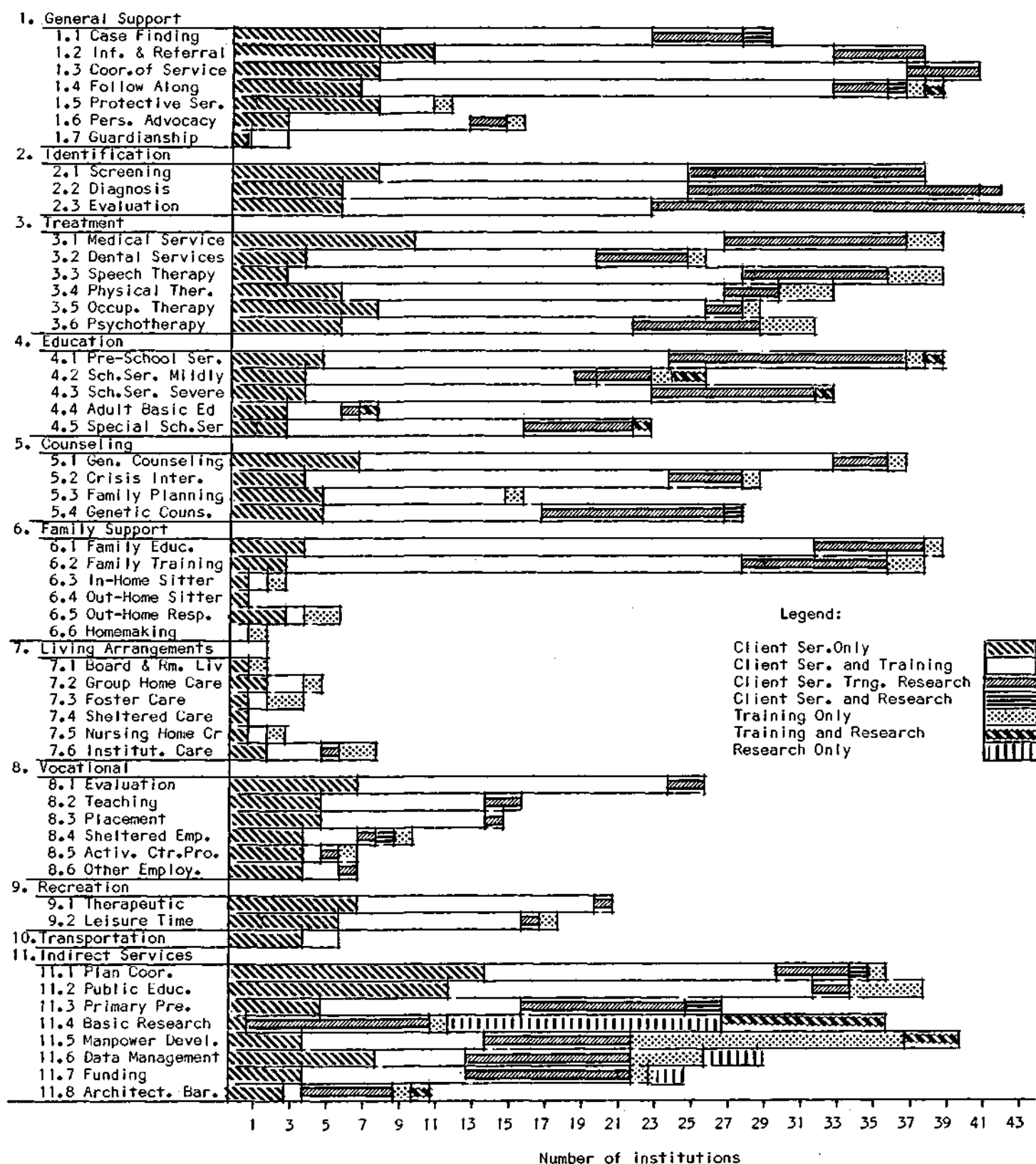


Figure V-1. Combination of Client Services, Training, and Research Activities for Each of the Services Provided by the University Affiliated Facilities

DIRECT SERVICES

The University Affiliated Facilities provide services to individuals with a variety of handicaps. The individuals served by UAF's can be divided into eleven different categories of causes of handicapping conditions. The eleven causes of handicaps served by the UAF's are:

1. Mental Retardation
2. Autism
3. Emotional Handicap
4. Cerebral Palsy
5. Physical Handicap
6. Epilepsy
7. Deafness
8. Blindness
9. Dyslexia
10. Learning Disabled
11. Metabolic Disorder

The variety of conditions for which direct services are provided by the University Affiliated Facilities indicates that the definition of developmental disabilities contained in PL 95-602 will have little effect on the services and clientele of the UAF. The present clientele and services provided are sufficiently varied to incorporate the population included under the definition.

Table 3 shows the number and percent of institutions which provide services for each classification of client. The clients are classified according to the cause of handicapping condition heretofore listed.

TABLE V-3. NUMBER AND PERCENT OF INSTITUTIONS PROVIDING SERVICES FOR EACH CAUSE OF HANDICAPPING CONDITION

Handicapping condition	Number of institutions	Percent of institutions
Mental Retardation	42	100
Autism	32	76
Emotional Handicap	25	60
Cerebral Palsy	35	83
Physical Handicap	30	71
Epilepsy	30	71
Deafness	22	52
Blindness	21	50
Dyslexia	29	69
Learning Disabled	30	71
Metabolic Disorder	30	71

Every UAF provides direct services for individuals who are mentally retarded. Eighty-three percent provide services for individuals who are cerebral palsied. Seventy-one percent provide services for the epileptics, and 76% provide services for the autistic.

Seventy-one percent of the UAF's provide services for the physically handicapped, learning disabled and those with metabolic disorders. Sixty-nine percent provide services for those with dyslexia and 60% provide services for the emotionally handicapped.

Fifty-two percent of the UAF's provide services for the hard of hearing and deaf, and half of the UAF's provide services for the blind.

Table 4 shows the demographics of clients in 21 UAF programs for FY '79 classified by active cases, referral source, age, ethnicity, and sex.

There were 4,227 individuals reported screened in 10 of 21 of the UAF's in FY '79. The 21 UAF's reported 12,991 new applications and 887 applications carried over from FY '78, for a total of 13,878 individuals.

The majority of individuals were referred to UAF's by private physicians. Twenty-seven percent of the individuals were so referred. Fourteen percent were referred by hospitals and 11% were referred by schools. Eight percent of the individuals were referred by community services, 7% by families of the individuals, and 4% were referred to the UAF's by crippled children's services. Public Health Services, Mental Health Services, and Social Services each referred 3% of the UAF clients.

The majority of individuals to whom the UAF's provide direct service are below age 11 years. Sixty-five percent of 10,829 new admissions in FY '79 in 21 UAF's were between 0-11 years of age. Eight percent were under one year of age. Thirty percent were between 1-5 years of age, and 27% were between 6-11 years of age. Eleven percent were between 12-17 years of age.

Adults, individuals over 18 years of age, accounted for 24% of the new admissions. Five percent were between 18-20 years of age, however there were four UAF's which had no individuals within this age category. Sixteen of the UAF's provided services for 1,075, or 10%, of the individuals between the ages of 21-59. Five UAF's served 949 individuals who were above the age of 60, which represented 9% of the new admissions.

It is interesting that 15% of the individuals admitted were Black. The 1,062 Black individuals admitted for service represent a significantly larger percent of the population when compared with the percent of Blacks in the national population.

TABLE V-4. DEMOGRAPHICS OF CLIENTS IN UAF PROGRAMS FOR FY '79 INCLUDING ACTIVE CASES, REFERRAL SOURCE, AGE, ETHNICITY, AND SEX

UAF	AL	CA	CO	GA	IA	IN	KS	KY	MI	MN	NE	NJ	NC	OH	OK	OR	PA	RI	SC	TN	WI	Total	%
State	AL	CA	CO	GA	IA	IN	KS	KY	MI	MN	NE	NJ	NC	OH	OK	OR	PA	RI	SC	TN	WI	No.	%
Number screened	0	100	1562	35	400	0	0	25	0	0	887	0	72	0	25	0	0	0	518	655	0	4,227	N/A
New applications	366	302	631	66	221	1493	590	96	227	142	483	349	447	742	350	2762	1561	530	260	704	666	12,991	94
Carried over	58	50	42	5	0	72	0	5	42	0	104	69	23	169	41	0	65	0	10	112	20	887	6
Total	423	352	673	71	221	1565	590	103	269	142	587	418	470	911	391	2762	1626	530	270	816	686	13,878	100
Referral Source																							
Private physician	96	99	82	0	43	955	45	9	29	10	97	29	76	279	9	661	621	0	58	300	274	3,854	27
Crippled Children	43	1	0	0	11	207	9	13	0	3	21	0	1	1	0	304	0	0	0	0	0	614	4
Hospital	14	92	0	0	115	103	168	38	8	24	41	3	101	122	12	331	873	0	1	0	0	2,046	14
School	86	10	95	14	29	103	63	28	53	30	44	90	55	176	111	367	0	0	57	25	52	1,508	11
Personal	0	19	158	21	13	0	200	3	30	23	96	105	57	0	77	0	0	0	76	25	52	955	7
Public Health	3	4	0	1	1	32	3	3	5	3	5	0	18	0	12	276	0	0	0	56	4	426	3
Mental Health	9	3	170	22	1	5	1	1	37	5	15	24	22	18	3	28	0	0	4	2	0	370	3
Social Services	11	11	0	0	3	10	23	3	9	29	23	72	11	31	21	110	0	0	41	4	16	426	3
Other Comm. Ser.	80	99	126	6	5	78	65	0	20	3	11	2	41	115	102	138	0	0	15	182	81	1,129	8
Other	21	4	0	2	0	0	13	0	36	12	130	24	65	0	3	497	132	530	0	30	1	1,500	11
Carried over	58	50	42	5	0	72	0	5	42	0	104	69	23	169	41	400	65	0	10	112	20	1,287	9
Total	423	352	673	71	221	1565	590	103	269	142	587	418	470	911	391	3132	1691	530	262	816	500	14,117	100
Age																							
Under 1	35	65	58	0	66	310	48	N	5	3	15	0	56	27	15	70	1	0	48	27	7	856	8
1 - 5	123	73	233	5	94	558	213	0	29	37	233	56	162	174	78	731	7	125	52	199	89	3,271	30
6 - 11	141	16	92	19	37	409	152		40	70	104	32	123	228	96	916	21	53	80	197	38	2,924	27
12 - 17	43	6	20	21	19	216	48	D	45	23	59	11	32	76	24	382	22	30	43	64	20	1,204	11
18 - 20	11	19	0	4	4	0	11	A	14	8	6	0	2	4	9	349	31	20	20	16	22	550	5
21 - 59	12	49	0	0	1	0	32	T	35	1	3	0	3	1	66	3	526	9	10	25	299	1,075	10
60 +	0	0	0	0	0	0	0	A	0	0	0	0	0	0	12	1	925	0	7	0	4	949	9
Total	365	228	403	49	221	1493	504		168	142	420	99	378	510	340	2512	1533	237	260	528	479	10,829	100
Ethnicity																							
White	278	158	N	31	206	1396	156	63	103	124	365	85	195	439	276	N	1162	N	195	367	289	5,910	82
Black	85	3	0	18	6	81	51	3	9	10	22	9	74	68	18	0	361	0	65	159	20	1,062	15
Hispanic	0	57		0	4	0	16	0	1	6	6	4	0	0	0	0	0	0	0	0	0	94	1
American Indian	0	0	D	0	0	0	6	0	1	1	5	0	1	0	3	D	0	0	0	0	0	17	-
Oriental	0	10	A	0	1	16	1	0	2	1	3	0	0	3	0	A	0	A	0	1	5	43	1
Other	2	0	T	0	2	0	3	0	52	0	19	1	2	0	0	T	0	T	0	1	2	84	1
Total	365	228	A	49	221	1493	233	86	168	142	420	99	272	510	297	A	1523	A	260	528	316	7,210	100
Sex																							
Male	224	91	253	31	116	844	285	0	99	112	266	77	238	351	174	2512	679	153	190	346	119	7,160	66
Female	141	137	150	18	105	649	219	0	69	30	154	22	140	159	126	0	854	84	70	182	360	3,669	34
Total	365	228	403	49	221	1493	504	0	168	142	420	99	378	510	300	2512	1533	237	260	528	479	10,829	100

Eighty-five percent of the individuals admitted for service were White, one percent Hispanic, and one percent Oriental.

The ratio of males to females was two to one. Sixty-six percent of the individuals admitted were male and 34% were female.

Table 5 contains client data for 21 UAF programs for FY '79 classified by active cases, status, classification of retardation, and medical classification.

Of 14,535 individuals processed in FY '79 at the 21 UAF's, 75% were admitted for services. Nine percent of the individuals were referred to other service agencies within the State. Six percent of the individuals were withdrawn from consideration for service. Nine percent were carried over for consideration for services in FY '80.

There were 23,793 individuals receiving services in the 21 UAF's in FY '79. Forty-seven percent were carried over from FY '78 and 45% were admitted to service during FY '79. One percent of the individuals came from cases closed in FY '79 and reopened the same year. Seven percent of the individuals came from cases which had been closed in prior years and reopened in FY '79.

Just over half of the 7,229 individuals on which diagnostic information was maintained were diagnosed as retarded. Fifty-five percent of the individuals were diagnosed as retarded. Forty percent were diagnosed as non-retarded. Five percent were not diagnosed.

Information from 13 institutions was maintained on the medical classification for 5,308 individuals. Twenty-three percent of the individuals were handicapped because of unknown prenatal influences. Fifteen percent were handicapped because of environmental influences. Eight percent were handicapped because of irregularities in metabolism or nutrition and 8% because of gross brain damage. Six percent were handicapped because of trauma or physical agent, 6% because of cromosomal abnormality, and 6% because of gestational disorder. Five percent were handicapped because of infection and intoxication and 3% because of psychiatric disorder.

TABLE V-5. CLIENT DATA FOR UAF PROGRAMS FOR FY '79 INCLUDING ACTIVE CASES, STATUS, CLASSIFICATION OF RETARDATION, AND MEDICAL CLASSIFICATION

UAF State	AL	CA	CO	GA	IA	IN	KS	KY	MI	MN	NE	NU	NC	OH	OR	PA	RI	SC	TN	WI	Total No.	%	
Number screened	0	100	1562	35	400	0	0	25	0	0	887	0	72	0	25	0	0	518	653	0	4,277	N/A	
New applications Carried over	365	302	631	66	221	1493	590	96	227	142	483	349	447	742	330	2762	1561	530	260	704	668	12,991	94
Total	365	302	631	66	221	1493	590	96	227	142	483	349	447	742	330	2762	1561	530	260	704	668	887	6
Disposition of Client																						13,878	100
Admitted	365	228	403	49	221	1493	573	86	168	142	420	99	272	510	300	2512	1523	330	260	528	502	10,784	75
Referred	50	1	270	6	0	0	47	6	0	120	56	133	119	0	75	250	0	61	10	97	29	1,330	9
Withdrawn	8	50	0	2	0	28	39	4	59	21	7	138	1	288	16	0	0	77	10	172	8	928	6
Other	29	0	0	0	0	0	0	0	0	1	2	0	0	0	43	0	0	0	0	0	126	201	1
Carried over	0	73	0	14	0	44	131	7	42	0	102	48	78	113	43	400	95	62	0	19	23	1,292	9
Total	452	352	673	71	221	1565	590	103	269	284	567	418	470	911	477	3162	1616	530	270	816	688	14,535	100
Status																							
Clients under care	1148	430	805	143	994	1762	624	156	368	142	1067	227	1162	1493	848	5732	1802	1919	521	1011	1199	23,793	100
Active cases carried over	744	193	394	66	750	269	152	61	172	0	492	124	641	689	500	3220	268	1621	157	10	697	11,210	47
New client	365	228	403	49	221	1493	504	86	168	142	420	99	272	510	300	2512	1533	258	260	528	502	10,853	45
Reopened-this year cases	1	1	0	0	14	0	20	0	0	0	105	0	45	18	8	0	1	0	81	0	0	294	1
Reopened-last year cases	38	8	18	28	9	0	148	9	48	0	70	4	204	276	40	0	0	40	23	473	0	1,436	7
Level of Retardation																							
Non-retarded	105	N	233	4	N	757	39	11	34	62	121	45	108	327	84	678	0	N	94	164	8	2,874	40
Mild	49	0	97	17	0	402	4	11	18	34	42	2	27	63	78	673	4	0	44	127	1	1,693	23
Moderate	24		51	14		157	0	15	21	12	43	5	21	46	63	359	8		26	96	8	969	13
Severe	17	D	28	10	D	76	1	21	14	6	16	0	8	29	48	139	14	D	13	59	1	500	7
Profound	17	A	12	0	A	2	1	13	4	6	7	0	6	20	9	11	7	A	7	54	2	178	3
Not specified	3	T	0	0	T	0	1	0	0	0	110	0	0	22	3	422	0	T	60	9	0	621	9
Not diagnosed	4	A	0	4	A	68	6	0	58	0	0	47	102	4	15	30	0	A	16	9	31	394	5
Total	219		421	49		1462	52	71	149	120	339	99	272	511	300	2312	33		260	509	51	7,229	100
Medical Classification																							
Infection & Intoxication	12	N	N	0	N	10	2	16	3	11	13	N	10	5	N	129	N	N	N	54	1	265	5
Trauma or physical agent	3	O	0	3	0	40	11	15	13	4	23	0	19	10	0	138	0	0	0	27	51	311	6
Metabolism or nutrition	7			1		220	17	1	0	2	4		10	8		133				3	3	409	8
Gross brain disease	0	D	0	0	D	46	2	5	2	6	6	D	6	295	D	15	D	D	D	26	22	431	8
Ulk, prenatal influence	24	A	A	21	A	353	12	22	24	6	72	A	46	35	A	430	A	A	A	156	2	1,203	23
Chromosomal abnormality	12	T	T	6	T	17	2	0	16	19	18	T	2	15	T	214	T	T	T	42	2	365	6
Gestational disorder	3	A	A	0	A	72	14	20	1	6	31	A	34	10	A	129	A	A	A	22	0	342	6
Psychiatric disorders	0			1		2	1	3	4	10	9		0	29		77				0	0	136	3
Environmental influences	2			10		490	35	8	5	18	14		8	18		168				5	0	781	15
Other conditions	59			7		316	10	0	81	38	220		137	86		99				1	0	1,064	20
Total	122			49		1566	106	90	149	120	420		272	511		1532				336	35	5,308	100

Table 6 shows the level of retardation of 3,961 individuals diagnosed as retarded in the UAF's during FY '79.

TABLE V-6. NUMBER AND PERCENT OF 3,961 INDIVIDUALS DIAGNOSED AS RETARDED IN UAF PROGRAMS DURING FY '79 BY LEVEL OF RETARDATION

Level of retardation	Number	Percent
Mild	1,693	43
Moderate	969	25
Severe	500	13
Profound	178	4
Not Specified	621	15
Total	3,961	100

Forty-three percent were diagnosed as mildly retarded and 25% were diagnosed as moderately retarded. Thirteen percent of the individuals were diagnosed as severely retarded and 4% as profoundly retarded. The level of retardation was not specified for 15% of the individuals.

It is interesting to note that 17% of the individuals were diagnosed as severely or profoundly retarded. The national statistic which is usually used is 8% of the retarded are severely or profoundly retarded. If it can be assumed that the UAF's serve a cross section of the handicapped population, and if it can be further assumed that 55% of the handicapped community is retarded, then the DD community must look at the 8% figure usually used to estimate the number of severely and profoundly retarded within the population of individuals who are mentally retarded. However, these assumptions are not yet validated and the subject should be studied further.

TRAINING

The University Affiliated Facilities provide training in a variety of situations during the year. The UAF's have training programs which can be divided into four categories. The four categories are:

1. Regularly enrolled university students take courses from UAF faculty members;
2. Students major in courses leading to a specialty of working with the handicapped;
3. University students participate in seminars, conferences, lectures, and other non-academic courses presented by UAF faculty members; and
4. Individuals from the general population concerned with individuals who are developmentally disabled participate in training programs conducted by the UAF's.

During FY '79, many of the UAF's reported the number of individuals in each of the four categories who participated in UAF training programs. Table 7 shows the number of UAF's reporting the number of students, majors, non-academic students, and individuals from the general public who participated in training programs in FY '79.

Category of participant	Number of UAF's reporting	Number of participants
University students taking courses in UAF's	38	14,549
University students majoring in UAF's	20	391
University students participating in non-academic UAF programs	25	32,495
Individuals from the general public participating in UAF training programs	28	98,911

Thirty-eight of the 48 UAF's reported that 14,549 university students took at least eight academic hours of courses taught by UAF faculty members. Twenty of the 48 UAF's reported having 391 students who are majoring in a program which will allow them to work with individuals who are handicapped. Twenty-five of the UAF's reported that 30,785 university students participated in UAF sponsored non-academic programs. Twenty-eight of the UAF's reported that almost 100,000 individuals from the general public participated in training programs dealing with individuals who are disabled.

Table 8 shows the number of UAF trainees categorized by academic level for 26 UAF's for FY '79.

Of the 13,814 university students taking 8 hours or more in the 26 UAF programs, nearly 35% of the students are working toward the AB degree. Over 19% of the students are graduate students working for their Master degree. Over 7% of the students are medical or dental students at the Doctoral level, and over 3% are non-medical doctoral students.

Over 8% of the students are professional practitioners. Four percent are intern medical or dental students and nearly 5% are students working toward their Associate degree. There are some students at the high school and the technical training level. Also, some students are resident medical or dental students.

TABLE V-8. NUMBER OF UAF STUDENTS CATEGORIZED BY ACADEMIC LEVEL FOR 26 UAF'S FOR FY '79

Academic level	AL	CA	CA	CO	DC	FL	GA	GA	IA	IN	IN	KS	KY	MA	MD	MI	MI	MO	MS	NC	NE	NV	NV	OH	OH	OH	OR	PA	RI	SC	SD	TN	UT	WA	WI	WV	Total No.	%		
High School	1	1	3	1	1	1	1	2	1	1	2	1	1	1	1	1	1	3	1	1	1	1	3	1	2	3	2	1	1	1	1	1	1	1	1	1	1	329	2.4	
Technical Training							16	316	1										5		11																	357	2.4	
AA Degree	2		3					303	94										210		30																	634	4.6	
AB Degree	40		22	46	2	20	265	1554	474	35	36	24	35	1	95	22	3		105	8	61	1	104	39	548	150	8	1	4	9	170	262	109	3	37	45	14	4,826	34.9	
Post AB Degree	24		13	36	4	1		75	75			9			1				399	188	3			9			2	2										267	1.9	
MA Degree	79	6	64	107	16	26	145	737	142	25	11	59	17	18	54	48	3	10	78	172	54	43	27	47	160	45	35	35	73	1	65	23	15	9	103	96	67	2,680	19.4	
Post MA Degree	8	1	13	25	1	1			4	1				1	5					1	4			7	5			2	2									89	.6	
Doctor Med/Dental	26		21	16	4	1		115	176			125		2	42	119	1		3	6	66			5	4													1,053	7.6	
Doctor Non-Medical	8		29	15	8	19	12	4	12	6		20		3	13	31			25	27	24	14	8	34	56	2	1	1										436	3.2	
Intern Med/Dental	4		3									8				6			2				248	5	229													551	4.0	
Resident Med/Dent	5	10	2	55	1				11		23	4		4	25	1				6	12		72	8														282	2.0	
Intern/res Non-Med	10		3																	4																		54	.4	
Fellow Clinic	1	3		6	1				1			1		2	18					4		5	19															115	.8	
Research Durr Day	24			2				20	278			4								28																		45	.3	
Prof Practitioner	485			48				813	28	7	2	163			11				28	78				6	7														1,113	8.2
Other	14	20																						1	23		1	15											1,003	7.3
Total	734	40	173	356	38	68	438	3862	1286	75	91	454	19	34	294	238	7	10	855	518	265	63	478	172	1062	205	125	146	85	242	374	414	29	300	158	96	13,814	100		

Table 9 shows the number of students who are majors in the LIAF program categorized by academic level for 18 UAF's for FY '79.

Eighteen UAF's report that 350 students were majors in UAF programs in FY '79. Fifty percent of these students were graduate students working toward the Master degree. Eleven percent were non-medical Doctoral candidates, and 9% were medical or dental Fellows. Six percent of the students were at the Post-Master level, 5% were Fellows in clinics, and 4% were graduates at the undergraduate level. There were students at the Associate and undergraduate degree level also involved in the program. Seven students, 2%, were non-medical interns, and five students were graduate medical students.

TABLE V-9. NUMBER OF STUDENT MAJORS CATEGORIZED BY ACADEMIC LEVEL FOR 18 UAF'S FOR FY '79

	AL	CA	CO	DC	FL	ID	IN	KS	MA	MD	NC	NY	NY	OH	OR	TN	WA	WI	TOTAL	
	1	1	1	1	1	1	2	1	1	1	1	1	3	1	2	1	1	1	No.	%
AA Degree	3																		3	1
AB Degree	1									5									6	2
Post AB Degree	4		3	3						1						1	3		15	4
MA Degree	26	6	1	10	21	7	3	21	7	22	3	21		8	4		12	3	175	50
Post MA Degree	7		4	1	1				1	5					2	3			24	6
Doctor Med/Dental			2		1					5						1			9	3
Doctor Non-Medical	3			5	9			1	1			14		9					42	11
Intern Med/Dental	3																		3	1
Resident Med/Dent														2					2	1
Fellow Med/Dental				1			2	1	3	6	2	4	5	2	1		5		32	9
Intern Non-Medical								3				1			2	1			7	2
Fellow Clinic			2	1					2	8	2				2				17	5
Research Post Doc								1		1									2	1
Research Curr Dev																				
Prof Practitioner																				
Other																	13		13	4
Total	47	6	12	21	32	7	5	27	14	53	8	39	5	21	12	5	33	3	350	100

Table 10 shows the number and percent of UAF students categorized by professional discipline for 38 UAF's for FY '79. The UAF's provide training to students from a wide variety of disciplines.

TABLE V-10. NUMBER AND PERCENT OF UAF STUDENTS CATEGORIZED BY PROFESSIONAL DISCIPLINE FOR 38 UAF'S FOR FY '79

Discipline	Number of students	% of students
Education	2,801	19.3
Nursing	2,129	14.6
Dental	1,566	10.8
Therapies (OT/PT etc.)	1,360	9.3
Speech	1,179	8.1
Medicine	1,109	7.6
Psychology	886	6.2
Genetics	707	4.9
Nutrition	559	3.8
Social Work	491	3.4
Rehabilitation	253	1.7
Parents of DD	220	1.5
Human Development	197	1.3
Law	156	1.1
Pharmacology	133	.9
Public Health	132	.9
Other	671	4.6
Total	14,549	100

The largest percentage of students is from education. The next largest number of students is from nursing. The third largest number of students is dental students. The fourth largest group is from therapies. The first four groups of students make up 54% of the students.

There were over 8% of the students studying speech skills. Students from medical disciplines accounted for more than 7% of the students. Psychology students accounted for over 6% of the students.

There were 4.9% of the students in genetics. The students in home economics and nutrition made up 3.8% of the students. The students from social work made up 3.4% of the students.

Those students from rehabilitation made up 1.7% of all students. The parents of developmentally disabled made up 1.5% of the student body. Human development, law, pharmacology, and public health students were all represented in UAF programs in FY '79.

Table 11 shows the number of major students categorized by discipline for 20 UAF's for FY '79. It is interesting to note that the first four disciplines account for almost 70% of the students but are not the first four disciplines represented by all UAF students.

TABLE V-11. NUMBER AND PERCENT OF MAJOR STUDENTS CATEGORIZED BY PROFESSIONAL DISCIPLINE FOR 20 UAF'S FOR FY '79

Discipline	Number of students	% of students
Psychology	81	20.7
Social Work	76	19.4
Speech	67	17.1
Medicine	46	11.8
Nutrition	42	10.7
Therapies	24	6.1
Dentistry	23	5.9
Nursing	16	4.1
Genetics	7	1.8
Parents of DD	5	1.3
Education	1	.3
Other	3	.8
Total	391	100

Over 20% of the students majoring in UAF programs are in psychology. Almost 20% are social work majors. Over 17% are majors in speech, and 11.8% are medical students.

Just over 10% of the major students are nutrition majors. Six percent are majoring in therapy and just under 6% are dentistry

majors. Four percent of the major students are from nursing. Genetic students represent 1.8% of the major students. Parents of developmentally disabled represent 1.3% of the students, and there is one education student.

Table 12 shows the number of university students involved in non-academic programs for 25 UAF's in FY '79. The UAF programs provide a variety of conferences, seminars, and other non-credit activities in which university students participate. Twenty-five of the UAF programs reported a total of 32,495 university students involved in activities during FY '79.

TABLE V-12. NUMBER OF UNIVERSITY STUDENTS INVOLVED IN 25 UAF PROGRAMS DURING FY '79

	AL	CA	DC	IA	IN	IN	KS	KY	MA	MD	MO	MN	NC	NE
	1	1	1	1	1	2	1	1	1	1	3	1	1	1
Number of students	7515	901	572	660	113	664	565	5	230	955	11	14	1928	949

TABLE V-12. NUMBER OF UNIVERSITY STUDENTS INVOLVED IN 25 UAF PROGRAMS DURING FY '79 (Con't)

	NY	OH	OH	OH	PA	RI	SC	TN	UT	WI	WV	Total
	1	1	3	3	1	1	1	1	1	1	1	
Number of students	122	2250	1775	547	116	329	687	5837	2361	2680	709	32,495

Table 13 shows the number of individuals from the general population who participated in special training programs in 28 UAF's for FY '79. The UAF's provide professionals with special seminars, para-professionals with technical training, and parents of handicapped children with specialized knowledge concerning their children.

There were almost 100,000 individuals involved in special training programs during FY '79 in 28 UAF's. There were almost 55,000 professionals involved in these programs and just over 17,000 para-professionals trained during this period. Over 6,000 parents of developmentally disabled children were trained in FY '79.

TABLE V-13. NUMBER OF NON-UNIVERSITY INDIVIDUALS PARTICIPATING IN SPECIAL TRAINING PROGRAMS IN 28 UAF'S FOR FY '79 BY CLASSIFICATION OF PARTICIPANT

	AL 1	CA 1	DC 1	FL 1	GA 1	IA 1	IN 1	IN 2	KY 1	MA 1	MD 1	MN 1	MO 3	MS 1	NC 1
Professional	3762	3179	2926	1905	81	707	2221	769	210	120	4500	115	63	2019	807
Paraprofessional	231	720	598	1106	1066	6162	0	0	0	12	820	35	239	2817	62
Parents	746	489	275	694	0	194	0	150	0	150	300	50	10	19	390
Unclassified	1029	1140	577	1142	13	2127	186	59	90	0	0	0	15	3	0
Total	5768	5528	4376	4847	1160	9190	2407	978	300	282	5620	200	327	4858	1259

TABLE V-13. NUMBER OF NON-UNIVERSITY INDIVIDUALS PARTICIPATING IN SPECIAL TRAINING PROGRAMS IN 28 UAF'S FOR FY '79 BY CLASSIFICATION OF PARTICIPANT (Continued)

	NE 1	NY 1	NY 3	OH 1	OH 3	OH 3	PA 1	RI 1	SC 1	TN 1	UT 1	WI 1	WV 1	Total	%
Professional	1868	925	30	7651	9656	115	601	256	1954	4703	0	2543	1011	54,697	55.3
Paraprofessional	0	500	15	418	863	0	432	30	408	311	0	156	70	17,071	17.3
Parents	42	350	0	471	1173	65	50	35	169	497	0	15	30	6,364	6.4
Unclassified	22	500	0	4243	3599	251	1434	487	297	449	2119	965	32	20,779	21.0
Total	1932	2275	45	12783	15291	431	2517	808	2828	5960	2119	3679	1143	98,911	100

RESEARCH

The UAF's are active in basic and applied research for the benefit of the developmentally disabled in the United States. The UAF's have conducted research in a variety of areas.

Table 14 contains a summary of the magnitude of resources for research used by the UAF's during FY '78 and FY '79.

Almost 40% of the research dollar for UAF's came from the Developmental Disabilities Special Projects. This source of funding, under Section 145 of PL 95-602, resulted in projects of 93.4 million over a two year period. However, it must be pointed out that the monies available for Special Projects has been greatly reduced and the DD Program is at present deprived of this necessary applied research component. Policy makers should strive to increase appropriations for Special Projects and reinstate this important program activity.

TABLE V-14. RESEARCH PROJECTS BY FUNDING SOURCES CONDUCTED BY THE UAF'S

Federal code	Funding source	Number of Projects	Amount	
			\$	%
13.231	MCH - Research	6	1,035,977	12.1
13.443	Hand. Res. & Dem.	13	1,206,698	14.1
13.627	Rehab. Res. & Dem.	3	2,045,668	23.8
13.631	DD - Sp. Projects	38	3,407,100	39.7
13.859	Pharmacology & Tox.	1	328,646	3.8
13.851	Comm. Disorders	2	194,592	2.3
13.852	Neurological Disorders	6	366,693	4.2
Total		69	8,585,374	100

Nearly 24% of the research dollars for UAF's came from the Rehabilitation Research and Demonstration monies. These monies are designed to conduct applied research in the area of rehabilitation services. The UAF's received just over \$2 million from this source in FY '78 and FY '79.

Handicapped Research and Demonstration Projects accounted for 14%, or \$1.2 million, for UAF research programs. Maternal and Child Health Research Programs accounted for just over \$1 million in research funds, or 12% of the research programs.

Research funds to conduct research in neurological disorders were awarded to one UAF. Research under pharmacology and toxicology account for one research program, and community disorders provided funds for two research projects.

Table 15 contains categories of research projects funded under 13.b31 DD Special Projects conducted by UAF's.

Just over 22% of the research projects were projects for special groups. There were eight projects in this category including projects for the aged and service programs.

TABLE V-15. RESEARCH PROJECTS FUNDED UNDER 13.631 DD SPECIAL PROJECTS CONDUCTED BY UAF'S BY CATEGORY OF PROJECTS

Category	No. of projects	Amount	%
Programs for Special Groups	(8)	\$ 756,697	22.2
Technical Assistance	(7)	479,085	14.1
Training	(5)	406,229	11.9
Advocacy	(3)	400,340	11.8
UAF Activities	(4)	307,616	9.0
Child Development	(2)	302,818	8.9
Non-Vocational Social Development	(3)	277,371	8.1
Alternative Living Arrangements	(2)	251,544	7.4
Public Awareness	(2)	106,161	3.1
Employment/Vocational Development	(1)	80,739	2.4
Standards/Needs Assessment	(1)	38,500	1.1
Total	(38)	\$3,407,100	100

The UAF's were granted seven projects to provide technical assistance to various components within the DD community. The UAF's conducted five training programs under grants from the

Special Projects. These programs accounted for almost 12% of funds received by the UAF's from DD Special Projects.

The UAF's received three projects to do applied research and training in the area of advocacy. Nine percent of the monies provided from DD Special Projects were used for UAF activities including establishing satellite centers and the coordination of UAF activities.

Research programs were conducted in three of the four priority areas listed in PL 95-602. Seven research projects in child development, non-vocational social development, and alternative living arrangements were conducted.

Two projects were conducted in public awareness, one project in employment/vocational development, and one in needs assessment.

Table 16 shows the projects funded under 13.443, Handicapped Research and Demonstration, conducted by UAF's. Most of the projects are in the area of sensory system research for infants and small children.

TABLE V-16. RESEARCH PROJECTS FUNDED UNDER 13.443 HANDICAPPED RESEARCH AND DEMONSTRATION CONDUCTED BY UAF'S

Project	Grant Period	Amount
Sensory Motor	7/78 - 6/79	\$ 75,040
Early Intervention	-	163,675
Project Pride	7/77 - 6/78	107,900
Assess Visual Acty.	7/77 - 5/78	111,031
-	-	175,000
Children School	10/77 - 9/78	88,945
Child Motor Ctr.	-	80,163
Res. Training Ctr.	-	100,000
Firs - Learning Sys.	7/78 - 6/79	101,916
Comparison	7/78 - 6/79	9,854
-	7/78 - 9/79	8,250
Downs Syndrome	-	103,480
Firs - Evaluation	10/77 - 9/78	81,444
Total		\$1,206,698

Table 17 shows the research projects funded under 13.231 Maternal and Child Health. These six programs funded research in different areas. One project was in employment and one for model programs. Early intervention was the topic of one grant.

TABLE V-17. RESEARCH PROJECTS FUNDED UNDER 13.231 MCH - RESEARCH CONDUCTED BY UAF'S

Project	Grant Period	Amount
Research - Effects of Employment	1/79 - 12/79	\$ 181,126
Material for Mentally Retarded	9/79 - 6/80	54,985
Model Program	7/78 - 6/79	224,973
Physical Habilitation	1/79 - 12/79	91,655
Early Intervention	7/77 - 6/78	357,657
Research	-	125,581
Total		\$1,035,977

Table 18 shows the research projects funded for the UAF at Maryland to conduct research in a variety of neurological disorders. The funding source for these projects was the community disorders program, neurological disorders program, and the pharmacology and toxicology program.

TABLE V-18. RESEARCH PROJECTS FUNDED UNDER 13.851 COMMUNITY DISORDERS, 13.852 NEUROLOGICAL DISORDERS, AND 13.859 PHARMACOLOGY AND TOXICOLOGY CONDUCTED BY UAF'S

Project	Grant Period	Amount
13.851 Comm. Disorder Language	1/79 - 12/79	\$ 32,716
13.851 Comm. Disorder Child Sensory	1/79 - 9/79	161,876
13.852 Neurol.Dis.Research Model Pro.	9/79 - 8/79	79,024
13.852 Neurol.Dis.Basic Research	-	62,774
13.852 Neurol.Dis.Biological Aspects	9/78 - 8/79	37,902
13.852 Neurol.Dis.Genetics	3/79 - 2/80	39,186
13.852 Neurol.Dis.Def. Brain Lip.	4/79 - 3/80	81,949
13.852 Neurol.Dis.Mobility	9/78 - 8/79	65,858
13.859 Pharmac.& Tox.MR Genetic & Tox.	1/79 - 12/79	328,646
Total		\$889,931

FISCAL RESOURCES

The annual income of the UAF's is in excess of one hundred million dollars. There are four sources of funds for the UAF's. The four sources of funds are:

1. General university funds;
2. Grants from national, state and local sources;
3. Fees for service; and
4. In-kind contributions which match grant funds.

Table 19 shows the source of funds for 42 UAF's for a one year period. Over 60% of the funds are derived from grants. Maternal and Child Health provides basic administration grants for UAF's, as does the DD Program. Most of the grants are provided for specific activities. These activities consist of direct client services, training, and technical assistance and research. The grants to 42 UAF's over a period of one year amounted to \$65.2 million.

TABLE V-19. SOURCES OF FUNDS FOR UAF'S FROM GENERAL FUNDS, GRANTS, FEES FOR SERVICE, AND IN-KIND CONTRIBUTIONS FOR A ONE YEAR PERIOD

Source of funds	Number of UAF's	Amount	Percent
General Funds	32	\$22,941,916	21.7
Grants	42	65,278,633	61.9
Fees for Service	19	13,855,450	13.1
In-Kind Contribution	17	3,409,713	3.3
Total	42	\$105,485,712	100

Universities, through general fees, provide 21.7% of the support of the UAF's. There are 32 UAF's which receive support from university general fees. This source of support produces just under \$23 million for UAF's.

There are 19 UAF's which receive fees for direct client services. One UAF operates an institution and one UAF provides

all rehabilitation services for the State. Several UAF's provide statewide direct client services. The fees for service account for 13% of the funds received by the UAF's. Fees account for just over \$13.8 million.

In-kind contributions account for 3.3% of the income of UAF's in 17 universities, which amounts to \$3.4 million.

Table 20 shows the distribution of grants received by 42 of the UAF's during a one year period. The national grants include the \$7.4 million received for basic support of the UAF's from the DD Program and it also includes \$3.4 in DD Special Project Grants reviewed in the research section of this report.

Just over 63% of the 65 million dollars' worth of grants are national grants from the Federal Government. The national grants amount to \$41.2 million in fiscal resources.

**TABLE V-20. AMOUNT AND PERCENT OF GRANTS FOR 42 UAF'S
CATEGORIZED BY NATIONAL, STATE, AND LOCAL SOURCES**

Source of grants	Amount	Percent
National	\$41,229,355	63.2
State	18,570,292	28.4
Local	5,478,986	8.4
Total	\$65,278,633	100

State DD Councils, State governments, and State service providers use the resources of UAF's to provide direct client services, technical assistance, and training and research. State grants accounted for 28.4% of the funds received in grants by the 42 UAF's for a total of almost \$18.6 million. This amount includes \$760,000 received from State DD Councils for training and research activities.

Local agencies, service providers, and organizations use the resources of UAF's for activities similar to those provided to State organizations. Grants from local organizations and agencies accounted for 8.4% of the grant monies received by UAF's. The local grants amounted to almost \$5.5 million.

There are 19 UAF's which receive fees for direct client services for an annual income of almost \$13.9 million. Table 21 shows the source of the fees for service paid to the UAF's.

*

TABLE V-21. AMOUNT AND PERCENT OF SOURCE OF FEES FOR SERVICE FOR 19 UAF'S FROM PARENT/GUARDIANS, COURSE, INSURANCE, AND FEDERAL/STATE REIMBURSEMENT

Source of fees	Number of programs	Amount	Percent
Parent/Guardian	13	\$ 1,407,203	10.1
Course Fees	3	28,385	.2
Insurance	12	748,680	5.3
Federal/State Reimb.	10	11,541,671	83.4
Other	6	129,515	1.0
Total	19	\$13,855,454	100

The majority of fees for service are obtained from Federal or State reimbursements for direct client services. UAF's receive \$11.5 million for reimbursement for services from Federal/State sources, which represents 83.5% of the fees received.

Ten percent of the fees for service are received from parents or guardians. The fees from parents or guardians amount to \$1.4 million. Just over 5% of the fees for service are reimbursed by insurance. Insurance reimburses UAF's about three-quarters of a million dollars. Course fees and other sources amount to the additional \$150,000 received for services provided.

APPENDIX

STATE ADMINISTERING AGENCIES

**DEVELOPMENTAL DISABILITIES
STATE PLANNING COUNCILS**

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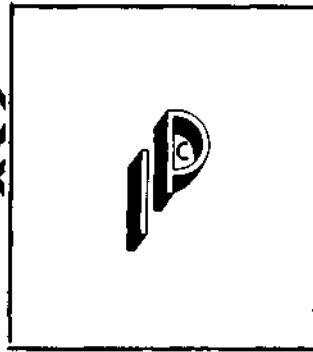
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