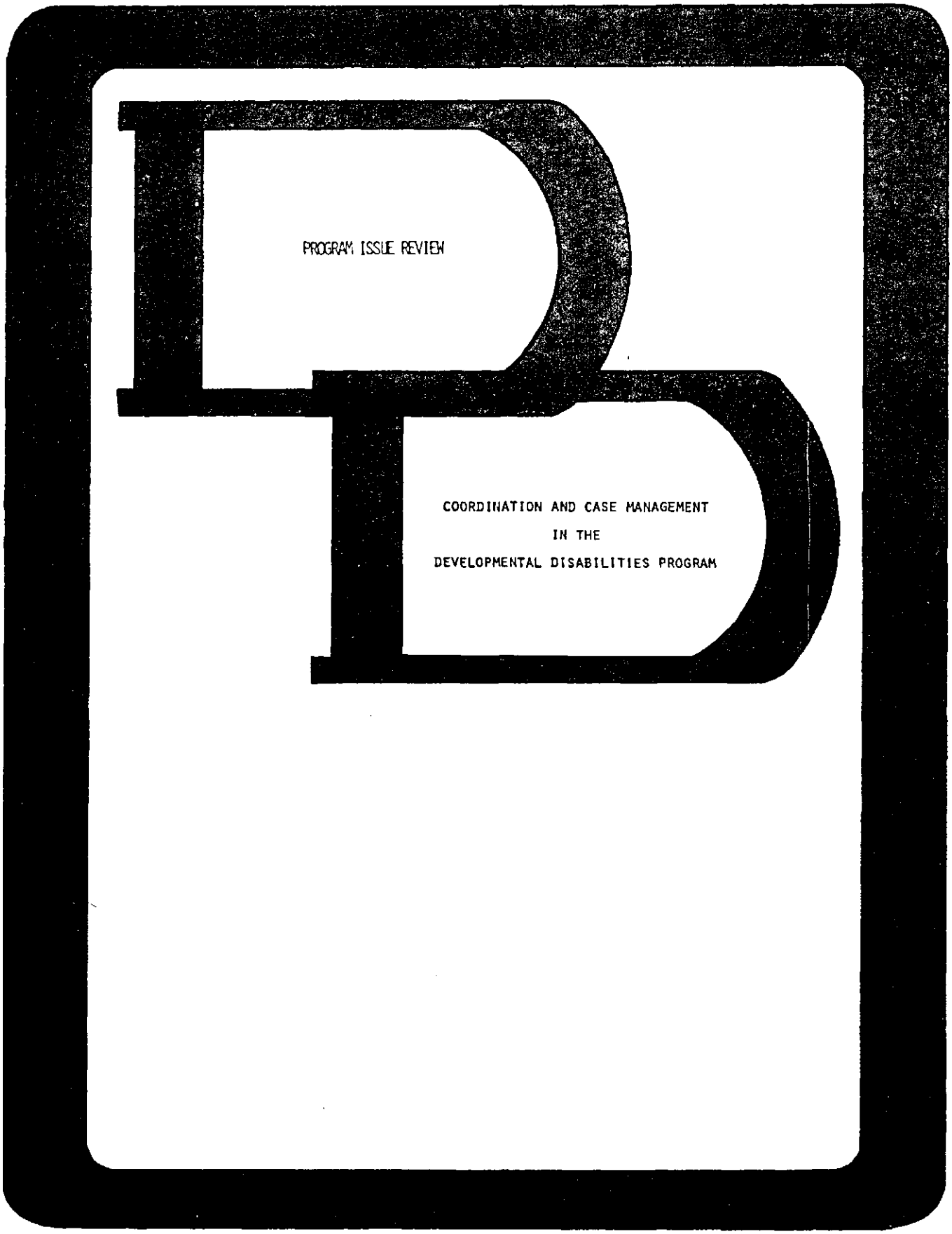
PROGRAM ISSUE REVIEW
COORDINATION AND CASE MANAGEMENT
IN THE
DEVELOPMENTAL DISABILITIES PROGRAM

TABLE OF CONTENTS

ACKNOWLEDGEMENTS

This comprehensive review of coordination and case management in the Developmental Disabilities Program was made possible by the interest and contributions of state council members and staff and of national and regional project directors.

EMC Institute wishes to thank the following people for their contributions of time, materials and frank discussions which have contributed to the understanding of coordination and case management:

Steve Berkshire	Executive Director Idaho Developmental Disabilities Council
Margaret Burns	Project Director Early Intervention Rural Needs Linked with Urban Resources (Maine)
Butch Chambers	Assistant Director Continuum of Services in Rural Areas of Maryland and Virginia
Steve Chupak	Executive Secretary Vermont Developmental Disabilities Council
Ron Cutter	Executive Director Ohio Developmental Disabilities Council
Manfred Drewski	Project Director Client Centered Management System (New Hampshire)
Gerald Gustwick	Tennessee Office of Developmental Disabilities
Connie Halter	Project Director Coordinated Regional Delivery System for Services to Developmentally Disabled Individuals
Mary Rita Hanley	Chairperson Pennsylvania Developmental Disabilities Council
Clell Hemphill	Executive Director Iowa Developmental Disabilities Council
Silvia Jackson	Assistant Director Wisconsin Uniform Services Classification
Carol LeMay	Executive Director **Maine Developmental Disabilities Council**

Kathy Lively	Project Director Comprehensive Rural Service Delivery System for the Developmentally Disabled (West Virginia)
Phillip S. Massey	Project Director Continuum of Services in Rural Areas of Maryland and Virginia
Roy Martin	Project Director Indiana Home Teaching System
Tom Scheinost	Executive Director South Dakota Developmental Disabilities Council
Candee Stanton	Staff Advocate Arizona Coalition for Persons with Developmental Disabilities
Martha Turner	Project Director Regional Special Projects Program (Kentucky)
Michael Weber	Executive Director Delaware Developmental Disabilities Council
Jane Wittenmyer	Project Director Wisconsin Uniform Services Classification

EMC Institute regrets that much of the wealth of detail discussed with the above contributors could not be included in full. This paper covers a wide range of problem areas and solutions in coordination and case management. For that reason, much of the examples given herein provide only an overview of project and program activities.

INTRODUCTION:
COORDINATION AND CASE MANAGEMENT
IN THE DEVELOPMENTAL DISABILITIES PROGRAM

This Issue Paper, one in a series prepared by EMC Institute, examines the problems and characteristics of coordination and case management in state Developmental Disabilities Programs. This paper is based on data from Fiscal Year 1978 developmental disabilities state plans and on information obtained from phone calls to selected coordination projects and state Developmental Disabilities Programs.

For the purposes of this review, coordination is defined as the orchestration of services, people and other resources to provide the most etticient and equitable delivery of services possible, using available funds and other resources at the state or local administrative (systems) level. Case management involves the same strategies at the client level. While enhancing service delivery, the side effect of coordination and case management is a reduction of service overlaps and of duplication of effort.

The following variables are examined as they relate to developmental disabilities services:

* Uses of coordination in council and service network objectives and activities
* Council and agency perceptions of the value and uses of coordination
* Problems and potential solutions in coordination and case management.

Coordination is a necessary activity for any state Developmental Disabilities Program, in order for that program to ensure a comprehensive, appropriate service system for its constituents. The proliferation of federal, state, and local/private human service programs has resulted in a plethora of service standards, eligibility requirements, target groups, and administrative requirements that can be more of a trap than a help to clients needing a variety of services. Different programs, for example, have different intake procedures, so that a client needing services from three different programs may be required to submit to three separate, sometimes redundant evaluations before services can be obtained.

Service providers may be unaware of all appropriate alternatives for services in other agencies, resulting in a well-meaning but detrimental mismatch of the client with services, as well as unnecessary duplication of services. Clients referred to other agencies may get lost in the bureaucratic mill, not only missing out on services but missing out on the enhancement of other services they do receive.

The remainder of this Introduction reviews the importance of coordination in the legislative perspective of PL 94-103, and highlights the new directions given to coordination and case management by PL 95-602.

The Importance of Coordination Under PL94-103

Under PL 94-103, the stated purpose of the Developmental Disabilities Formula Grant Program was to "improve and coordinate services for the **developmentally** disabled" (1385.1); the program was also to achieve a reduction in duplication of

effort (1386.46[c]). PL 94-103 planning guidelines addressed coordination through a description of "Adult Programs" (state plan paragraph 4.3) and "Interagency Coordination" (state plan paragraph 5.3).

Except for regulatory and guidelines statements cited here, the what and how of coordination were left to the states to decide. Although little written direction was given in this area, coordination at the administrative and client levels was clearly central to the intent of PL 94-103.

Coordination has become vital with the emphasis on the Developmental Disabilities Program goals — deinstitutionalization and institutional reform, community alternatives, early intervenition and adult programs. For example, the concepts of deinstitutionalization and community alternatives have fostered the concept of institution and community working together to provide appropriate services. In order for deinstitutionalization to work, both institutional and community providers must have some common (coordinated) idea about whether and when a client can be better served in the community, what steps are needed to ready the client for community living (including IHP development), and how to help the client accomplish the transition from centralized institutional care to noncentralized community programs. Deinstitutionalization efforts must coordinate with the development of community alternatives, so that released residents have services available to them.

Even institutional reform activities have necessitated the involvement of community programs. Programs such as Vocational Rehabilitation and Special Education provide education and training in institutional settings; institutions are developing new roles such as personnel training, research, technical assistance and outpatient programs which require coordination with community service and support systems. In the case of closing institutions, administrators must work with the community service network to provide alternative employment for institutional personnel.

There is a need for early intervention programs, such as the Title XIX Early Periodic Screening, Diagnosis & Treatment program (EPSDT), to coordinate with health and developmental service providers and Child Find programs. In addition, EPSDT must coordinate with providers of transportation to this service. Follow-up must be carried out to ensure that children receive needed services.

Coordination is also essential for the provision of Adult Programs. While Special Education and Early Intervention programs have at least the potential to provide integrated, case-managed services for children, no single federal or state agency has responsibility for comprehensive services to the adult age group. In addition, more persons in this group do not have parents or legal guardians to advocate for service provision in their behalf, and case management services become particularly important.

The examples above illustrate the importance and focus of state Developmental Disabilities Program coordination and case management activities under PL 94-103. With the passage of PL 95-602, however, this focus has shifted in several ways.

The Mandates of PL 95-602

PL 95-602 (Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978) has upgraded the status of coordination and case mangagement

in the Developmental Disabilities Program. The purpose of Title V of this Act is to assure that clients receive needed services through a system which, among other things, coordinates those services (Section 101 [b][l]). The coordination of services within a priority area with other services is a specific service activity (Section 133 [b] [4][B] [iv]). Case mananagement is now one of four priority service areas (Section 102 [8][c]). This greater emphasis on cooperative activities is important, since it is clear that the need for coordination and case management permeates all aspects of service delivery for the developmentally disabled. This shift also implies that, at the systems coordination level, the state council in its role as advocate must strengthen its ability to coordinate.

It can be argued that the composition of the state council, involving representatives of agencies, consumer organizations, and other providers, is itself a forum or impetus for coordination. The mandated review and comment on relevant state plans (Section 137 [b][3]) also provides for coordinative input to the service network. Indeed, since the developmental disabilities state p1an_is required to include a comprehensive review of the service network (Section 133[b] [2] [B] [i], it can be viewed as a research tool for coordination of needs and activities.

However, these council mandates form only the basis of what councils need to do in order to achieve program coordination. To clarify this issue of the role of the council, this paper analyzes the status of coordination and case management in state Developmental Disabilities Programs, examines some exemplary projects and council activities which may help other states to clarify their roles in these areas, and discusses the implications of the priority service areas of PL 95-602 with respect to coordination and case management.

The format of this paper differs from the format of other papers in this series: the "Conclusions and Implications" section is followed by two "Problems and Solutions" sections which discuss systems coordination and case management. Those sections are followed by an analysis of Fiscal Year 1978 state plans, which is in turn followed by a discussion of the methodology and limitations of this paper.

CONCLUSIONS AND IMPLICATIONS:
COORDINATION AND CASE MANAGEMENT
IN THE DEVELOPMENTAL DISABILITIES PROGRAM

This section reviews the importance and uses of coordination and case management in state Developmental Disabilities Programs. These findings are from an analysis of Fiscal Year 1978 developmental disabilities state plans.

This section also examines ways in which coordination activities undertaken by the states under PL94-103 might be continued with minimum dislocation under the PL95-602 priority service areas.

Findings of the Analysis

1. A review of state needs and barriers in coordination identified two major problems in the service system which affect both case management services and coordination at the systems level:

- The biggest barrier to achieving coordination was "fragmentation or duplication of services and responsibilities" (67.3% of all citations of coordination barriers) The target o*f coo*rdination, then, is itself a barrier to achieving coordination.

- In the twenty-four state plans which identified needs in coordination, nearly two-thirds of all coordination needs mentioned were needs relating to case management, particularly information and referral services. While most major state agencies and many private agencies provide this service, agencies' information is often inadequate or too out-of-date to insure the best possible referral for a client.

Not only does fragmentation act as a barrier to coordination, it apparently also decreases agencies' abilities to maintain good quality information and referral services and may multiply the problems of the case manager.

This barrier is complex in nature. The following are some examples of its manifestations:

- Differing federal program regulations have led to differing service standards and eligibility restrictions, which inhibit programming for clients who need a wide spectrum of services from more than one program.

- Due to different mandates, to the state political or economic climate, and/or to a bureaucratic tendency to guard their own turf, state agencies may be reluctant to acknowledge mutual problems and responsibilities; as a result, major service programs may operate nearly autonomously and in isolation from the service network. Agencies with duplicate services may also be in competition for clients.

- Clients are often subjected to multiple intake and evaluation procedures; the various requirements of EPSDT, Child Find and other screening programs are one example.

- Several states reported uneven availability of services throughout the state, particularly in rural areas, and pointed out that this is one result of uncoordinated planning and policy implementation.

- The responsibilities for deinstitutionalization planning and implementation are unsettled questions in a number of states. Without a clear delineation of provider responsibilities in the whole deinstitutionalization process, many residents leave the institution only to return to it because release planning has not involved all necessary elements of the service network.

Additional factors complicating the implementation of case management services and systems coordination are: provider competition for scarce funds, often without any system for prioritizing funding needs and uses; confidentiality requirements; different program reporting requirements; and other administrative barriers.

2. A review of council and agency coordination objectives and activities yielded the following:

- Nineteen percent of council coordination objectives are devoted to activities related to case management. This is a surprisingly low percentage, considering the large needs identified in case management services (See #1, above). However, some case management needs are being addressed indirectly, through other coordination objectives which address uniform IHP development, personnel training and service standards design.

- A large proportion of council activities and objectives relating to coordination had vague or unclear targets, particularly those dealing with case management and related services. Some of the lack of clarity is undoubtedly due to unclear writing of the objectives/activities. However, based on the assessment of the importance of coordination to councils (See #3, below), many of the objectives/activities may not have a clear target.

The above findings imply that some councils are addressing their case management needs, and in a variety of ways which will provide proper support to the case management function — by not only providing services but also by reducing fragmentation in IHP development, and so on. Other councils may need intensive education in strategies for meeting case management needs, particularly those councils which choose case management as their priority service area under PL 95-602.

Note that the lack of clear targets of the objectives/activities was not confined to case management alone, and its implication will be addressed in #3, below. Of those objectives/activities which did have clear targets or expected outcomes:

- The majority will have an impact either on "general services" or the four Developmental Disabilities Program goal areas of PL 94-103 (deinstitutionalization and institutional reform, community alternatives, adult programs and early intervention). This is not surprising, since these targets address problems which involve the whole service network and cut across all services.

- Previous state plan analysis* had shown that few plan year objectives addressed the program target groups: rural and urban poverty area residents, and the severely handicapped. Most of the specific mention of these groups is in objectives relating to coordination, implying that some councils are directly addressing the often multiple needs of these groups by coordinated often multiple service delivery.

The above findings show that the councils were using coordination and case management activities and objectives to address the mandates of PL 94-103. The new focus of PL 95-602 will not affect the target groups mentioned above, but "general services" and the national program goals have been deleted in favor of specific priority areas. The potential strategies for transition of coordination efforts from the goals of PL 94-103 to the priority areas of PL 95-602 is discussed below under "Implications for Transition to PL 95-602."

3. Nearly ninety percent of the states (councils and service networks together), attach some importance to coordination, but only slightly more than two-thirds of the councils, considered alone, considered coordination important; only one-fourth placed great emphasis on coordination. In addition, the analysis showed that:

- Service network agencies, more than councils, view coordination as a tool for improving services, instead of an end unto itself in case management services. The assessment also indicates that agencies are more cognizant of the uses of coordination than are councils. This may be due to the fact that agencies, as service providers, are more likely to be attuned to this means for obtaining or improving services.

- In nine states, the assessment indicated that the council saw no role for itself in coordination and/or had no idea how to initiate or maintain such coordination.

These findings, coupled with the fact that a large proportion of council activities and objectives had unclear targets, imply that councils need assistance in developing their skills to address their coordination and case management needs — i.e., how to work as a team which may represent disparate interests.

Implications for Transition to PL 95-602

The above findings indicate two potential problems for councils in implementing PL 95-602:

1. A disparity exists between the magnitude of gaps and problems in case management services reported in state plans and the apparent extent and quality of councils' efforts to address these problems. States which choose case management as their priority service area may need assistance in implementing this area in two components of the Developmental Disabilities Program:

*EMC Institute, Program Issue Review, "Goals and Objectives of the Developmental Disabilities Program," 1979.

a) Knowledge of model projects and other states' efforts in the area of case management. While this paper examines some case management projects, many other worthwhile efforts need to be shared among the states. Establishing a high-quality information exchange in this and related areas may be a priority task for the new Office of Information and Resources for the Handicapped established by PL 95-602 (Section 15 of the Rehabilitation Act of 1973).

b) Information on strategies by which state developmental disabilities councils can provide support to case management projects funded with DDSA monies. In some cases, this will simply mean information sharing along the lines of a) above; in other cases, it may require raising the consciousness and confidence of state council members to understand that they have a legitimate role to play as a body to develop uniform IHP's and standards, seek interagency referral agreements, and other systems advocacy functions which can enhance the delivery of case management services.

2. Many of the coordination and case management activities/objectives reviewed for this analysis address either "general services" or the four priorities of PL 94-103 (deinstitutionalization and institutional reform, community alternatives, early intervention and adult programs). PT 95-602 establishes four priority service areas — case management, child development. community alternative living arrangements, and nonvocational social-developmental services. On the surface, this change appears to hold a potential for massive dislocation of the focus of state Developmental Disabilities Program coordination (and all other) efforts. However, closer inspection of the repealed and current mandates suggests that such dislocation may not be necessary.

- First of all, the Law does not prohibit coordination activities encompass all priority areas and which do not use DDSA funds. In addition, some systems coordination activities (such as planning for a coordinated transportation system) may be fundable with the DDSA planning monies. Many council information coordination activities take place within council or committee meetings, and therefore do not require funding (other than administrative). A program may thus be able to continue funding of many of its systemwide coordination efforts, regardless of the priority service area addressed in its plan.

- Second, "service activities" (Section 133[b][4][B][iv]) allows a number of advocacy related activities, including "the coordination of services in [the chosen priority] area with the provision of other services." This should enable states to insure, for example, that the development and provision of community alternative living arrangements continues to be coordinated with institutional release planning and services and with community support services such as day activities, recreation, transportation, medical and vocational services.

- Third, the choice of the case management priority service area will allow states to continue and expand case management activities — including the systems-level coordinative service activities cited above.

Based on this discussion and on the mandates of PL 95-602, it apppears that coor—dination must still be a major part of state Developmental Disabilities Programs. Continuation and expansion of systems coordination and case management activities simply requires that states take full advantage of the flexibility allowed by the strategies outlined in the Law under "service activities "(Section 133[b][4][B][iv]), funding restrictions and the case management priority service area.

DATA & ANALYSIS:
COORDINATION AND CASE MANAGEMENT
IN THE DEVELOPMENTAL DISABILTIES PROGRAM

The information in this analysis is based upon data in those twenty-nine Fiscal Year 1978 developmental disabilities state plans which contained specific references to coordination. Details of the approach to this analysis are discussed in the Methodology & Limitations section at the end of this paper.

The paragraphs below examine problems in coordination identified in the twenty-nine state plans, the relationship of plan year objectives and activities to these problems, and state perceptions of the importance of coordination.

Problems in Coordination

Few agencies identified problems in coordination in the state plans, so this discussion covers mainly those problems identified by state councils.

Problems in coordination and case management arise from the presence of at least one of two circumstances in a state: unmet needs for these activities and/or barriers to achieving coordination and case management. The frequency with which these problems are identified in the state plans is shown on Table 1. Note that the problem areas most frequently identified fall under case management needs, i.e., local coordination of individual client services. The largest number of case management needs are for information and referral services on Table 1. Information and referral is probably provided to some extent in every state and territory in the Developmental Disabilities Program. In many states, the quality of information and referral, rather than a lack of such services, is the major problem. Even where information and referral services are widespread, the referring agencies' knowledge of other services is often either out-of-date or inadequate to allow a choice of the best possible referral for an individual client.

It should also be noted that, while only nine percent of identified needs were specific to follow-along, service gaps in follow-along were identified by thirty-three percent of the states which identified gaps.* This too, then, is a major need in client-level service coordination.

In order to meet the needs identified in coordination, councils must be aware of the barriers which inhibit its development within the state. The types of barriers identified are given below in Table 2.

*EMC Institute, Program Issue Review, "Gaps and Barriers in the DD Service Network," Philadelphia, 1979.

TABLE 1

UNMET NEEDS FOR COORDINATION

PROBLEM AREA	FREQUENCY OF CITATION	PERCENT OF ALL CITATIONS
Case Management Services Needs:	41 citations	61.2%
Information & Referral	23	34.3
Follow-Along	6	9.0
General Case Management	10	14.9
Coordination of Case Management Activities	2	3.0
Coordination of:	26 citations	38.8
Specific Services	8	11.9
General (all) Services	7	10.5
DD Program Goal Activities (Deinstitutionalization, Adult Programs, etc.)	6	9.0
Planning	5	7.5
TOTAL CITATIONS	67 citations	100.0%
TOTAL STATE PLANS ADDRESSING COORDINATION	29 state plans	53.7% of all state plans

TABLE 2

BARRIERS TO ACHIEVING COORDINATION
FROM 29 FY 1978 DD STATE PLANS

BARRIER	FREQUENCY OF CITATION	PERCENT OF ALL CITATIONS
Fragmentation/Duplication of Services and Responsibilities	35 citations	67.3%
Administrative Barriers	10	19.2
Lack of Funds	5	9.6
Lack of Council Awareness	2	3.8
TOTAL	52 citations	100.0%

As shown by Table 2, "Fragmentation/Duplication of Services and Responsibilities" was the most frequently identified barrier to the coordination of planning and service delivery.

Two of the *states* which identified barriers cited lack of council awareness of the need, process, and problems of coordination as a barrier in achieving coordination. While this represents less than four percent of the two states which identified needs and barriers in coordination, two states are two too many in a program whose purpose is to improve program coordination. Council orientation and technical assistance should be cognizant of the important role that the council can serve in achieving coordination.

Not all state plans used in this analysis listed barriers or needs relating to coordination. However, none of these plans specifically stated that no coordination-related problems exist.

Current Coordination Activities and Objectives

State councils and service network agencies are involved in coordination activities to satisfy short-range objectives and also as an ongoing means of maintaining quality service delivery. Activities and objectives were examined by type of coordination and by targets of the activities and objectives.

Based on this review there are four major types of coordination:

1. CASE MANAGEMENT - the coordination of individual client services. This includes information and referral and follow-along services and IHP development and implementation. This type of coordination is itself a part of the continuum of developmental disabilities services. It is usually the responsibility of local providers, although state-level administration can provide support through technical assistance, state-wide client tracking systems, development of interagency case managers and updating of referral information.

2. PARTICIPATION - the coordination of planning, service delivery and/or administration. This can occur among two or more independent organizations which will give and get material benefits (upgraded or expanded services, additional resources or decreased use of resources) from the exchange. Local providers may be involved in participatory coordination at a state-regional level; such coordination is also effective at the state agency administrative level, where it can impact on the statewide service network. State councils are often involved in this type of coordination, to enhance comprehensive planning and to obtain services.

3. FACILITATION - negotiation by an outside agent to initiate or achieve coordination of policy, planning or service delivery between two or more bodies. This is an influencing role often ascribed to the developmental disabilities council, Facilitation may be active, as when a council seeks a joint solution to a specific problem from certain agencies in the service network; or it may be passive, as when a council views itself as a general forum where agencies and providers can discuss whatever problems arise.

4. CONTROL - coordination of planning, service delivery or policy through holding the strings. An agency which administers several federal programs can coordinate the work of these programs to some extent by dictating policies and procedures from a state administrative level. (Much of the routine administrative activities of an umbrella agency may loosely be defined as coordination by control.) A developmental disabilities council can "coordinate" the development of a service delivery system by controlling the location and type of DDSA service projects vis-a-vis existing gaps, or by drafting legislation pertaining to developmental disabilities services.

The coordination activities and objectives of the twenty-nine state plans used in this analysis are shown on Table 3 by type of coordination. The targets of these activities and objectives are shown on Table 4. Unfortunately, the purpose or target of many of the activities and objectives was not clearly stated in the plans, so that much information may have been lost. Note particularly the relatively large proportion of council activities and objectives for which targets were unclear or vague. Some of these vague targets may simply be due to lack of clear writing but in view of the assessment of the importance of coordination given later in this section, it is likely that many may not have a clear target. Determination of the scope of this problem would require a detailed state-by-state review of all objectives and activities, a task which is beyond the scope of this analysis.

Agency involvement in coordination activities is far more heavily represented in Tables 3 and 4 than council involvement in such activities; the reverse is true for the objectives. The uneven reporting is probably due to the state plan format, which is more conducive to reporting of specific agency activities and council plan year objectives; it does not necessarily follow that agencies are more involved in coordination activities than state councils, or that more council plan year targets are concerned with coordination than are agency objectives.

As shown by Table 4, the majority of activities and objectives which relate to coordination will affect either "General Services" or the four Developmental Disabilities Program goal areas (deinstitutionalization and institutional reform, community alternatives, adult programs and early intervention). This is not surprising, since these targets address problems which involve the whole service network and cut across all services.

Note the large number of agency activities in information and referral and follow-along services. As was pointed out in the discussion of problems, this heavy involvement does not mean that these services are adequate or coordinated; it simply means that a lot of these services are offered. In the case of follow-along, this may not even be true; these data were taken mainly from Summary Table 3-1 in the developmental disabilities state plans, which displays all services offered by all agencies. What is checked for "Follow-Along" in some agencies may really be follow-up — an activity which may only involve one phone call shortly after the client leaves a service to find out, for example, if the client is still employed.

On the other hand, councils and agencies are each devoting only 19% of their coordination objectives to case management. This is extremely suprising in view of the large number or case management needs identified by these states, and the large number of identified barriers involving fragmentation of services and responsibilities. Apparently, neither state councils nor service networks are adequately addressing these problems. This apparent discrepancy is corroborated by a review of the targets of council case management objectives and activities, none of which had targets for impact which could be identified by the analyst. Some of these objectives and activities probably do have intended targets or outcomes, which have been obscured by unclear writing. However, the magnitude of the lack of targets shows that some councils do need to step up efforts in the development and improvement of case management services.

Other councils are addressing these services indirectly: one-third of council control objectives have targets which support case management services, through

TABLE 3

SUMMARY OF COORDINATION ACTIVITIES & OBJECTIVES

TYPE OF COORDINATION	ACTIVITIES				OBJECTIVES			
	Agencies		DD Councils		Agencies		DD Councils	
	Number of Activities	Percent of Activities	Number of Activities	Percent of Activities	Number of Objectives	Percent of Objectives	Number of Objectives	Percent of Objectives
Case Management	168	75.0%	6	13.6%	7	15.6%	21	19.3%
Information & Referral	103	46.0	2	4.5	5	11.1	9	8.3
Follow-Along	54	24.1	1	2.3	-	-	3	2.8
General Case Management (IHP's, etc.)	11	4.9	3	6.8	2	4.4	9	8.3
Participation	73	32.6	20	45.5	25	55.6	39	35.8
Facilitation	2	0.9	15	34.1	6	13.3	23	21.1
Active	2	0.9	8	18.2	5	11.1	23	21.1
Passive	-	-	7	15.9	1	2.2	-	-
Control	-	-	-	-	6	13.3	26	23.9
Unclear/vague	1	0.4	3	6.8	1	2.2	-	-
TOTAL	224	100.0%	44	100.0%	45	100.0%	109	100.0%

TABLE 4

TARGETS OF COORDINATION

TYPE OF COORDINATION	MAJOR ACTIVITY TARGETS		MAJOR OBJECTIVE TARGETS	
	AGENCIES	DD COUNCILS	AGENCIES	DD COUNCILS
Case Management				
Information & Referral	General Services: 69 Specific Services: 7 DD program goals: 5	-	Specific Services: 5	-
Follow-Along	DD program goals: 54	-	-	-
General Case Management	Specific Services: 6	-	-	-
Participation	DD program goals: 42 General Services: 18	DD program goals: 3	Specific Services: 10 DD program goals: 14	DD program goals:14 General Services: 7 Specific Services: 6
Facilitation	-	DD program goals: 8	-	General Services:10 DD program goals: 6
Control	-	-	Support functions: 5	Support functions:8 General Services: 8 Specific Services:5
TOTAL	DD program goals:104 General Services: 87 Specific Services:13 unclear/vague: 40	DD program goals: 11 unclear/vague: 33	Specific Services: 15 DD program goals: 14 Support functions: 5 vague/unclear: 11	General Services:25 DD program goals:20 Specific Service:11 Support functions:8 vague/unclear: 45

uniform standards or IHP design, personnel training, and funding — i.e., the maintenance and upgrading of services.

Under other control objectives, both councils and agencies emphasized service support functions such as quality control and personnel training. In addition, specific services are being addressed through council control objectives far more frequently than through council activities; such services are usually examined across all service network agencies. Through these control objectives, councils are also sponsoring coordination services which address the special target populations which are being given little attention by the service network — rural and poverty areas and severely handicapped individuals.

Note the emphasis of both agencies and councils on participatory coordination, i.e., the involvement of two or more bodies to achieve a specific result. As is to be expected, councils are more involved than agencies in facilitating coordination among service providers, and most of this facilitation is active.

Specific participants in council and agency objectives and activities do not appear to correlate with specific types of coordination. The characteristics of responsible agents are given below.

- Vocational Rehabilitation and Education are among the most frequently mentioned participants in both agency activities and agency objectives, followed by Health and Mental Retardation agencies, Title XX and Special Education. However, umbrella agencies and "all human service agencies" received the most mentions.

- Councils also frequently cite the involvement of consumer organizations in their coordination activities and objectives. This is particularly important in some rural areas in which most local services are provided via contract with private providers. In such states, local chapters of the consumer organizations either have direct contact with these providers or are themselves part of the local provider network.

- Little mention was made of council coordination with the activities of the Protection and Advocacy System.

Looking at specific service targets, the most frequently mentioned services were education, transportation, training and employment, health and treatment, and client advocacy. As was mentioned above, services and other functions relating to the four national Developmental Disabilities Program goals are frequently referred to, including institutional education services as part of institutional reform. On a national scale, states do perceive the importance of coordination in achieving these goals. However, with the exception of adult training and employment, only two targets could be identified as relating to adult programs; both of these were targets of council objectives. It could be said that most of the general coordination targets will impact on adult programs; yet it is ironic that the adult programs goal, which specifies coordination as one of its targets, is scarcely acknowledged in these objectives and activities as a discrete Developmental Disabilities Program goal.

Perceptions of the Importance of Coordination

The activities, objectives and barriers identified in a state plan provide some clues to the importance of coordination and case management to the council and

the service network. The assessment of the importance of coordination to the states in this sample is given in Table 5.

TABLE 5

THE IMPORTANCE OF COORDINATION
TO COUNCILS AND SERVICE NETWORKS
FROM 29 FY 1978 DD STATE PLANS

RANK	NUMBER OF STATES	PERCENT OF STATES
Highly Important	7	24.1%
Somewhat Important	19	65.5
Unimportant	3	10.3

More service networks than councils view coordination as a tool for improving services, instead of an end unto itself in case management services; the assessment also indicates that agencies are more cognizant of the uses of coordination than councils. This may be due to the fact that agencies, as service providers, are more likely to be attuned to this means for obtaining or improving services. Based on the available data, nearly one-third of the councils examined here apparantly consider it unimportant. In nine states, factors in the assessment indicated that the council saw no role for itself in coordination and/or had no idea how to initiate or maintain such coordination. It is also noteworthy that only one of these nine states saw coordination as an implementation tool for obtaining other kinds of benefits. Four of these states cited major systemwide barriers to service delivery due to fragmented services and unclear agency responsibilities, yet no plan data indicated that the council intended to research the problems or identify joint solutions or strategies. Three other states had objectives relating to coordination either as an end product such as case management services, or as an implementation tool. The responsible agency for these objectives was either the council or just one state agency with no indication in the implementation plan that other council agency representation would provide support for implementation of objectives which, realistically, should be network-wide in impact.

One state had "coordinated services" as a major goal — an area that needs the involvement of agency planners and district administrators as well as policy-makers — yet only the council was responsible for these objectives and no provision was made in the implementation plan for specific responsibilitites of the state agency representatives. This gives the impression that the council as a body is tackling service coordination without truly involving other agencies.

A second state which is host to a model service coordination project is heavily involved in the coordination of state agencies' planning information — but only for the development of the development disabilities state plan. No attention is given to the planning information needs of the other agencies, or how to standardize other program data to facilitate interagency client tracking or other activities. Indeed, this coordination activity seems to have been undertaken only to produce a developmental disabilities plan document, since

program goals and objectives for the most part do not truly address the identified problems which are within the purview of the council.

These problems are not limited to the above examples; even some states which apparently viewed coordination as important showed weaknesses in planning relating to coordination. Nine of the states reviewed the need to involve other agencies (or more agencies) in their implementation plans; eight states need to get involved in the research and development of joint solutions to problems affecting several agencies.

The above discussion identifies some of the barriers to coordination which may be created by the perceptions of the actors within the state. However, the potential for coordination does exist in most states in the sample; as Table 5 shows, nearly ninety percent attach some importance to coordination.

PROBLEMS AND SOLUTIONS IN SYSTEMS COORDINATION

This section discusses unmet needs and barriers in coordination of services at the state or other administrative level. This information has been gleaned from state plan narratives, EMC Institute technical assistance experience, and discussions with council members and with council and coordination project staff.

The importance of acheiving the coordination of services for the developmentally disabled was discussed in the Introduction to this paper. Recent reports by the U.S. General Accounting Office* and the Children's Defense Fund** cited lack of coordination among programs at the federal, state and local level as one of the major reasons for the failures in deinstitutionalization and the Early and Periodic Screening, Diagnosis, and Treatment program.

As the analysis of state plans shows, few states in the sample placed great emphasis on their mandate to coordinate services for the developmentally disabled. The reasons appear to be twofold: first, some councils see their role in coordination and case management as very passive or nonexistent; second, a few plans imply that coordination is important to the council, but the council lacks knowledge about how to initiate such activities. Both of these problems may be aggravated by a lack of key program decision-makers on the council.

These problems, and the ways in which states have overcome them, are discussed in the paragraphs below.

The Passive Council Role

Eight developmental disabilities plans stated or implied that the council takes a passive role in coordination. These plans characterized the council as a natural forum for mutual problem-solving (because it contains representatives of state and private providers and consumer groups), yet most of these plans did not indicate what problems were addressed or what mechanisms exist within the council to encourage such problem-solving. Some of the same plans stated that the council promoted interagency planning through reviewing and commenting on all state plans, but no specific examples were given of the effects of such review and comment.

Six of these plans did not mention any other council activities or objectives which related to coordination. In fact, two state plans listed only agency plan year objectives, i.e., those objectives which the agencies had developed for their own programs. These two plans did not contain any council objectives, designs for implementation or other plans by which the council or other agencies could assist in the achievement of the agency objectives. Unless other activities, not stated in the plans, are occurring in these states, these plans demonstrate a passivity that amounts to extreme insensitivity to the basic advocacy and planning functions of the council.

*U.S. General Accounting Office, Returning the Mentally Disabled to the Community: Government Needs to Do More, January, 1977; pages 56-64, 172-176, 182, and 186, specifically address problems in systems coordination which relate to the Developmental Disabilities Program.

**Children's Defense Funds, EPSDT: Does It Spell Better Health Care for Poor Children?, June, 1977; page 164 ff.

In many states, review and comment on other state plans takes place when the plans are in final draft and will only be denied executive approval in the event of serious deficiencies or conflicts in the plan. While council review of the plans at this point in time can avert severe problems in developmental disabilities services, this process occurs too late to have a constructive impact on the development of agency plans. In some states, Developmental Disabilities Program involvement in other agency planning must begin up to eighteen months prior to plan publication, when agencies are developing initial budgets. Of the six states which cited the review and comment process, only one also stated that it had access to agency budgets. In other states (most of which also cited "council membership" as an aid to coordination), the plans gave no indication that coordination was occurring even though the states had identified systemwide barriers relating to coordination.

Coordination and joint problem-solving do not automatically occur simply because consumer and service network representatives sit in the same room for several hours each month, or because state plans are reviewed. A council must have sufficient belief in its own legitimacy to demand that agency representatives at least contribute to the understanding of joint problems; but the council must also operate in a spirit of mutual help for agencies and consumers with problems. For example, of the eight councils whose plans implied this kind of passive role, two routinely sought and obtained joint solutions and interagency planning, within the framework of the developmental disabilities council. Given this kind of council policy, a passive (but positive) forum can work.

The following are some examples of how "passive" facilitation techniques can promote coordination, or at least establish an atmosphere in which coordination is likely to occur:

- In larger states, a council meeting may be one of the few times when agency or program personnel see each other; it may be the only time when they sit down with representatives of the people they serve. Spokespersons for the councils in Iowa and Pennsylvania stressed the importance of a non-adversary atmosphere — the emphasis on a need to listen to, understand and help solve problems rather than place certain members on trial. Such an atmosphere does not reinforce a defensive, "turf-guarding" stance by agency members. One of these states also stressed the fact that the open atmosphere of the council encourages camaraderie among all members, which in turn reduces the danger of friction among members when discussing sensitive problems.

- The Iowa State Council reviews state plans during A-95 review, but only as a last check; agency members are involved in an ad hoc planning committee which studies mutual problems and potential solutions before program plans are finalized. Through the A-95 process council staff provide regular feedback to the state clearinghouse on proposed projects which affect the developmentally disabled, instead of being just passively and periodically involved only for state plan review.

- Several councils require regular reports of program or project activities, to be presented and discussed at full council meetings. This is a form of service network monitoring which increases members' understanding of the programs and problems in the state. One executive director also.

cited this type of monitoring as a means of program support: a show of continuing council interest and encouragement in program progress, and a desire to be informed about problems in order to contribute to their solution. This is a potentially vital positive function of monitoring, which is often seen as a negative activity.

- The state of Idaho recently passed a statute giving the State Council authority as the central point of coordination in the state. While details of this authority and of state agency roles are not spelled out in the legislation, this is one means of bringing the coordination role of the council to the attention of state government.

- Several states have committees which are concerned primarily with some form of service network coordination. The most successful of these committees have specific, written roles and agency representation. The existence of such committees reinforces the concept of the council as a facilitator of cooperation.

- Several other states utilize personnel outside of the council to help staff specialized task forces or ad hoc committees, drawing on expertise or fresh points of view to acquaint members with potential joint problem solutions. Public attendance at council meetings under state "sunshine" laws is also encouraged, to foster awareness and information exchange.

With the exception of lobbying and other legislative support needed to obtain the Idaho statute, all of the above examples can occur solely within the framework of council or committee meetings and provide a medium in which cooperation can grow. These facilitation activities are essentially passive in nature, but when compared with the examples of very passive councils given at the start of this section, the examples above appear relatively active, positive and encouraging.

Of course, all of the above is predicated on the assumption that council membership is in regular attendance and consists of people with the power to accomplish change. This is not the case in some state councils.

Council Membership and Attendance

In a discussion with council members and staff, those states which were most successful in fostering coordination emphasized council participation of agency personnel in key program management positions. An agency representative may have the best of intentions, but support is meaningless if that representative does not have the power to make or implement decisions in policy and service delivery. By the same token, council members who do not maintain good attendance at council meetings are less well-informed about problems, council activities and programs, and thus are in a poor position to make decisions about cooperative or other council ventures. Poor attendance, particularly of high-level agency personnel, implies disinterest in the work of the council or of any cooperative efforts, and makes a belief in council legitimacy even harder to maintain.

Several techniques, or a combination of methods, can be used to enhance attendance and support:

- The Pennsylvania Council has very strong attendance requirements for all members. Key representatives of all state agencies are on the council. If such a member cannot attend a meeting, he or she must send a proxy with a letter authorizing the proxy to vote on behalf of the agency. Without such authorization, proxies may not vote or speak to issues before the council. Such incidents are also followed up by a letter of reminder to the agency representative by the Executive Committee, to emphasize the importance of authorization.

- In Tennessee, council staff work with key-position council members to resolve problems informally. In addition, the state Departments of Mental Health/Mental Retardation, Education, Public Health and Corrections have established a new task force on areas for coordination; among other things, high-level agency personnel work together on this task force to resolve service problems in selected highly complex individual client cases.

- The Interagency/External Linkages Committee of the Ohio Council involves the mandated programs and other key programs such as Headstart. This committee reviews state plans, provides a forum for mutual issues and information exchange, presents program reports to the council and conducts cooperative evaluations and other resource uses. The emphasis is on key people from the state and local programs, rather than on administrators of agencies which may represent two or three programs.

- Several states emphasized the importance of agency member participation on all committees as a means of furthering agency interest and understanding. Such members may be extremely busy with agency duties, but are more likely to make positive contributions if they know there are areas in which they can contribute.

- The chairperson of the Pennsylvania Council pointed out the value of the council as a place to acquaint trainees or new management personnel with the service network in a non-territorial way. Such personnel can sit on full council and committee meetings as a means to gain insight into more than just developmental disabilities services. In this way, the council can be an additional resource to state and local providers.

- The Vermont State Council recently provided support to the state Department of Mental Health and the Division of Special Education by giving positive testimony to the state legislature on the budgets of these agencies.

- Regional councils in Maine are composed of the same consumer-provider mix as the state council. These councils engage in joint planning and problem-solving at a more local level of authority. They also serve as a resource to the formalized Information and Referral System of the Bureau of Mental Retardation.

- In South Dakota, the State Council and the Office of Developmental Disabilities are supporting cooperative training of institutional and community service personnel through the state Developmental Disabilities Training Institute (DDTI). In cooperation with state agencies such as the Department of Social Services, the Department of Health, and Vocational Rehabilitation, DDTI and the council pool resources to provide training on such things as:

- the problems of coordinated follow-along community placements and training;
- joint training of Vocational Rehabilitation counselors and Adjustment Training Center personnel.

In addition to providing more uniform, better quality training at a lower individual agency cost, this technique has been found to increase coordination because local providers trained in this manner obtain a better understanding of each other's problems and referral processes. Such an undertaking forces agencies to be aware of the Developmental Disabilities Program as a positive resource.

The above examples show that the council and its administrative arm can take steps to catch and hold the interest of the state and local service network. But there are other problems involved in coordination which are discussed below.

Council Initiation of Coordination

As was stated above, a number of councils appear to see the importance of coordination but lack the knowledge about how to initiate such coordination. Although a number of states have been successful in this, some problems do remain:

- A number of states report that most state agencies and local providers are receptive to the idea of coordination; they realize that in the long run it can save resources. Unfortunately, there are often no short-term incentives to the service network; agencies are unwilling to assume additional responsibilities or alter existing ones without additional funds.

- Federal programs, even within HEW, often have different or no priorities, so there is no policy incentive for state-level cooperation.

- Differing program regulations, standards, clientele and reporting mechanisms hinder interagency solutions to interagency problems. Because these requirements are often dictated from the federal level, state agencies may have little or no control over the lack of uniformity among such requirements. Even where the state does have the option to standardize such requirements, standardization may be unattractive to the service network because of the high costs involved in such a tran sition.

- In states where the council has been weak and where other barriers to cooperation exist, the service network may have a history of competition and turf-guarding that does not provide a climate in which to foster coordination and joint problem-solving. Some providers may also see coordination as a political maneuver which could result in loss of control over their clients or funds.

These and other disincentives exist to some degree in many states. The council may find them extremely hard to overcome, and may have to develop attractive "carrots" to persuade the agencies to cooperate. The council may have to start on a small scale and demonstrate the benefits of coordination before agencies will act on a larger scale. Examples of such incentives have already been discussed above.

Note that several of those examples involve services which affect more than just developmentally disabled people; most state agencies are concerned with larger target groups. Agency decision-makers must see the council as a forum which is sensitive to the wider demands being made upon existing programs. Therefore, the council must not expect that agencies will always put the developmentally disabled first. A council which maintains such an expectation is likely to overlook the fact that it must become a responsive and attractive resource to the service network — through information sharing, legislative advocacy, and mobilization of public support for agency activities.

Of course, the council is not the only starting point for coordinative efforts. Recipients of regional and national significance grants are also a coordination resource for such vital support functions as planning and advocacy:

- The Wisconsin Human Services Classification Project seeks to develop uniform definitions for all public and private providers to use in program planning. Phase I of this project has produced a list of generic service definitions and management (support) functions. These definitions and functions are independent of providers, settings, service objectives and target groups, which shall be defined during Phase II. Using these as part of this project, providers will be able to develop a matrix of definitions which describe specific programs. The classification scheme will be incorporated into the state planning, budgeting and reporting information systems, for uniform, state-level information use. While the primary incentive for this project was a state mandate for cooperative county Social Services/Mental Health plans, and although the project is receiving Developmental Disabilities Program funds, the resulting scheme should benefit all providers, who will be able to speak the same planning "language."

- Demonstrating that coordination should also begin "at home," The Arizona Coalition for Persons with Developmental Disabilities coordinates the advocacy efforts of four disability areas within the state. The coalition monitors and provides input to state legislation; organizes letter-writing and fund-raising campaigns; and provides technical assistance to constituent organizations. The Coalition is planning several specific ventures, including parent training on PL 94-142 and a newsletter to all federal contractors in Arizona on Sections 503 and 504 of the Rehabilitation Act. Unlike many consumer organizations, the Coalition's funding allows it to utilize paid professional staff to coordinate advocacy groups' activities and fill in staff gaps among these groups. A recent major achievement of the Coalition was to provide coordinated individual and group testimony which resulted in the passage of a statewide zoning preemption allowing small group homes.

  The Coalition has informal ties with the State Council, and its private sector emphasis forms a complementary triad with the council (governmental emphasis) and the Protection and Advocacy System (individual cases).

PROBLEMS AND SOLUTIONS IN CASE MANAGEMENT

In the previous section, the discussion centered mainly around coordination from an administrative level: joint planning, policy-setting, and sharing of resources such as training funds and information. This section deals with those elements of coordination which directly affect the client: information and referral, and follow-along and other case management functions.

The lack of case management services is also a major barrier to the delivery of services to the developmentally disabled. The problem is such a significant impediment to deinstitutionalization that the U.S. General Accounting Office recommended to the Congress that:

> Because the lack of coordination and case management at the local level was identified as a major problem, the Congress should consider requiring state Developmental Disabilities Programs to concentrate on the solution to this problem.*

As was noted in state plan analysis, most agencies have a capacity to provide information and referral and some case management services, but many states identified severe problems or gaps in these services. Furthermore, very few objectives or special activities focused on filling gaps or alleviating problems in these services. This points up a serious deficiency in council and service network efforts.

In view of the fact that many states identified problems in this area, it can be assumed that most councils in this sample consider these services to be important. However, this appears to be an area, as in other types of coordination, in which the council may have little idea about where to begin. Some of the same barriers to other types of coordination exist in case management—notably provider fears about loss of control, a problem cited by several states and project directors. In addition, one council executive director stated that some agencies did not understand the concept of follow-along, a problem which may impede obtaining state funds for a follow-along project.

A few states have become directly involved in case management. Several states have established toll-free information and referral hotlines. At least two councils have hired regional case managers but report only moderate success — apparently because the managerial function was not coordinated with local providers.

Implementation of the case management concept may be more mysterious to many council members than the concept of policy-level coordination, and for this reason many councils have either been disappointed with their results or have avoided the issue altogether. However, state councils and Federal Developmental Disabilities Offices have funded a number of projects which have successfully implemented case management services for the developmentally disabled.

*United States General Accounting Office, Returning the Mentally Disabled to the Community: Government Needs To Do More, January, 1977, page 182.

The projects discussed in this paper are not the only projects in the nation which deal with case management services. They are presented here as a demonstration of some of the ways and means being used to achieve coordination at the client level.

Continuum of Services in Rural Areas of Maryland and Virginia

Assistant Project Director: Butch Chambers
Maryland Department of Health & Mental Hygiene
Holly Center

This case management system includes Information and referral, long-term follow-along and individual service coordination needs. Each case manager is assigned to a separate geographic area of the Eastern Shore region of Maryland and Virginia. Case managers meet monthly and share resources. As needed along the state border areas, referrals may be made across state lines.

An interesting aspect of this project is that each case manager is responsible for knowing the residents at Holly Center Institution from his or her area; case managers share release plan development with the Holly Center case worker. Knowing both the individual resident and the locality, the case manager can sometimes find a more appropriate situation in the community for a certain resident than can the Center worker.

The case managers have proven to be a definite resource in these rural areas; the project is considering expanding into the state of Delaware in the coming year.

Client Centered Management System

Project Director: Manfred F. Drewski
Division of Mental Health
New Hampshire

The Division of Mental Health is implementing this project through contracts with the private regional mental health boards in New Hampshire.

The focus of the case managers will be upon the complex needs of semi-dependent clients. In the initial project phase, effort will be made to study the referral and case managerial process and to estimate optimum caseloads. Once these parameters have been established, the Division of Mental Health, and the Departments of Public Health and Public Assistance will enter into referral agreements concerning use of the case managers.

Rural and Urban Models for Local Services Coordination

In order to demonstrate the feasibility of local coordination, the Ohio Council gave grants to the Columbus North Area Mental Health Center (urban) and to Ohio University at Athens (rural). Both projects utilize local interagency committees to address administrative matters and individual cases. The urban model concentrates more on systems coordination and on the specialized needs of people with multiple diagnoses; the rural model deals with all age groups and levels of impairment and the local committee more frequently addresses individual cases. Both models have proved successful. Among other outcomes, psychologists in the urban model now feel comfortable serving the developmentally disabled.

Coordinated Regional Service Delivery Systems for Services to Developmentally Disabled Persons

Project Director: Constance Halter
Bancroft School & Community Clinical Services
Haddonfield, New Jersey

This project seeks to establish a flexible function for county case managers, in managing individual cases between agencies. In order for the case manager function to be responsive to local needs, the counties involved in this project were asked to assess their needs for this function. In most participating counties the function is expected to involve collaborative intake and follow-along. A regional planning committee will also keep track of local needs to enable the case managers to better respond to them. The program or agency where the case manager is physically located will contribute some in-kind support to the case manager; however, additional funds are needed to provide such case management support as counseling and verification.

In addition to the above individual case manager functions, several other projects are utilizing the team and other resource concepts to provide coordinated service delivery. Two of these projects are described below.

Comprehensive Rural Service Delivery System for the Developmentally Disabled

Project Director: Kathy Lively
Appalachian Mental Health Center
Elkins, West Virginia

In the rural areas of West Virginia, the Mental Health Centers are the source of most services specifically for the developmentally disabled. Five service workers are working in ten rural counties to fill gaps in these services using volunteer agencies and other resources. Some case management, including follow-along, is involved in this activity. The workers attempt to concentrate on the most complex cases, for whom education and other programming is often difficult. During the first year, workers have done current and projected (five years) needs assessments on individuals, to collect data for future program development.

This project has organized "councils of agencies" in several of the larger counties in the project area to assist in group problem-solving and to develop awareness of the needs of the developmentally disabled.

Transportation is, of course, a major problem in this area. Service workers are using volunteer agencies whenever possible to provide transportation; in addition, the workers are going to step up home visits to clients. As an example of their work, a regional transportation system, operating between county seats in this area of the state, was being underutilized. Members of this project, familiar with the handicapped people in this region, were able to demonstrate a need for transportation to other areas of the region; they were able to persuade the system to alter some routes to serve the handicapped on routes off the main state roads.

Regional Special Projects Program

Project Director: Mrs. Martha Turner
Owsley County Board of Education
Booneville, Kentucky

A three-pronged resource network is being used by this project to provide comprehensive education, health and social/welfare services to pre-school children and their parents/families:

- paraprofessionals
- professionals from a variety of disciplines
- local interagency committee

Paraprofessionals do home visiting and train parents in home developmental care; these workers also work with children (in) at a project center under the supervision of a professional team. While the county board of education has a mobile education facility for outreach to the school aged homebound, the paraprofessionals are able to complement this outreach effort by concentrating on the needs of the developmentally disabled, ages birth to six years.

The state Department of Education, the regional Mental Health Agency, the regional Health Agency and others provide traveling specialists, who are consulted by this project as needed.

An interagency committee representing health, mental health, social and education servies and Community Action Agencies will develop a plan of action in individual cases involving complex needs, or in cases where the provision of family services will enhance the child's progress. Participating agencies have agreements of confidentiality and participate in quality control reviews. This committee has been instrumental in reducing duplication of services and increasing the complementary nature of comprehensive services.

Note that, while the focus of this program is education, there is an understanding of the need to coordinate all serivces to improve the impact of education.

Early Intervention: Link Rural Needs with Urban Resources

Project Director: Margaret Burns
Infant Development Center
Pineland Center, Maine

In order to achieve comprehensive early intervention in a rural setting, this project has established an outreach team consisting of a home worker, a psychologist, a physical therapist and an educator to rotate among satellites attached to local providers. When the team establishes a need for more comprehensive evaluation than can be given locally, the child is transported to the Infant Development Center.

In order to make this concept work, the first task of the team was to become known in the local community. The team met with all agencies in the area to introduce themselves and their purpose, and to advertise the fact that referrals could be made to them for screening. Because so few services are offered in rural areas, parents often do not try to obtain services for their preschool children; but after the first referrals, knowledge about the satellites traveled quickly by work of mouth and other parents rapidly began to seek services there. The word-of-mouth process worked well because these services are so badly needed in rural communities.

The team works closely with local teachers and education evaluation teams to set up optimum individual programs for children of school age. Some indicators of project success:

- At its inception, physicians were reluctant to refer patients to the team because it provides nonmedical services. However, confidence in the work of this project has increased to the point where referrals from physicians have increased by fifty percent since the inception of the project.

- The state Department of Education is already planning to budget these positions to ensure continuation of these services when the project ends.

- The project director has been appointed to a state education commission on preschool programming.

The projects reviewed above share certain traits which apparently add to their success:

- Systems coordination at the local level is viewed as a basic component of the case management function.
  These basic projects foster formal or informal meetings of local providers to iron out referral and administrative procedures, to do some cooperative planning, and to develop program plans or support mechanisms in very complex individual cases.

- Not all developmentally disabled people are expected to need case management services.
  Many clients who need only short-term, sporadic services, or who can have all of their needs handled by one agency, may not need these services from a specialized developmental disabilities case manager. In most cases, this special case managerial function is expected to concentrate on cases with complex individual or family needs, multiple disabilities and programming requiring services from several agencies. Decisions about the need for case management services are made jointly by the client or the client's legal representative and the case manager.

- The case manager function has certain overall objectives but is extremely flexible in style of implementation.
  Just as the needs of the individual vary, so do the socio-policital climate, the available service and other resources, and the personalities of the case managers, from area to area. Emphasis is on appropriate individual solutions, not on uniform solutions or on certain services or providers.

- No pressure is placed on skeptical providers to buy into the case management system.
  As was noted above, some providers may view the case management function as a threat to their jurisdiction over the client. Emphasis in these projects is on demonstration of the benefits of the function, even on a very small scale, with a few providers; once these benefits are demonstrated, providers are more receptive to the use of the case manager.

- The case manager function does not expect to rely solely on Developmental Disabilities Program funds.
  The case managers use a variety of other resources to support their own activities as well as to finance services for clients. Local programs may provide office supplies, secretarial help, or consultation on complex cases. At the state level, efforts to find permanent funding for the case managers are begun early in the life of the project, to avoid a hiatus when special project funds run out. Because the case manager function is seen as a means or enhancing services provided by most agencies, permanent funding and expansion of the case management program are already anticipated by some of the projects examined here.

METHODOLOGY & LIMITATIONS: COORDINATION & CASE MANAGEMENT IN THE DEVELOPMENTAL DISABILITIES PROGRAM

Methodology

For the purposes of this analysis, the following data were collected from twenty-nine Fiscal Year 1978 developmental disabilities state plans:

- By agency (Section III of state plans): - agency/program objectives pertaining to coordination - problems in coordination - current coordination activities and their targets
- Barriers to coordination (Sections III & IV).
- Current council coordination activities (Section V)
- Objectives pertaining to coordination (Section VI):
  - nature of objectives
  - participating agencies or groups
  - priority of goals
  - targets of the objectives
  - relationship to the four major Developmental Disabilities Program goal areas (deinstitutionalization, community alternatives, early intervention, adult programs).

These data were arranged by organization (council or agency) and strategy (current activity or plan year objective) to determine the trends, strengths and weaknesses in coordination across the sample states.

In order to examine these data in a meaningful way, they were grouped by type of coordination described in the objective or activity as follows: case management, participation, facilitation, and control.

In order to assess the importance of coordination in the sample states, the following areas were reviewed:

1. Coordination problem areas - the number and type of barriers identified by the council (Section IV) and the service network (Section III) in each state; note was made if barriers were vague or non-specific.

2. Coordination activities - whether the council (Section IV) and service network (Section III) activities were identified in the plan. The provision of case management services by the service network were not counted as activities for this assessment, since in many programs such services are mandated, or a practical necessity, not an indication of importance; however, activities concerned with the improvement or support of case management services were included. Note was made if the activities were too vague or non-specific for their targets to be identified.

3. Coordination objectives - whether the council (Section VI) and the service network agencies (Section III) listed objectives relating to

coordination. While valid for the council this is a poor indicator of the importance of coordination to the service network; not all plans contained agency goals and objectives, although at least some agencies in each state are presumed to have formal goals and objectives. As with coordination activities, some case management services objectives were excluded because they were merely references to what an agency was already doing. Note was made if the objectives were too non-specific for their targets to be identified.

4. Goal priorities - for council (Section VI) objectives, the priority of each goal involving coordination targets was ranked as high, medium or low.

5. Barriers addressed by objectives - the proportion and type of barriers addressed by the plan, including the proportion of barriers addressed which related to the four Developmental Disabilities Program goals. This review gave an indication of whether the council is prepared to identify and contribute to solutions to state coordination problems.

6. Coordination as a tool - indicates whether the council and service network coordination activities and objectives address problems other than coordination and case management, i.e., whether coordination is viewed as a positive means to improve services for the developmentally disabled. This indicator has a bearing on how the council and the agencies view coordination strategies for general problem-solving.

7. Importance of coordination - an assessment of the degree of importance to both the council and the service network, based on the six factors above, and upon the factor of bias — the analyst's assessment, based on EMCI experience, that more may be going on in the state than is actually stated in the plan.

Finally, this analysis was supplemented by an evaluation of council involvement in coordination, as well as problems and potential ways to increase that involvement. Based on the results of this analysis, additional information was collected from the following sources:

- Phone calls to selected states, for data clarification and to obtain details of exemplary coordination strategies.

- Review of reports, proposals and other literature from projects of regional and national significance, to enhance discussion of exemplary coordination projects.

Limitations of the Data and Analysis

Limitations of the data are twofold. First, the poor quality and the incompleteness of some state plans may have masked some activities. Second, while coordination is one of the mandates of the Developmental Disabllitites Program, it is actually a means to the end of improving the utilization of services and reducing unnecessary duplication of effort. As such, barriers and agency/council efforts in coordination were not given as much attention as, say, the services needed and provided by the service network. While the data collection methodology attempted to overcome this problem by comprehensive review of the state plans followed by phone contacts

(this page was inadvertently left out of the printed document)
for clarification, it is likely that some valuable state coordination activities, not noted in the plans, were not given attention in this paper.

In addition, the state plan itself is understandably service-oriented. Except as coordination pertains to case management and information and referral services, the Develpmental Disabilities State Plan Guidelines format does not force the examination of coordination in the state. Even though provision is made tor examination of "Adult Programs" (state plan paragraph 4.3) and council activities in "Interagency Coordination" (state plan paragraph 5.3), if a state chooses not to analyze these paragraphs in detail, much information on the status and need of coordination may be lost. The same is true of the agency analysis (Section III): many states did not report agency/service network barriers or gaps that do not relate to specific services, unless they present major, overriding problems in the provision of services.

As a result, the analysis is highly subjective. The minor treatment given coordination in most plans left the analyst to conjecture the probable impact of coordination activities on the service network.

Given the comparatively specific requirements for agency services and gaps analyses, it is not surprising that twenty-five of fifty-four state plans contain no specific information on coordination, other than agency data on information and referral and follow-along services. The purpose of this state plan analysis was to characterize and evaluate what is going on in the states, so these twenty-five plans were rejected from the sample. The fact that these plans contain no information on coordination does not mean that coordination does not occur in these states, or that it is unimportant. Indeed, data from two state plans in the sample indicated that coordination was unimportant in those states, but it is known from EMC Institute experience in those states that coordination is a major part of council activities. Apparently coordination is so much a fact of life in some states that the activity is not specified in the state plan.

It was felt that phone calls to the rejected twenty-five states would serve no useful purpose: without sufficient background information on these states' coordination activities, such calls would only yield general information not suited for this analysis.

To some extent, the assessment of the importance of coordination to agencies and councils suffers from the same problem. An attempt was made to correct this through phone calls to selected states and through input from EMC Institute Regional Technical Assistance Coordinators. The assessment data was also weighted, in cases where plan data gave a conflicting impression that suggested that coordination received more emphasis in actual practice than was evident in the plan.

Probably, the biggest hole in the data is in agency objectives and availability of services: although the planning guidelines call for the inclusion in the state plan of agency goals and objectives for any agency, it is more probable that these states simply did not include this information, rather than that no agencies have goals and objectives which pertain to the developmentally disabled. Few states gave analysis of factors affecting service availability; again, this is probably negligence rather than lack of barriers and other factors.

Prepared by:

EMC Institute
24 Maplewood Mall
Philadelphia, Pa. 19144