



PROGRAM ISSUE REVIEW

GAPS & BARRIERS
IN THE
DEVELOPMENTAL DISABILITIES
SERVICE NETWORK

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PREFACE

This paper is one of a series prepared under HEW, Office of Human Development, Grant of National Significance # 54-P-71220/2-01, on pertinent issues on planning, administration, monitoring and evaluation in the developmental disabilities formula grant program (DDFGP) of Public Law 94-103.

Issues to be addressed in the series are:

- 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
- Developmental Disabilities Service Utilization
- Characteristics of Developmental Disabilities State Planning Councils
- Gaps and Barriers in the Developmental Disabilities Service Network
- Goals and Objectives of the Developmental Disabilities Program
- Designs for Implementation

The analysis presented in each of the issue papers is based on information in Fiscal Year 1978 developmental disabilities state plans. As a result, what is presented in each paper is defined, to varying degrees, by the data recorded in the state plans. The nature and effect of limitations on specific analyses due to source data problems are described in each paper.

The preparation of developmental disabilities state plans for Fiscal Year 1978 was a monumental effort nation-wide as well as at all jurisdictional levels. The state plans themselves attest to the diligence and care of the investment: over 75% of the 54 state plans contain 50% or more of the information requested in the State Plan Guidelines and over 30% of the plans provide 70% or more of the information.

In the Developmental Disabilities Program the "who" is equal in importance to the achievements themselves. Many national, regional and state constituents of the program have contributed to the overall excellence of the developmental disabilities state plans by their direct support, assistance and spirited debate of planning issues. Frankly, it would be difficult to acclaim each of the over 150 persons at national, regional, and state levels who were instrumental in development of the state plans.

It should be recognized that state level planners and council members who participated in developmental disabilities state plan development have gathered a substantial information base for the Developmental Disabilities Program. In many instances situational and resource difficulties had to be overcome by the councils to produce this meaningful and important document in their states. The Developmental Disabilities Program councils and staff are the principal contributors to the content of these papers.

The staff of each regional developmental disabilities office has contributed guidance as well as many hours of assistance to both the states and EMCI technical assistance staff. Regional officers of the Developmental Disabilities Program shared in the primary development of the developmental disabilities state plans.

At the national level there has been continued direction, awareness of the importance of the comprehensive planning mandate and support for the operational effort to enhance state and regional offices' capability to implement the planning guidelines. The Developmental Disabilities Office Director, executive staff and those in the Program Operations and Research and Evaluation Divisions were key contributors to the momentum of the Fiscal Year 1978 developmental disabilities state plan development effort.

Final compilation and analysis of the information in developmental disabilities state plans is the result of effort by the EMC Institute staff. Data compilation and paper development were conducted by:

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INTRODUCTION;

GAPS & BARRIERS IN THE DEVELOPMENTAL DISABILITIES SERVICE NETWORK

This Issue Paper, one in a series prepared by EMC Institute, contains an analysis of gaps in developmental disabilities services, using information from Fiscal Year 1978 developmental disabilities state plans.

The variables examined in this paper are as follows:

- The major gaps and needs identified by the states;
- Barriers that affect the alleviation of these problem areas.

In the context of this paper, a gap is the difference between available services and the need or demand for those services. At the state and national level, identification of gaps in developmental disabilities services is a necessary precursor to councils' setting of long-range goals, plan year objectives and priorities. Knowledge about the barriers which affect these gaps is an important basis upon which councils and administering agencies can develop practical strategies for overcoming those gaps. A gap in one service can have a major impact on the rest of the service system. Transportation is a good example: when a client lacks the means to get from home to the service location, the effect is the same as if no service existed. Special living arrangements is another example: without an adequately supervised place to live, a person who could otherwise live semi-independently may be forced to remain in an institution; conversely, a group home in a community without adequate treatment and habilitation services effectively becomes a small warehouse for people. Thus the identification and understanding of gaps in services and the barriers which affect them have a primary influence on planning for the national program goal areas (deinstitutionalization and institutional reform, community alternatives, early intervention and adult programs), and on state directions in improving services for the developmentally disabled.

In addition, identification of gaps and barriers in services is imperative for state councils in fulfilling their implied mandate for advocacy. Understanding of the gaps and problems provides councils with the tools to influence service providers and state legislatures to make adequate, appropriate, and/or improved services available to all developmentally disabled people in the state.

The remainder of this Introduction provides a brief overview of the requirements of PL 94-103 pertinent to the identification of gaps and barriers.

Legislative & Planning Background

PL 91-517 as amended by PL 94-103 and its regulations required that state developmental disabilities councils identify gaps in services and assess the effectiveness and accomplishments of the service system in meeting the needs of persons with developmental disabilities.

In response to these mandates, the Developmental Disabilities State Plan Guidelines requested a display of gaps in services which included the following:

- A numerical estimate of gaps by service type
- A narrative analysis of these gaps including identification of barriers to filling gaps and potential solutions for filling the gaps
- Narrative analysis of barriers and special needs and conditions in the state which affect national priority areas (deinstitutionalization, community alternative, early intervention and adult programs), state programs on council operations.

Of course, problem identification is only the first step in the development of strategies to overcome those problems. The responsiveness of state plans to identified gaps and barriers, and the distribution of Formula Grant Program monies among these problem areas, will be discussed in "The Relationship of Developmental Disabilities Program Activities to Gaps and Barriers." *

This paper concentrates on the Fiscal Year 1978 state plan narrative analysis of priority service gaps and related problems and the relationship of these problems to the mandates of PL 95-602.

* EMC Institute, Program Issue Review, 1979

CONCLUSIONS & IMPLICATIONS:

GAPS & BARRIERS IN THE DEVELOPMENTAL DISABILITIES SERVICE NETWORK

Based on the analysis of Fiscal Year 1978 developmental disabilities state plans, lack of community services is the greatest problem in state Developmental Disabilities Programs. Major gaps in these services prevented states from achieving the national program goal areas (deinstitutionalization, community alternatives, adult programs and early intervention) of PL 94-103:

- A need to establish or improve a wide range of community programs and community-readiness institutional programs was identified by over ninety (90%) percent of the states;
- Most states agree that special living arrangements, such as group homes and foster care, are a prerequisite for the community placement of developmentally disabled people who need a semi-independent living situation. Over three-fourths of the states which identified service gaps specified high-priority gaps in residential services, and nearly two-thirds of those gaps were in special living arrangements.
- Developmental day care services for all age groups are necessary for some consumers to remain with their families or in a semi-dependent environment in the community. Pre-school developmental day care is often one of the components of follow-through in early intervention programs. Fifty-nine (59%) percent of the states which identified gaps cited major gaps in day care services.
- A large number of states also identified program needs relating to "prevention." Prevention efforts were not a mandate of the Developmental Disabilities Program under PL 94-103. Prevention services include genetic counseling, pre-natal and post-natal care and public awareness and education - community services which also impact upon the PL 94-103 priority area of early intervention.

This analysis identified six major barriers to the provision and improvement of community services within the states. In order of most frequent mention by the states, these are:

1. Lack of public awareness of existing services and lack of advocacy and education which relate to the development of new services. The public is insufficiently aware of the needs and rights of the developmentally disabled. Lack of

understanding about the handicapped has caused opposition to zoning changes to allow small group homes and other community facilities; it may also deny legislative support to appropriation of state funds for new services. Clients are inadequately informed about their rights and services, and all too frequently services agencies do not have a comprehensive knowledge of viable service alternatives for the developmentally disabled.

2. Lack of funds, inhibiting program expansion, especially in the development of new community services designed to further deinstitutionalization. While some existing services can be expanded within reason, Federal and state program fiscal constraints often prohibit the coverage of startup costs of new services. Service grants by state councils are often a major source of startup funds within the states, as a result. However, given the much-needed planning, advocacy and quality assessment mandates of councils, the concentration of Formula Grant Program funds exclusively on service startup is not the answer. Instead, councils must continue to explore other ways in which public and private sector funds can be tapped for program startup costs.
3. Coordination of services and agency planning, which was identified as a barrier by nearly two-thirds of the states. The service continuum for developmentally disabled people either does not exist or is inadequate because of unnecessary duplication of services and/or a lack of coordination among agencies. In the same vein, major gaps in case management services were cited by seventy percent (70%) of the states which identified gaps. Once again, these are barriers which affect all types of service delivery in the Developmental Disabilities Program, and may require a two-pronged Federal approach to remedy:
 - a) Place extremely strong emphasis on coordination of existing Federal service programs, at the Federal and state level;
 - b) Provide technical assistance to state councils in the development of attractive incentives for coordination by service network agencies, in order to further practical implementation of Federal policies on coordination.
4. Lack of transportation, and the existence of other problems associated with non-urban areas, which create barriers to utilization of most services. In addition, a lack of transportation isolates the handicapped from social and other community activities. Since roughly one-fourth of the population of this country is in non-metropolitan areas,* transportation may be a priority for Federal action.

*United States Bureau of the Census, Statistical Abstract of the United States: 1976, Washington, D.C.

5. Lack of adequate information for planning for and management of services, which block the delivery of quality services. While nearly half of the states which cited this need related it to Developmental Disabilities Program planning, others cited specific needs which impact on the other problem areas cited above: client tracking systems, information and referral systems and needs assessments on which to base deinstitutionalization and the development of new services.
6. Lack of adequate personnel development to ensure the high quality of existing programs. Frequently, generic service staff lack experience or training in working with the handicapped and so are not able to adequately respond to the needs of the developmentally disabled. As with other service components, a lack of funds for professional salaries may inhibit personnel upgrading. Rural areas often lack the cultural and economic attractions which are likely to draw physician specialists and other professionals.

A potential seventh major barrier concerned individual habilitation plans (IHP's). Nearly one-fifth of the states indicated needs in this area. Most of these needs were for development rather than implementation of the use of IHP's. Unfortunately, no details were given in the plans on whether this need exists only in DDSA-funded programs or in other agencies as well. While only a small percentage of all states cited this need, the emphasis on the need for IHP development within these states has two possible implications which impact on all areas of services to the developmentally disabled:

- 1) If a number of state Developmental Disabilities Programs have not yet developed workable IHP's, it may be impossible for these states to implement the proposed IHP-based evaluation system; and/or
- 2) In some states, programs such as Vocational Rehabilitation, Special Education and Title XIX may be violating their mandates for individualized program planning.

State developmental disabilities councils also expressed their own needs for training, technical assistance and education in the scope and performance of their responsibilities. While the wide range of potential council roles in advocacy implies that technical assistance will continue to be a council need, the large number of states which cited a need for orientation of new council members argues that council orientation activities need to be packaged and internalized so that councils do not need to rely heavily on outside assistance for this most basic of roles.

Relationship of Existing Gaps to the Mandates of PL 95-602

Obviously, the most serious nationwide gaps in the developmental disabilities services network - in residential services, case management, early intervention and developmental day care - can be dealt with directly under the new priority service areas mandated by PL '95-602. The choice of a priority service area, however, will be a major issue in a state which has large gaps in more than one category of services. In such a case, the state developmental disabilities council must closely examine the source and nature of all major gaps to determine which closely-allied gaps can best be addressed through seed monies and demonstration projects under one priority service area, and which are likely to yield to council efforts in agency and legislative influencing and other advocacy activities.

The new legislation does address some of the major barriers to service delivery in the states:

- The barriers caused by lack of coordination and case management have their own priority area under PL 95-602.
- Councils still have the ability to use approximately one-third of their funds for planning. Some of these funds can be channeled to alleviate states' needs for better information development; in view of the modified definition of developmental disabilities and the new focus of PL 95-602 on priority service areas and personnel skills assessment, the need for quality information is likely to be more pivotal to program success in future years than under PL 94-103.
- The council's mandate to assess the skills of service delivery personnel, the increased strength of the mandate to university affiliated facilities to provide inter-disciplinary training, and the emphasis of Special Projects on projects to attract and maintain professionals in rural areas, focus attention on the need for quality personnel development.
- By linking needed transportation to priority area services, it may be possible for the council to continue to address the wide range of needs for this service; social-developmental services, for example, appears to offer a wide potential for transportation use and coordination.

However, PL 95-602 does not directly address several major problem areas identified in this analysis: community alternative services (other than residential); lack of funds for general program startup and expansion; and lack of general public awareness of the capabilities, needs, and services for the developmentally disabled.

In Fiscal Year 1978 state plans, serious gaps in community alternative living arrangements were a major barrier to the development of a community service system, but they were not the only barrier. A place to live outside of the institution does not in itself constitute quality care. In recent years the news media in many states have publicized the deplorable living conditions and lack of community ties in unlicensed nursing and boarding homes. Given the restrictions of the priority service area, "community alternative living arrangements," there are several ways in which state councils can address the gaps in a quality manner:

1. Develop and advocate for statewide adoption of standards for group homes which require formal agreements for access to medical, social, and other services in the community, and arrangements for counseling and recreation services at the home itself.
2. Identify needs for coordination between generic community services and group home and/or family support programs; develop, enact and monitor coordination agreements among service providers on the state council and at the local level.
3. Selectively use seed monies to establish or expand community services needed to support the quality of community living arrangements.
4. If the availability of community living arrangements is not the major problem, and gaining access to other existing community services is, the council may choose the "case management services" priority instead of, or in addition to, the community living arrangements priority area. The provision and other support of such services can ensure that a client receives a continuum of services to support community living. The case management concept can also be a way for the council and other groups to document unmet community service needs at the local level - an extremely powerful source of data to use in state legislatures to advocate for increased funds for housing and other services.

The above are merely a few very general strategies for dealing with more global problems in community services. With an understanding of the state and local level mechanisms for service funding and delivery, a state council should be able to develop its own specific strategies for dealing with this problem within priority service area constraints.

The general lack of funds for service start-up or expansion in many states is also not addressed by PL 95-602 in a manner which applies to the whole developmental disabilities service network. The use of Formula Grant Program dollars as seed monies for service start-up or expansion is, of course, implied in the provision of direct services under each priority area. However, compared to the funds available to most other programs, the Developmental Disabilities Formula Grant Program has too few dollars available to make a

dent in major gaps, unless councils continue to exercise their general advocacy mandate to convince legislators, other providers, and the general public to give fiscal support to new services for the handicapped. If councils concentrate solely on the provision of direct client services, there is also the danger that the council and the program will eventually become locked in their own categorical, special services niche and lose their ability to effect system-wide change for all substantially handicapped. Judicious use of Formula Grant dollars for client services will continue to be a need under PL 95-602, but councils will need to strengthen their advocacy role - within the service priority areas, "to expand the availability and use of services" [Section 133 (b)(4)(B)(iv)], and as general advocates within the service network, across all priority areas.

Thus, although advocacy is only briefly mentioned in PL 95-602, public awareness and advocacy need to be more vital than ever under the new law. The wider target population will require new strategies for public education about the needs and capabilities of the severely handicapped - people who are usually more visible (assuming they are located in the community) than their more mildly disabled counterparts, and are therefore more likely to be avoided, feared or rejected.

Public awareness campaigns cost money, sometimes a great deal of money, for films, TV and radio spots, slide shows, meetings, newsletters and other efforts, including sensitivity training of public service workers, legislators and the general public. Some widely-targeted awareness efforts may be fundable under the priority service areas. For example, in the community alternative living arrangements area, the development of group homes or the community acceptance of the handicapped in any community living situation may be blocked by public misconceptions about this group of people. In such a situation, documentation of this problem could justify funding of a public awareness campaign to gain acceptance of the handicapped living in the community.

The council has one more tool to use which transcends the priority service areas and has the potential to raise public and provider awareness of the disabled. With the modified definition, the council can become a resource to federal recipients on compliance with Section 504 of the Rehabilitation Act. Providing assistance on 504 compliance is likely to cost the council little or nothing, but it may be both an awareness and an influencing activity which can open the door to more gap-filling than can direct service provision.

DATA & ANALYSIS:

GAPS & BARRIERS IN THE DEVELOPMENTAL DISABILITIES SERVICE NETWORK

This section contains an analysis of program problem areas cited in fifty-three Fiscal Year 1978 developmental disabilities state plans. The following types of data and information are reviewed:

- Service gaps (as opposed to utilization gaps) in developmental disabilities services
- Needs in the national program goal areas (deinstitutionalization, institutional reform, community alternatives, early intervention, and adult programs)
- Special state needs and barriers to gap-filling
- State developmental disabilities council needs

Almost all states identified gaps in all services and discussed a variety of needs in all national, state and council program areas; review of all identified problems would not yield information on the priority problem areas which may require closer Federal attention. In order to concentrate on the most pressing gaps and needs, therefore, EMC Institute reviewed state plan narrative gap analyses to determine which problems were most critical within each state.

Gaps in Services

Few states conducted an analysis of utilization gaps in services; therefore, this analysis concentrates on the service gaps which, in the judgement of EMC Institute, were the five most critical gaps within each state.

Tables 1 and 2 show the major direct and support service gaps identified by the states in Fiscal Year 1978 state plans. Thirty-nine (39) states analyzed gaps in direct services, and thirty-three (33) states analyzed support services gaps. The remainder of the states did not identify gaps. Most of the states which did not analyze gaps cited a lack of information on which to base such an analysis. This rationale is supported by the fact that a need for information for planning was also cited by nearly half of the states, as will be discussed below (See Table 8). Some states only identified gaps in a broad service category, such as employment services, and did not specify gaps in individual services, such as sheltered employment and other employment; this may also be related to the states' need for better information for planning.

The most frequently cited major gaps occurred in residential services, particularly special living arrangements; day care; and case management services.

TABLE 1
GAPS IN DIRECT SERVICES

	RESIDENTIAL		DAY CARE		EDUCATION		TRAINING		EDUCATION/TRAINING		EMPLOYMENT					
	SPECIAL LIVING		DOMICILIARY CARE		PRE-SCHOOL ADULT		SCHOOL AGE		PRE-SCHOOL ADULT		TOTAL SHELTERED OTHER					
	TOTAL*	ARRANGEMENTS	TOTAL*	SCHOOL ADULT	TOTAL*	AGE	TOTAL*	AGE	TOTAL*	SCHOOL ADULT	TOTAL	SHELTERED OTHER				
Number of states reporting gaps (39 states total)	30	18	2	23	3	5	10	7	5	4	15	3	14	18	10	4
Percent of states reporting gaps (#/39)	76.9%	(46.2%)*	(5.1%)	59.0%	(7.7%)	(12.8%)	25.6%	(17.9%)	12.8%	(10.3%)	38.5%	(7.7%)	(35.9%)	46.2%	25.6%	10.3%

TABLE 2
GAPS IN SUPPORT SERVICES

	IDENTIFICATION		INFORMATION		CASE MANAGEMENT			FOLLOW-UP		TREATMENT		FAMILY/PROGRAM SUPPORT			
	TOTAL*	DIAGNOSIS EVALUATION	REFERRAL	TOTAL*	COUNSELING	PROTECTIVE ALONG	TOTAL*	MEDICAL	OTHER	TOTAL*	PORTATION	CARE	RECREATION		
Number of states reporting gaps (33 states total)	17	6	6	5	23	2	3	11	12	1	1	17	8	4	3
Percent of states reporting gaps (#/33)	51.5%	(18.2%)*(18.2%)	(15.2%)	69.7%	(6.1%)	(9.1%)	(33.3%)	36.4%	(30.0%)	(30.0%)	51.5%	(24.2%)	(12.1%)	(9.1%)	

* Includes number of states which identified gaps in individual services, plus those states which were only able to identify gaps in the broad service category.

** Because not all states identified gaps in individual services, the actual percentage of states having gaps in individual services may be higher than is reported here; for this reason, individual service percentages are given in parentheses.

Deinstitutionalization & Community Alternatives

The program area of deinstitutionalization and its companion area of appropriate alternative community care programs comprised the single largest topic of need addressed by the states. Forty-eight (48) of fifty-three (53) states and territories cited gaps in services related to these areas, as shown by Table 3.

While "deinstitutionalization", i.e., elimination of inappropriate institutional placements, is a high national priority for Federal human services programs, the emphasis on community programs in Table 3 indicates that a lack of community alternative services was the largest single barrier to returning the developmentally disabled to the community in Fiscal Year 1978.

It was not possible to identify specific community services which had the largest gaps related to deinstitutionalization, because many states included most or all services in this program problem area under "community alternatives."

TABLE 3

**DEINSTITUTIONALIZATION & COMMUNITY
ALTERNATIVES NEEDS IDENTIFIED IN FY 1978
DD STATE PLANS**

<u>AREA OF NEED</u>	<u>PERCENT/NUMBER OF STATES</u>
Improve or Establish Community Programs (general)	68.7% (33)
Establish Community Placements or Residential Facilities	64.6% (31)
Institutional Reform	48.3% (26)
Non-Specific	37.7% (20)
Upgrade Services	31.2% (15)

Adult Programs

Thirty-four (34) states addressed gaps in adult programs and related community support programs. The results are given in Table 4.

TABLE 4

ADULT PROGRAM/COMMUNITY SUPPORT SERVICE NEEDS
IDENTIFIED IN 34 FY 1978 DD STATE PLANS

<u>AREA OF NEED</u>	<u>PERCENT/NUMBER OF STATES</u>
Adult Programs (broadly addressed)	70.6% (24)
Coordination/Integration of Services	44.1% (15)
Protection and Advocacy	29.4% (10)
Increase Counseling Services	5.9% (2)

In addition, Table 2 shows that nearly seventy percent of the states which identified gaps cited major gaps in case management services - counseling, protective and advocacy and follow-along services - which were cited under adult programs in the regulations of PL 94-103.

Prevention and Early Intervention

Thirty-six (36) states cited needs in the area of prevention and early intervention, as shown by Table 5.

TABLE 5

PREVENTION & EARLY INTERVENTION NEEDS
IDENTIFIED IN 36 FY 1978 DD STATE PLANS

<u>AREA OF NEED</u>	<u>PERCENT/NUMBER OF STATES</u>
Prevention & Early Intervention (broadly addressed)	75.0% (27)
Expansion or Improvement of Early Screening, Diagnosis & Evaluation	38.9% (14)
Parent Training	16.7% (6)

The emphasis in the area of prevention and early intervention was on closing gaps in early screening, diagnosis and evaluation. Major identification service gaps (Table 2) were also cited by one-half of the states which addressed gaps by type of service.

A large number of states cited needs in "prevention." While not strictly within the legal scope of the Developmental Disabilities Program under PL 94-103, prevention includes such activities as public awareness and education, pre-natal and post-natal care and treatment and genetic counseling which are closely related to early intervention.

Individual Habilitation Planning

As shown by Table 6, eight (8) states addressed individual habilitation plan needs.

TABLE 6

INDIVIDUAL HABILITATION PLAN NEEDS
IDENTIFIED IN 8 FY 1978 DD STATE PLANS

<u>AREA OF NEED</u>	<u>PERCENT/NUMBER OF STATES</u>
Develop IHP's	87.5% (7)
Develop Methods to Implement IHP's	25.0% (2)

Note that development of individual habilitation plans, rather than implementation of such plans, was the major need cited.

State Planning Council Needs

Thirty (30) states identified specific needs of the state planning council. As Table 7 shows, the outstanding needs identified by the states occurred in orientation, training and technical assistance.

TABLE 7

STATE COUNCIL NEEDS IN ORIENTATION
TRAINING & TECHNICAL ASSISTANCE IDENTIFIED IN
30 FY 1978 DD STATE PLANS

<u>AREA OF NEED</u>	<u>PERCENT/NUMBER OF STATES</u>
Council Orientation, Training and Technical Assistance	80.0% (24)
Planning	33.3% (10)
Organization & Administration	30.0% (9)
Influencing	26.7% (8)
Monitoring & Evaluation	20.0% (6)

While "orientation, training and technical assistance" are ambiguous needs, the fact that nineteen (19) of the states emphasized the need for orientation suggests that councils have an ongoing need to be reacquainted with their overall roles and responsibilities.

Other Barriers and Needs in the Developmental Disabilities Program

Public awareness, protection and advocacy emerge as major needs for the expansion and use of services, particularly the development of community alternative residences. The second major need - funds for service expansion - also impacts heavily on the development of housing and other community services. While the Protection and Advocacy System and increased council emphasis on public education may help alleviate the lack of awareness and advocacy, the improvement or establishment of community services may still remain the most serious gap in the deinstitutionalization effort (Table 3), due to the lack of funds to close this gap.

Nearly half of the states which cited "information development" as a need related this in a general way to Developmental Disabilities Program planning. Yet others cited specific needs for client tracking systems, information and referral systems, and needs assessments on which to base deinstitutionalization and the development of new services.

Table 8 illustrates other priority needs identified by forty-eight (48) states.

TABLE 8

**MOST FREQUENTLY CITED STATE NEEDS & BARRIERS
IN 48 FY 1978 DD STATE PLANS**

<u>NEEDS AND BARRIERS</u>	<u>PERCENT/NUMBER OF STATES</u>
Public Awareness & Education, Protection and Advocacy	62.5% (30)
Lack of Funds to Expand Services	54.2% (26)
Information Development	47.9% (23)
Personnel Development	41.7% (20)
Rural Problems	20.8% (10)
Transportation	31.2% (15)

Personnel development is a need which relates directly to the quality of existing services. The improvement or upgrading of community and institutional services is a theme which runs throughout problem areas in Table 3. The lack of adequate personnel development is therefore a barrier to filling these gaps in the continuum of services.

The special problems of non-urban areas - lack of transportation and long travel times to services - causes problems in client use of existing services. Seven (7) of the fifteen (15) states which cited transportation as a problem identified it as a barrier to utilization by the developmentally disabled of services which are already in place. Nearly one-fourth of the states also identified major gaps in transportation as a service (Table 2) in itself, and not just as a necessary support function for other services.

METHODOLOGY & LIMITATIONS:
GAPS & BARRIERS IN THE DEVELOPMENTAL DISABILITIES SERVICE NETWORK

Methodology

The purpose of this analysis was to identify the major gaps in the developmental disabilities service network and the major barriers to service delivery in the states. To accomplish this, the following variables were examined, using information in Section IV, "Developmental Disabilities Program Gaps," of fifty-three Fiscal Year 1978 developmental disabilities state plans:

- the five services experiencing the most critical gaps in each state plan (as judged by EMC Institute review of narrative gap analysis).
- state needs in the national developmental disabilities program goal areas:
 - deinstitutionalization and institutional reform
 - community alternatives to institutions
 - early screening, diagnosis and evaluation (prevention & early intervention)
 - adult programs
- Other state needs and barriers in state Developmental Disabilities Programs
- state developmental disabilities council needs

All states used some adaptation of the Developmental Disabilities State Plan Guidelines in presenting information on gaps. Identified gaps in services were presented according to the developmental disabilities service categories in the guidelines. In some states, although information on gaps was worked into those categories, other services not specifically included in the service categories were also analyzed for gaps. In analysis for this paper, these services were placed into one of the seven (7) broad categories of services given by the guidelines. The types of services for which gaps identification was done are listed below in Table 9 with their corresponding broad service categories; they are also listed in the state plan guidelines and are expanded from the sixteen developmental disabilities services specified by PL 94-103.

Development of the conclusions and implications for this paper was supplemented by review of Title V of PL 95-602* to make this paper as relevant as possible to current program mandates.

*EMC Institute, "An Analytical Review of the Developmental Disabilities Assistance and Bill of Rights Act," October 30, 1978.

TABLE 9

CATEGORIES AND TYPES OF SERVICES GIVEN
IN THE STATE DD PLAN GUIDELINES

DIRECT SERVICES

- Residential
 - Domiciliary Care*
 - Special Living Arrangements*
- Day Activity Programs by Age Group
 - Day Care*
 - Education*
 - Training*
- Employment
 - Sheltered*
 - Regular

SUPPORT SERVICES

- Identification
 - Diagnosis*
 - Evaluation*
 - Information & Referral*
- Case Management
 - Counseling*
 - Protective, Socio-Legal*
 - Follow-along*
- Treatment
 - Medical*
 - Dental
 - Special
- Family/Program
 - Transportation
 - Personal Care*
 - Recreation*

Limitations of the Data & Analysis

Developmental Disabilities State Plan Guidelines ask for an identification of needs in national goal areas, state programs and the state council. Potential areas of need are listed in the guidelines, and some states only discussed their needs in the listed areas; thus some actual needs may not have been identified by those states which felt constrained to present their information only in the areas of need cited by the guidelines.

The guidelines also request an analysis of two types of gaps in services: gaps in the utilization of existing services by the developmentally disabled, (utilization gaps) and gaps which can only be filled by the expansion of services (service gaps). Few states analyzed utilization gaps; therefore, this analysis of gaps refers only to service gaps.

This analysis of service gaps is limited by three factors, two concerning the nature of state plan data and the third caused by the data collection methodology used for this analysis:

*Cited in PL 94-103 regulations, 1385.2(a)(20)

- The extent to which states were able to identify gaps in specific services has varied from state to state, and many states were able to identify gaps only in the broader categories of services (see Table 9). Thus other major gaps than those identified here may exist in specific services in some states which only identified gaps in the broad service categories.
- While this analysis was limited to the five most critical service gaps in each plan, few states actually prioritized their gaps. The reviewers were thus required to make a judgment, based on the state plan narrative, about which service gaps were most important to the state. For this reason, some reviewer bias may exist in this analysis. The reader should also note that more states than are shown in this analysis actually have gaps in specific services, but such gaps were not recorded if they were judged to be of lesser priority in these states.
- State plan guidelines request a numerical estimate of gaps in services. Thirty-one states calculated such estimates in Fiscal Year 1978 state plans. Unfortunately, many of these states questioned the quality of their own estimates (as was noted in the analysis section of this paper, nearly one-half of the states cited a need for more valid information). Several of the states which produced numerical estimates also did not include narrative analyses of gaps to support their figures. Because of the above problems with these data, it was felt that the numerical data on gaps might confuse rather than emphasize the major problem areas identified by the states in narrative analyses. For this reason, only qualitative assessments of gaps (narrative analyses) in Section IV of the state plans were used in the analysis of service gaps for this paper.

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