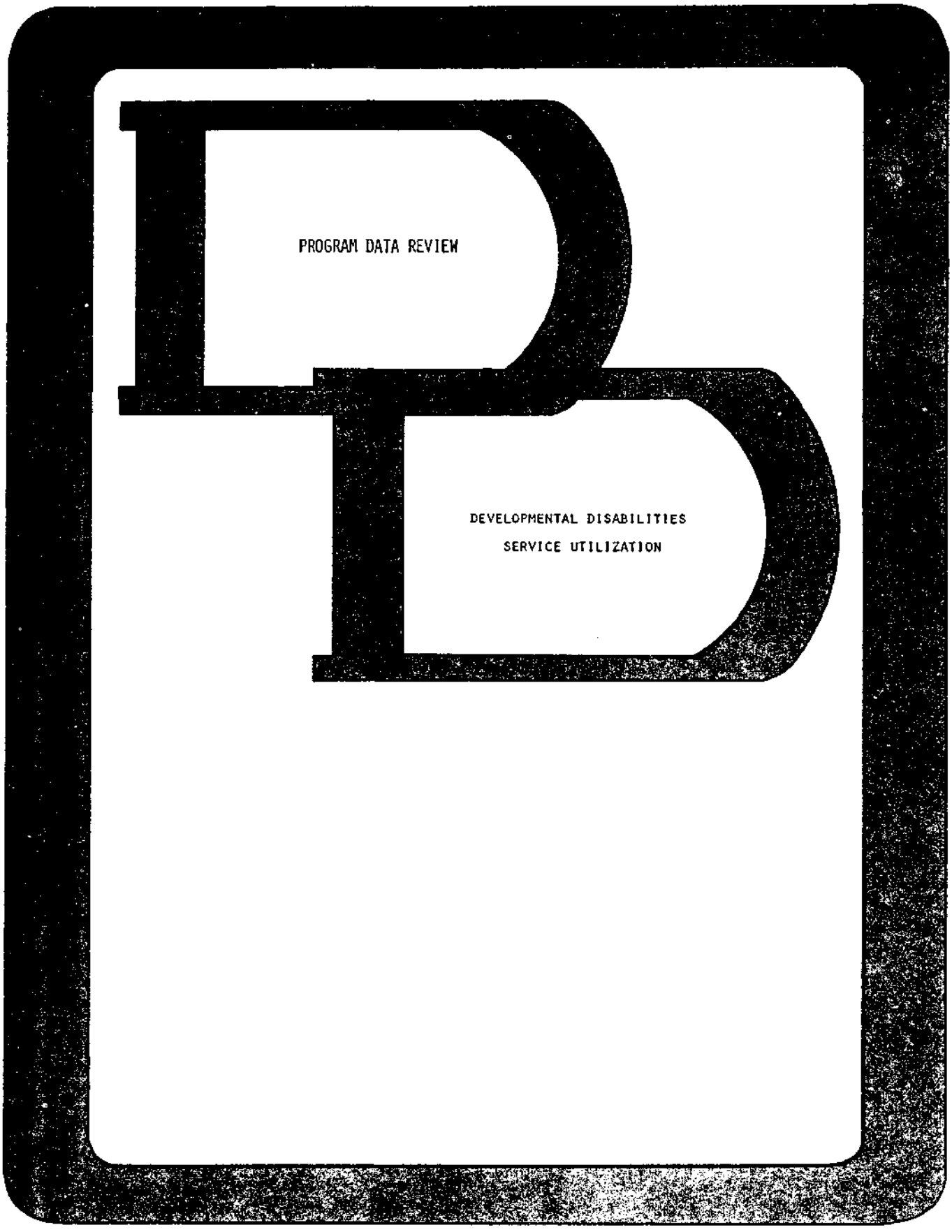
PROGRAM DATA REVIEW
DEVELOPMENTAL DISABILITIES
SERVICE UTILIZATION

Prepared by:

EMS Institute
24 Maplewood Mall
Philadelphia, PA 19144

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Comments should be addressed to:

Dr. Janes Jacks
Bureau of Developmental Disabilities
Office of Human Development Services
Rehabilitation Services Administration
U.S. Department of Health,
Education & Welfare

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PREFACE

This paper is one in a series prepared under HEW, Rehabilitation Services Administration, Office of Human Development Services, Grants of National Significance #54-P-71220/2-01 (FY 1978) and #54-P-71220/2-02 (FT 1979) on pertinent issues in planning, advocacy, administration, monitoring and evaluation in the Developmental Disabilities Formula Grant Program.

During Fiscal Year 1978, the following topics were addressed through developmental disabilities state plan analysis:

- Prevalence of the Developmental Disabilities
- Rates of Prevalence of the Developmental Disabilities
- Characteristics of the Developmentally Disabled
- Developmentally Disabled Population Service Needs
- Approaches to Developmental Disabilities Service Needs Assessment
- Characteristics of Developmental Disabilities State Planning Councils
- Designs for Implementation

During Fiscal Year 1979, analysis of most identified issues will be based on state plan analysis augmented by the contributions of state program and council, special project and UAF personnel to provide clarification and examples of unique approaches to Developmental Disabilities Program activities. These issues and data reviews are designed to be responsive to the new mandates of Title V of PL 95-602 (Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978):

- Gaps and Barriers in the Developmental Disabilities Service Network
- Goals and Objectives of the Developmental Disabilities Program
- Developmental Disabilities Service Utilization
- The Relationship of Developmental Disabilities Program Activities to Gaps and Barriers
- Monitoring and Evaluation in the Developmental Disabilities Program
- Coordination and Case Management in the Developmental Disabilities Program
- Child Development Activities
- Social-Developmental Services
- Community Alternative Living Arrangements
- Potential Impact of Title V, PL 95-602, on DD Program Plan Year Activities
- Impact of the Developmental Disabilities Program
- Defining the Developmental Disabilities Population
- An Analytical Review of Title V of PL 95-602
- An Analytical Review of Changes in the Rehabilitation Act of 1973

The contributions of many persons in the field of developmental disabilities have enhanced examination of these topics. Paper development was conducted by:

Irwin Schpok, Project Director
Joan Geller, Project Manager

Mary Rita Hanley
Janet Elfring
Sarah Grannis
Ann Schoonmaker
John LaRocque

Manuscripts were typed by Karen Boucek, Betty Fenwick and Tim Schoonmaker.

INTRODUCTION;

DEVELOPMENTAL DISABILITIES SERVICE UTILIZATION

This Program Data Review, one in a series of Issue Papers prepared by EMC Institute, contains an analysis of the utilization of generic services by the developmentally disabled population. It is based upon data contained in Fiscal Year 1978 developmental disabilities state plans.

The implied philosophy of the Developmental Disabilities Program is that developmentally disabled people can receive appropriate services primarily through the existing generic service system, without the establishment of new categorical service programs. With the exception of specific, highly-tailored services which may require powerful incentives to develop in the generic service system, many of the service needs of the developmentally disabled are expected to be met by existing generic programs in education, training, treatment, diagnosis and evaluation, housing and other areas.

Knowledge of the extent to which the developmentally disabled have access to generic services was required by PL 94-103 and its regulations, to assess the quality, extent and scope of services available to the developmentally disabled within a state. PL 95-602 (Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978) continues the requirement that states assess the extent and scope of services in other agencies.

Data on generic service utilization are an essential tool for state developmental disabilities councils to use in meeting their mandates to comprehensively plan and advocate for the developmentally disabled. These data contribute to council judgments on such issues as:

- whether developmentally disabled people are in fact accessing all generic services to which they are entitled; and if not, why not?
- which agencies and programs in the state may be more responsive to the developmentally disabled and may be more sensitive to. expanding services for this group of people;
- which service needs are not being met by the generic system, i.e., what gaps exist;
- whether generic agencies are using all available program resources to meet the needs of the developmentally disabled; and,
- what additional fiscal or legislative actions should be pursued by the council and the state legislature to ensure the provision of services to all developmentally disabled people.

This paper examines the utilization of services by the developmentally disabled on a national scale.

FINDINGS:

DEVELOPMENTAL DISABILITIES SERVICE UTILIZATION

This analysis of generic service utilization by the developmentally disabled revealed the following:

- The developmentally disabled have most success in accessing services provided by institutions, special education, agencies for MR/DD and other handicaps, and Title XX and related social service programs. Developmentally disabled people are using relatively large proportions of the services provided by these agencies.

- Institutions, vocational programs and providers of special education services appear to be responding to the specialized service needs of the developmentally disabled. While these agencies are primarily direct service providers (of domiciliary care and education), a much larger proportion of the support services provided by these agencies are given to the developmentally disabled, possibly to enhance the effectiveness of the direct services provided to this group of people.

- Most of the agencies reviewed in this analysis receive federal funds under various human service programs. However, institutions, special education and agencies for MR/DD and other handicaps rely primarily on non-federal monies to provide services to the developmentally disabled and others.

These findings merely identify service utilization patterns. It is not practical to compare utilization rates to service utiliation gaps at this time because few states conducted a detailed identification in Fiscal Year 1978 state plans.* However, some comparison can be made of the extent of utilization found by this analysis to the lack of needed services reported by the states.

On the surface, the data contained in this paper appear to contradict state assertions that large gaps exist in community alternative services, since developmentally disabled people obviously have access to a sizable share of most services in the programs reviewed for this analysis. Yet such gaps obviously exist; the lack of a comprehensive system of community-based services has thwarted efforts to return the disabled to the community in many states.

* EMC Institute, Program Issue Review, "Gaps and Barriers in the Developmental Dissbilities Program," 1979.

Probable reasons for the continued existence of large gaps in community alternatives are:

1) The national thrust for deinstitutionalization has probably placed demands on the community service system that cannot be handled by existing services;

2) Many people who could return to the community may need specialized services that generic service agencies are not currently providing;

3) Specialized programming for the developmentally disabled often requires on-going case management to ensure the continuity of appropriate service provision. Case management services, including follow-along services which are appropriate to the needs of these clients, are reported as weak or absent in many states. This was one of the major problems in deinstitutionalization found by a recent report of the United States General Accounting Office.*

Therefore, even though the utilization data show that the developmentally disabled are accessing a healthy proportion of generic services, the specialized needs of this population cannot always be met with existing resources.

* United States General Accounting Office, Returning the Mentally Disabled to the Community: Government Needs to Do More, January, 1977.

DATA AND ANALYSIS:

DEVELOPMENTAL DISABILITIES SERVICE UTILIZATION

This analysis examined data reported by one hundred and sixty-four (164) programs in thirty-four (34) Fiscal Year 1978 developmental disabilities state plans. The following variables were examined to determine the degree to which the developmentally disabled are utilizing existing services:

- service capacity of the program providing developmental disabilities related services;
- utilization of these services by developmentally disabled people;
- expenditures for these services by fund source (federal, state and other).

Service programs were collapsed into the following categories according to the focus of the services they provide, with their services characterized on Table 1:

Institutions - includes programs/agencies which are primarily responsible for institutional care within a state.

Education - includes only state education programs responsible for implementing PL 94-142 (Education for all Handicapped Act).

Vocational - includes Vocational Rehabilitation, Vocational Education and Employment programs.

Health - includes Crippled Children's Services, Maternal and Child Health, Medical Assistance, general health and community mental health programs.

MR/DP & Other Handicaps - includes mental retardation, developmental disabilities and other programs/agencies primarily responsible for community-based services for the handicapped.*

Title XX & Related - includes Title XX, income maintenance programs and other public and private social service programs.

* Some DDSA service projects are probably included in this data, in the 7 states which reported utilization data in Section III under a DD administering agency. However, without a detailed comparison of these data with the designs for implementation in the same plan, it is not possible to pinpoint DDSA service data.

TABLE 1

SERVICES AVAILABLE TO THE DEVELOPMENTALLY DISABLED BY PROGRAM CATEGORY

PROGRAM CATEGORY	DIRECT										SUPPORT											
	RESIDENTIAL		DAY PROGRAMS						EMPLOYMENT		IDENTIFICATION			CASE MANAGEMENT			TREATMENT			FAMILY/PROGRAM SUPPORT		
	DOMICILARY CARE	SPECIAL LIVING ARRANGEMENTS	PRE-SCHOOL		SCHOOL AGE		ADULT		SHELTERED EMPLOYMENT	OTHER EMPLOYMENT	DIAGNOSIS	EVALUATION	INFORMATION & REFERRAL	COUNSELING	PROTECTIVE AND OTHER SOCIAL AND SOCIO-LEGAL	FOLLOW-ALONG	MEDICAL	DENTAL	OTHER SPECIAL	RECREATION	PERSONAL CARE	TRANSPORTATION
			DAY CARE	EDUCATION/TRAINING	DAY CARE	EDUCATION	TRAINING	DAY CARE	EDUCATION/TRAINING													
MR/DD & Other Handicaps	□	○	○	○	○	□	○	○	○	□	○	○	○	○	○	○	○	○	○	○	○	○
Institutions	□	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Title XX & Related Social Services	□	□	○	○	○	○	▯	○	○	○	○	○	□	□	□	○	○	○	○	○	□	○
Education		▯		○		□	○		○		○	○	○	○		○	○		○	○	○	○
Vocational		▯				○	○		□	□	□	□	○	□		○	○	▯	▯	▯	▯	
Health	▯	▯	▯	▯	▯	▯	▯	▯	▯	▯	□	□	○	○	○	○	□	□	□	○	○	○

□ = primary services of this type of program
○ = other services provided by this type of program
▯ = minor services (small capacity) provided by this type of program

Service Capacity & Utilization

Developmentally disabled people appear to have had most success in accessing services provided by institutions, programs for the handicapped, special education and Title XX and related social service programs. This information is summarized in Table 2 and displayed in detail in Table 3.

TABLE 2

SUMMARY OF DD UTILIZATION OF SERVICES BY
AGENCY/PROGRAM CATEGORY, FROM FY 1978 DD STATE PLANS

	Percentage of DD Utilization of Existing Services	
Agency/Program Category	Direct Services	Support Services
MR/DD & Other Handicaps	94%	94%
Institutions	66%	86%
Title XX & Related	20%	9%
Special Education	18%	37%
Vocational	6%	27%
Health	5%	7%

Note the low utilization rate for direct vocational services. Utilization for the twelve Vocational Rehabilitation programs included in this sample averaged about fifteen (15) percent; utilization rates for the six Vocational Education programs and two large regular employment programs tended to one (1) percent or less, and therefore lowered the rate for this program category.

While the percentages for Special Education and Title XX and Related programs are much lower than for programs for MR/DD and other handicaps and for institutions, the former have a much larger, more diversified clientele than programs relating to mental retardation and developmental disabilities. In fact, these "low" percentages represent a relatively large number of developmentally disabled people, as shown by Table 3. The same is true for support services provided by Health programs.

TABLE 3

CAPACITY & DD UTILIZATION OF SERVICES
BY PROGRAM CATEGORY, FROM 34 FY 1978 DD STATE PLANS
(Number of programs reporting is in parentheses)

		MR/DD & OTHER HANDICAPS	INSTITUTIONS	TITLE XX & RELATED	SPECIAL EDUCATION	VOCATIONAL	HEALTH
DIRECT SERVICES	Capacity	95,089 (18)	194,199 (24)	197,430 (18)	2,533,590 (21)	1,445,468 (20)	189,695 (6)
	DD Utilization	89,213	127,533	38,821	455,750	79,258	8,569
	% DD Utiliation	93.8%	65.7%	19.7%	18.0%	5.5%	4.5%
SUPPORT SERVICES	Capacity	195,582 (14)	159,422 (12)	1,760,975 (15)	736,572 (7)	239,447 (9)	30,696,425 (32)
	DD Utilization	182,876	136,668	164,645	275,354	63,598	2,190,184
	% DD Utilization	93.5%	85.7%	9.3%	37.4%	26.6%	7.1%
ALL SERVICES	Capacity	335,571 (22)	368,973 (24)	2,007,684 (28)	3,512,027 (26)	2,621,675 (28)	31,593,281 (36)
	DD Utilization	310,478	264,201	212,992	803,741	174,667	2,603,329
	% DD Utilization	92.5%	71.6%	10.6%	22.9%	6.7%	8.2%

It should also be noted that institutions, special education and vocational agencies, which are primarily direct service providers (of domiciliary care, education and training, respectively), provide a much higher proportion of support services than direct services to the developmentally disabled. This suggests that these types of providers are responding to the specialized needs of developmentally disabled people with more than the usual amount of support services to enhance the effectiveness of the primary domiciliary, educational and vocational services.

Table 4 shows utilization rates by service type aggregated acrosss all programs reviewed in this analysis.

TABLE 4

CAPACITY & DD UTILIZATION OF SERVICES BY SERVICE TYPE
FROM 34 FY 1978 DD STATE PLANS
(Number of programs reporting is in parentheses)

		RESIDENTIAL SERVICES		PRE-SCHOOL		SCHOOL AGE			ADULT		EMPLOYMENT	
		Domiciliary Care	Special Living Arrangements	Day Care	Education/ Training	Day Care	Education	Training	Day Care	Education/ Training	Sheltered	Other
DIRECT SERVICES	Capacity	100,854(19)	66,663(25)	18,752(16)	28,660(23)	56,648(13)	2,616,368(39)	31,647(19)	8,098(13)	324,270(24)	204,517(19)	167,361(21)
	DD Utilization	29,094	11,618	6,386	8,600	4,816	463,326	29,422	5,418	43,756	59,197	6,197
	DD Utilization Rate	28.8%	17.4%	34.1%	30.0%	8.5%	17.7%	93.0%	66.9%	13.5%	28.9%	3.7%

		IDENTIFICATION		CASE MANAGEMENT			TREATMENT			FAMILY/PROGRAM SUPPORT		
		Diagnosis & Evaluation	Information & Referral	Counseling	Protective	Follow-Along	Medical	Dental	Other	Recreation	Personal Care	Transportation
DIRECT SERVICES	Capacity	1,891,793(43)	495,338(26)	914,778(26)	59,314(14)	320,845(18)	119,161,752(29)	524,496(15)	497,034(26)	96,109(24)	388,435(22)	583,510(29)
	DD Utilization	302,927	94,387	230,018	6,319	51,341	1,772,363	76,102	141,799	77,852	47,738	179,637
	DD Utilization Rate	16.0%	19.1%	25.1%	10.7%	16.0%	1.5%	14.5%	28.5%	81.0%	12.3%	30.8%

Sources of Funds for Services

Non-federal resources are being heavily accessed to provide services to the developmentally disabled and others. These data are summarized below in Table 5, and displayed in detail in Table 6.

Although existing backup data for Table 6 would allow us to calculate a mean service cost for these programs and their services, such calculations were not done because they may be misleading. Services for more severely handicapped developmentally disabled people may tend to cost much more in professional time, dollars and other resources than services for other clients, and developmental disabilities state plans do not identify actual developmental disabilities service costs to agencies.

TABLE 5

PERCENT OF NON-FEDERAL DOLLARS USED TO PROVIDE SERVICES, BY PROGRAM CATEGORY, FROM FY 1978 DD STATE PLANS

	Non-Federal Funds as a Percentage of Total Service Expenditures	
Agency/Program	Direct Services	Support Services
MH/MR Institutions	91%	78%
Special Education	81%	97%
MR/DD & related	46%	82%
Vocational	57%	24%
Health	30%	51%
Title XX & related	33%	25%

TABLE 6

EXPENDITURES FOR SERVICES BY PROGRAM CATEGORY
AND SOURCE OF FUNDS, FROM 34 FY 1978 DD STATE PLANS*
(Number of programs reporting is in parentheses)

		MR/DD & OTHER HANDICAPS	INSTITUTIONS	TITLE XX & RELATED	SPECIAL EDUCATION	VOCATIONAL	HEALTH
DIRECT SERVICES	Federal	39,326 (9)	66,782 (12)	44,409 (6)	166,890 (13)	84,468 (13)	1,084 (1)
	State	24,860	586,348	19,899	466,514	105,911	465
	Other	8,312	55,696	1,697	247,854	3,404	-
	Total	72,498	708,826	66,005	881,258	193,783	1,544
	% Non-Federal Funds	45.8%	90.6%	32.7%	81.1%	56.5%	30.1%
SUPPORT SERVICES	Federal	1,113 (4)	4,249 (4)	44,653 (9)	932 (3)	2,696 (3)	202,379 (19)
	State	3,404	12,465	12,468	12,045	748	196,916
	Other	1,597	1,653	2,107	17,987	100	14,787
	Total	6,114	18,367	59,228	30,964	3,544	414,082
	% Non-Federal Funds	81.8%	76.9%	24.6%	97.0%	23.9%	51.1%
ALL SERVICES	Federal	70,664 (14)	78,392 (12)	147,632 (16)	199,543 (14)	814,415 (22)	220,270 (11)
	State	44,880	790,205	41,673	696,004	135,476	200,416
	Other	66,454	58,609	17,185	347,340	5,424	17,644
	Total	181,998	927,206	206,490	1,242,887	955,315	438,330
	% Non-Federal Funds	61.2%	91.5%	28.5%	83.9%	14.8%	49.7%

* Expenditures are given in thousands of dollars

METHODOLOGY AND LIMITATIONS

Methodology

This paper had the following objectives:

1. To identify the agencies in which the developmentally disabled have had most success in utilizing services.

2. To identify the types of services most heavily utilized by the developmentally disabled.

3. To determine the fund sources for services utilized by the developmentally disabled.

To achieve these objectives, the following information was obtained from thirty-four (34) Fiscal Year 1978 developmental disabilities state plans, by agency or program:

- capacity of each type of service being utilized by the developmentally disabled;

- utilization of that service by the developmentally disabled;

© amount of funds used by type of service and fund source (federal, state, other).

These data were aggregated by program category to yield a nationwide perspective; service utilization data were also aggregated by type of service.

Limitations of the Data and Analysis

While usable information was collected for one hundred and sixty-four (164) programs, this represents only a small proportion of the developmental disabilities-relevant programs nationwide. For example, the eight Federal programs, specified as primary developmental disabilities service providers by PL 94-103, represent four hundred and thirty-two (432) programs across fifty-four states and territories. Other relevant programs, such as private providers and youth and aged service programs also have the potential to report this information.

Federal reporting requirements for most of the relevant programs do not mandate service reporting by categories that facilitate identification of the developmentally disabled; some state management information systems do not promote the accessibility of this information; and Fiscal Year 1978 was the first plan year in which most states followed the Federal Comprehensive DD State Plan Guidelines. Therefore only a small proportion of the potential program data was available in these state plans.

The number of reporting programs varies among the tables so that comparisons among Tables 3, 4 and 6 should be made with caution. Not all thirty-four states reported program data for both services and service expenditures. Also, some programs only gave total program data, not data by type of service. This frustrated an original intention of this paper to examine the relationship between funding patterns and program utilization rates: the utilization rates for the few agencies which reported all the data tend to be much different from those which reported only capacity and utilization; the states which reported all data are apparently too few to be representative of the nation as a whole and do not provide a large enough sample to make comparisons among funding patterns.

The program data were collapsed into program categories because of the lack of numbers of reporting programs. Both this categorization and the original reporting format of these programs have obscured some of the characteristics of the individual programs. Some programs provide both institutional and community services for the disabled. In some state plans, institutional and community services were reported separately, and it was possible to split the program data between two program categories. However, other programs combined community and institutional data; with the exception of residential services, it was impossible to tell how many services went to institutional and how many to community based clients. In such cases, each program was assigned to the category which described the primary emphasis of its services. Thus some institutional data (domiciliary care) appears under programs for MR/DD and other handicaps rather than under institutions.