



PROGRAM ISSUE REVIEW

THE RELATIONSHIP OF
DEVELOPMENTAL DISABILITIES PROGRAM
ACTIVITIES
TO GAPS & BARRIERS

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The opinions expressed herein do not necessarily reflect
the official position of the Bureau of Developmental Disabilities.

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PREFACE

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

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

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

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

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

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

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INTRODUCTION:

THE RELATIONSHIP OF DEVELOPMENTAL DISABILITIES PROGRAM ACTIVITIES TO GAPS & BARRIERS

This Issue Paper, one in a series prepared by EMC Institute, provides a national perspective on the relationship of Developmental Disabilities Program goals, objectives and implementation plans to the gaps and barriers in services identified in Fiscal Year 1978 developmental disabilities state plans.

The objectives of this analysis are as follows:

1. To determine the extent to which major categories of state plan goals and objectives respond to the major categories of gaps identified in state plans.
2. To determine the extent to which major categories of state plan goals and objectives address the major barriers to special program needs and service provision identified in state plans.
3. To identify major gaps, needs or barriers not addressed by goals and objectives.
4. To identify any goals and objectives that do not address major gaps and barriers.
5. To compare designs for implementation and planned expenditures of funds to the gaps and barriers identified in state plans.

This paper is based on separate analyses contained in the following papers in this Program Issue Review series: "Gaps and Barriers in the Developmental Disabilities Service Network," "Goals and Objectives of the Developmental Disabilities Program," and "Designs for Implementation." The analysis, methodology and details of these three subjects can be found in those papers. The inter-connections among them are discussed here.

CONCLUSIONS & IMPLICATIONS:

THE RELATIONSHIP OF DEVELOPMENTAL DISABILITIES PROGRAM ACTIVITIES TO GAPS & BARRIERS

The goals, objectives and implementation plans which appear in Fiscal Year 1978 state plans do address the gaps, barriers and special needs identified by state councils in those plans. The analysis was able to track each of the twelve major program problem areas, shown on Table 1, through long-range goals and plan year objectives, because of the frequency with which these problem areas were addressed.

However, the relationship of program activities to problem areas is not a direct, obvious relationship for all problem areas covered in the analysis:

.The ordering of goals and objectives does not always reflect the priorities of the problems identified. The relationship between problem areas and activities is obvious for such major state needs as deinstitutionalization and community alternatives, which are also among the most frequently mentioned goals. However, strategies to overcome some other program areas are often incorporated into goals which address other needs. For example:

- Day care is the second most frequently mentioned gap in the state plans reviewed, as shown by Table 7. Yet day care is not the target of any long range goals or of the most frequently used objectives identified for this analysis. Instead, many day care gaps are addressed as part of the effort to implement deinstitutionalization and community alternatives.
- In the same context, lack of public awareness - a major barrier to the development of services - was addressed under such goal areas as early intervention and community services, as well as those dealing with awareness and advocacy.
- Lack of funds for services was dealt with by funding new services and also by emphasizing inter-agency coordination of services to avoid duplication of expenditures.

These indirect means of dealing with problem areas show that councils are aware of the systems implications of these problems. For example, day care is viewed as a support service to community programs rather than an end in itself. Thus some state plan activities are indirectly responsive to identified problem areas.

. The amounts of funds allocated to the problem areas identified in the state plans do not correspond to the relative seriousness of the problem areas. As Table 1 shows, "money for services" was the target of the largest block of allocations, even though specific systems or barriers (such as public awareness and deinstitutionalization) received more mention as problem areas. This lack of correspondence between priority and allocations is only an apparent discrepancy; some problem areas, such as public awareness, require much effort in terms of time but little in terms of money.

Of the objectives reviewed for this analysis, only two types appeared to have no relationship to the identified problem areas: "Administration of Programs" (council functions objectives), and "Monitor and Evaluate Services," which appears under several types of goals. The first deals primarily with council housekeeping. The second, while it does not directly relate to meeting the specified problem areas, is a support function - as well as a council mandate - which can contribute to fulfillment of those goals which do relate to the problem areas.

From the above, it can be stated that councils are responding to the major problem areas in their states.

TABLE 1

PROBLEM AREAS, GOAL CATEGORIES & FUNDING TARGETS
IN ORDER OF MOST FREQUENT MENTION
IN FY 1978 DD STATE PLANS

<u>PROBLEM AREAS (A11)</u>	<u>GOAL CATEGORIES</u> (6 most frequently mentioned)	<u>FUNDING TARGETS</u> (6 most frequently mentioned)
Gaps: Special Living Arrangements	Deinstitutionalization	Money for Services
Day Care	Prevention/Early Intervention	Deinstitutionalization/Community Alternatives
Needs: Case Management	Quality of Services	Transportation
Deinstitutionalization and Community Alternatives	Community Alternatives	Case Management/Adult Services
Adult Programs	Public Awareness	Public Awareness
Prevention	Increase Services	Prevention & Early Intervention
Barriers:		
Public Awareness		
Money for Services		
Transportation		
Information		
Personnel Development		
Council Orientation		

FIGURE 1

DEVELOPMENTAL DISABILITIES PROGRAM PROBLEM AREAS,
GOALS & OBJECTIVES IN FY 1978

PROBLEM AREA	GOALS	OBJECTIVES
	DEINSTITUTIONALIZATION	Community Programs Appropriate Placement Institutional Reform
SPECIAL LIVING ARRANGEMENTS	PREVENTION AND EARLY INTERVENTION	Early & Periodic Screening, Diagnosis & Evaluation Public Awareness Home Training
DAY CARE		
CASE MANAGEMENT	QUALITY OF SERVICES	Monitor & Evaluate Services Public Awareness Institutional Reform
DEINSTITUTIONALIZATION & COMMUNITY ALTERNATIVES	COMMUNITY ALTERNATIVES	Alternative Living Arrangements Support Services Public Awareness
ADULT PROGRAMS	PUBLIC AWARENESS	Educate General Public Educate Service Providers Educate Legislators
PREVENTION		
	INCREASE SERVICES	Identification Services Educational Services Transportation Services
PUBLIC AWARENESS		
MONEY	PLANNING	State Plan Implement legislation Plan for Community Programs
TRANSPORTATION		
INFORMATION	PROTECTION & ADVOCACY	Establish & Support P & A System Information Development
PERSONNEL DEVELOPMENT		
COUNCIL ORIENTATION	COUNCIL FUNCTIONS	Administration of Programs Council/Staff Improvement Public Awareness
	ADULT SERVICES	Provide Services Improve Services Increase Funding
	ADVOCACY/INFLUENCING	Public Awareness Support P & A System Monitor and Evaluate Services
	COORDINATION	Interagency Coordination Service Integration Influencing

DATA & ANALYSIS:

THE RELATIONSHIP OF DEVELOPMENTAL DISABILITIES PROGRAM ACTIVITIES TO GAPS & BARRIERS

For the purpose of this analysis, Developmental Disabilities Program goals, objectives and activities are analyzed for their responsiveness to program "problem areas:" the service gaps and special program needs and barriers emphasized as major problems in Fiscal Year 1978 state plans. These problem areas are ranked in the left-hand column of Figure 1 by their frequency of mention in the plans. Categories of long range goals are ranked by frequency of mention in the center column of Figure 1. The two or three types of plan-year objectives most frequently used to satisfy each of these goals is given in the right hand column of Figure 1.

There are few obvious one-to-one relationships between the problem areas and the goals and objectives listed on Figure 1. However, a more detailed analysis shows strong correlations among these lists. The following paragraphs discuss the major gaps, barriers and program needs identified by the states and the direct and less obvious ways in which they are addressed in long range goals, plan year objectives and allocations of DDSA funds.

Problem Areas: Special Living Arrangements, Deinstitutionalization and Community Alternatives

The problems are discussed together because the states perceive a clear connection between the program needs for "Deinstitutionalization" and "Community Alternatives," and the service gap in "Special Living Arrangements;" the removal of Inappropriate placements and the utilization of community services cannot be realized until appropriate living facilities exist in the community. Of the forty-eight (48) states which identified gaps in services, seventy-seven percent (77%), cited gaps in special living arrangements -making this one of the most critical gaps in developmental disabilities services nationwide. Forty-eight (48) of fifty-three (53) state plans discussed needs for deinstitutionalization and community alternatives, with the following frequency:

Improve or establish community programs (broadly addressed)	68.7% of reporting states
Establish community placements or residential facilities	64.6%
Institutional Reform	48.3%
Upgrade Services	37.7%
Non-specific	21.2%

Figure 2 illustrates the response of the states to this problem area. Objectives directly addressing the development of alternative living arrangements are a common feature under "Community Alternatives" goals, in order to fill the identified gaps in community residential facilities. Note that objectives designed to further deinstitutionalization and community alternatives are also given under goals relating to "Planning" and "Quality of Services."

Of these objectives addressing these problem areas, those referring to "Appropriate Placement" and Institutional Reform" tend to be less measurable and specific than the other objectives (although some institutional reform objectives do detail critical steps for upgrading institutional care). The lack of specificity may exist because these objectives are a direct reference to the language of 1386.42; councils should adopt more specific, measurable language in writing objectives for such areas.

Fiscal Year 1978 funds going toward these problems in thirty-six (36) states are as follows:

DDSA allocations	\$2.573 million
Non-DDSA contributions	2.974 million
Total Funds	5.547 million

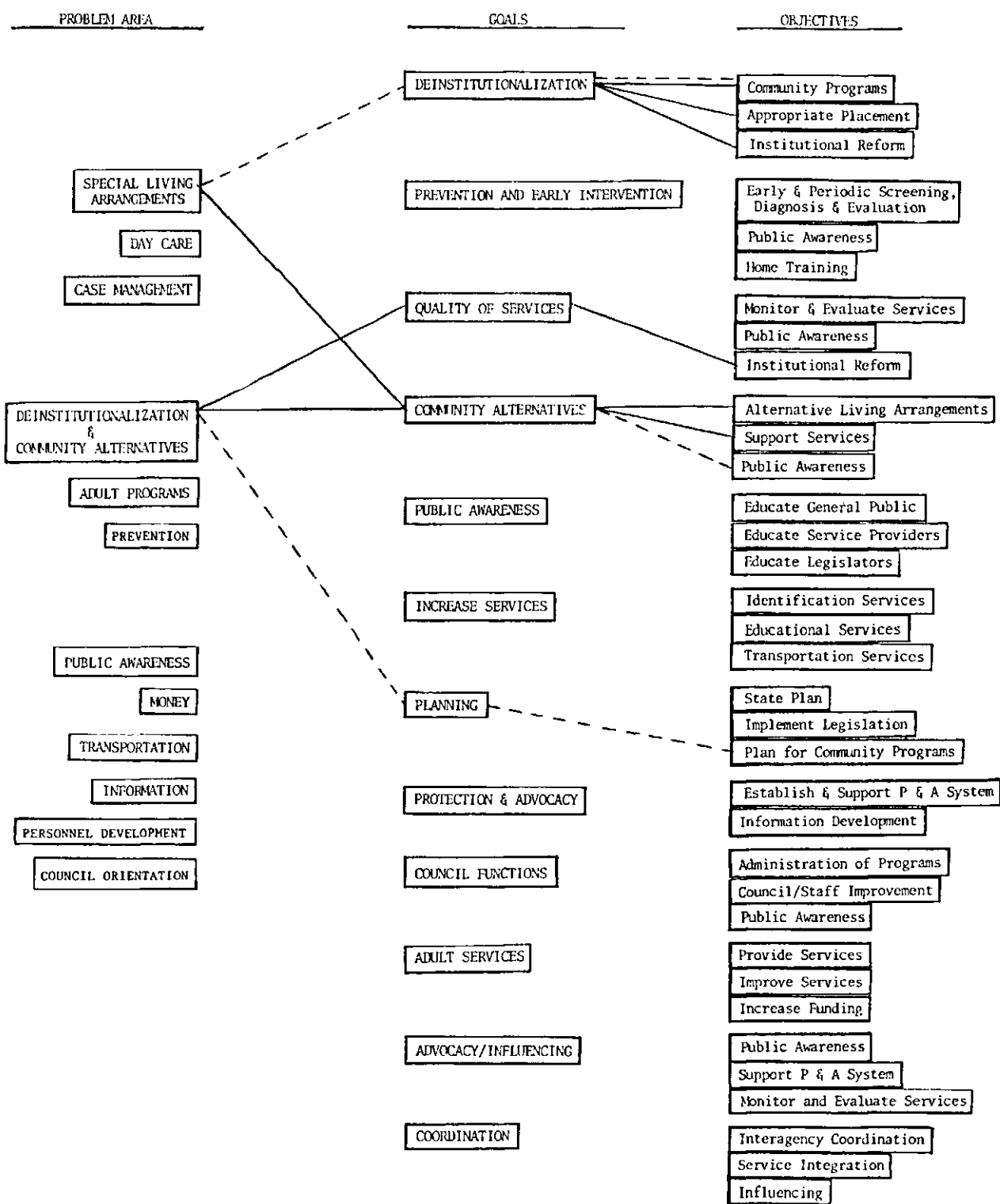
These funds represent twenty-three percent (23%) of all funds going to state Developmental Disabilities Formula Grant Program activities in Fiscal Year 1978.

Of course, more money may actually be going to these problem areas than is shown by this nationwide analysis. Less frequently used objectives under such goals as "Adult Services" and "Increase Services," for example, also address services which affect the continuum of community alternative services. As with other problem areas, these figures also do not reflect in-kind contributions from other sources, particularly time donated by key agency decision makers in joint planning.

Note that objectives to increase public awareness are a major component of "Community Alternatives" goals. Public awareness is itself a major problem area and will be discussed below.

FIGURE 2

GOALS & OBJECTIVES RELATING TO DEINSTITUTIONALIZATION,
COMMUNITY ALTERNATIVES & SPECIAL LIVING ARRANGEMENTS



———— DIRECT RELATIONSHIP

----- INDIRECT RELATIONSHIP

Problem Area: Day Care

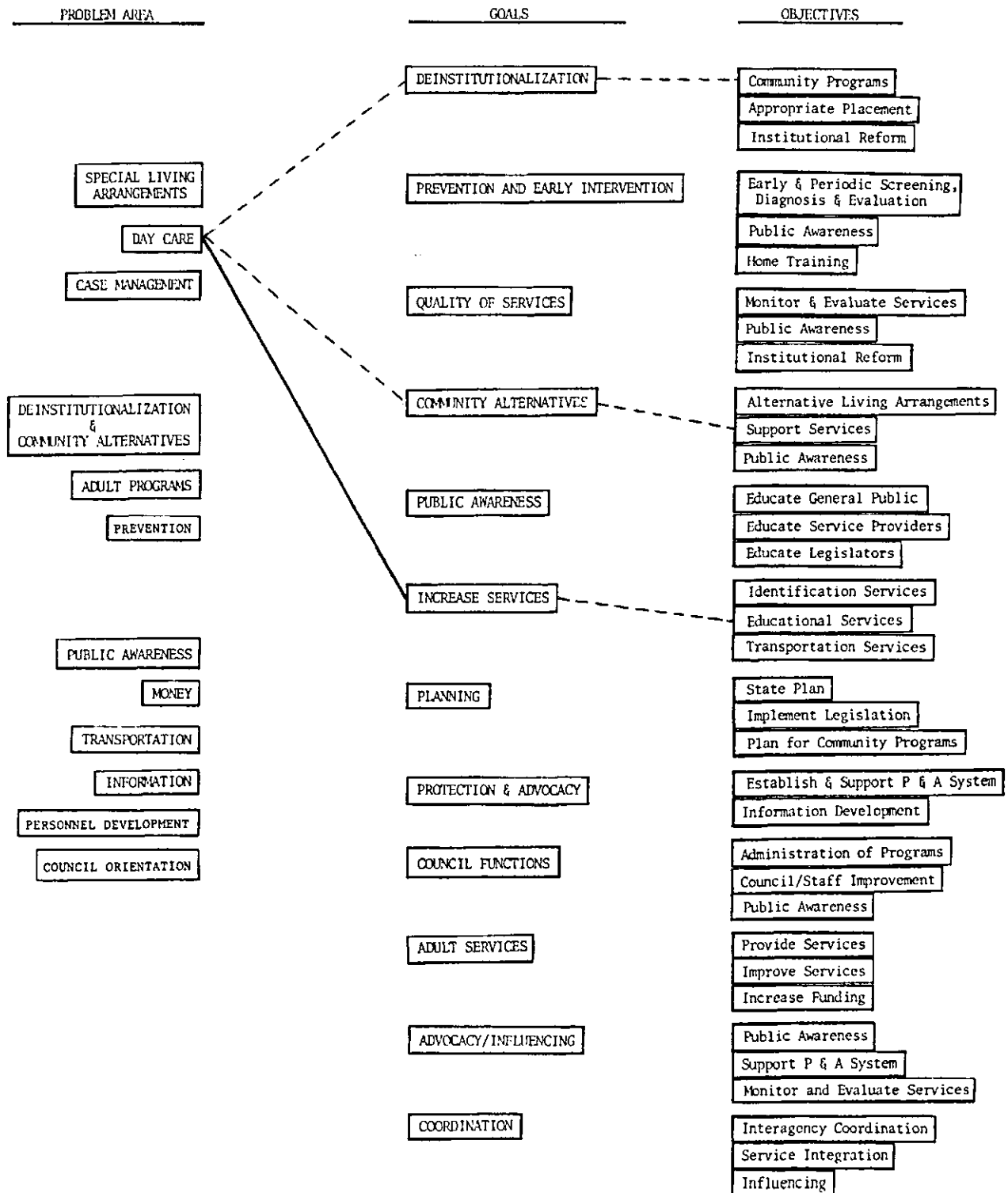
Over half of the thirty-nine states which identified gaps specified service gaps in day care. As such, day care is a critical gap nationwide, second only to gaps in residential services.

The lack of day care services affects a wide variety of other community programming. Developmental day care may affect a young child's ability to participate in regular school classes later on; it may affect the utilization of special education, sheltered workshops and other services which do not involve full-day programming. Because of this fact, day care service gaps are dealt with indirectly, under goals for other services. The relationship of day care gaps to Fiscal Year 1978 goals and objectives is given on Figure 3.

Because day care is addressed indirectly, it is not possible to specify how many DDSA or other funds are going toward this service.

FIGURE 3

GOALS & OBJECTIVES RELATING TO DAY CARE



———— DIRECT RELATIONSHIP

----- INDIRECT RELATIONSHIP

Problem Areas: Case Management & Adult Programs

Gaps in case management services - counseling, protective and particularly follow-along services - are examined with the special needs of adult programs, because of the relationship between these two problem areas.

Seventy percent (70%) of the states which identified gaps cited major gaps in case management services, particularly follow-along. Coordination of services and agency planning was identified as a need by nearly two-thirds of the states, and was addressed as a need relevant to adult programs by forty-four percent (44%) of the states.

Not only are the above areas major problems in themselves, they affect the ability of the service system to develop community alternative programming and to coordinate any service delivery. Their absence can weaken an otherwise comprehensive service system. For this reason, states have addressed case management gaps through objectives pertaining to the goals of "Community Alternatives" and "Coordination," as well as "Adult Programs" and "Increase Services."

In goal implementation planning for adult programs, most states also concentrated on providing or improving discrete services such as training, education and employment.

Also note on Figure 4 that "Increase Funding" is a major objective under adult programs. Lack of funding is a major barrier to most Developmental Disabilities Program areas, as is discussed below. It is apparently most acute in adult programming because adults are the largest group not given comprehensive services under existing legislation, in contrast to the school age group which is addressed by PL 94-142.

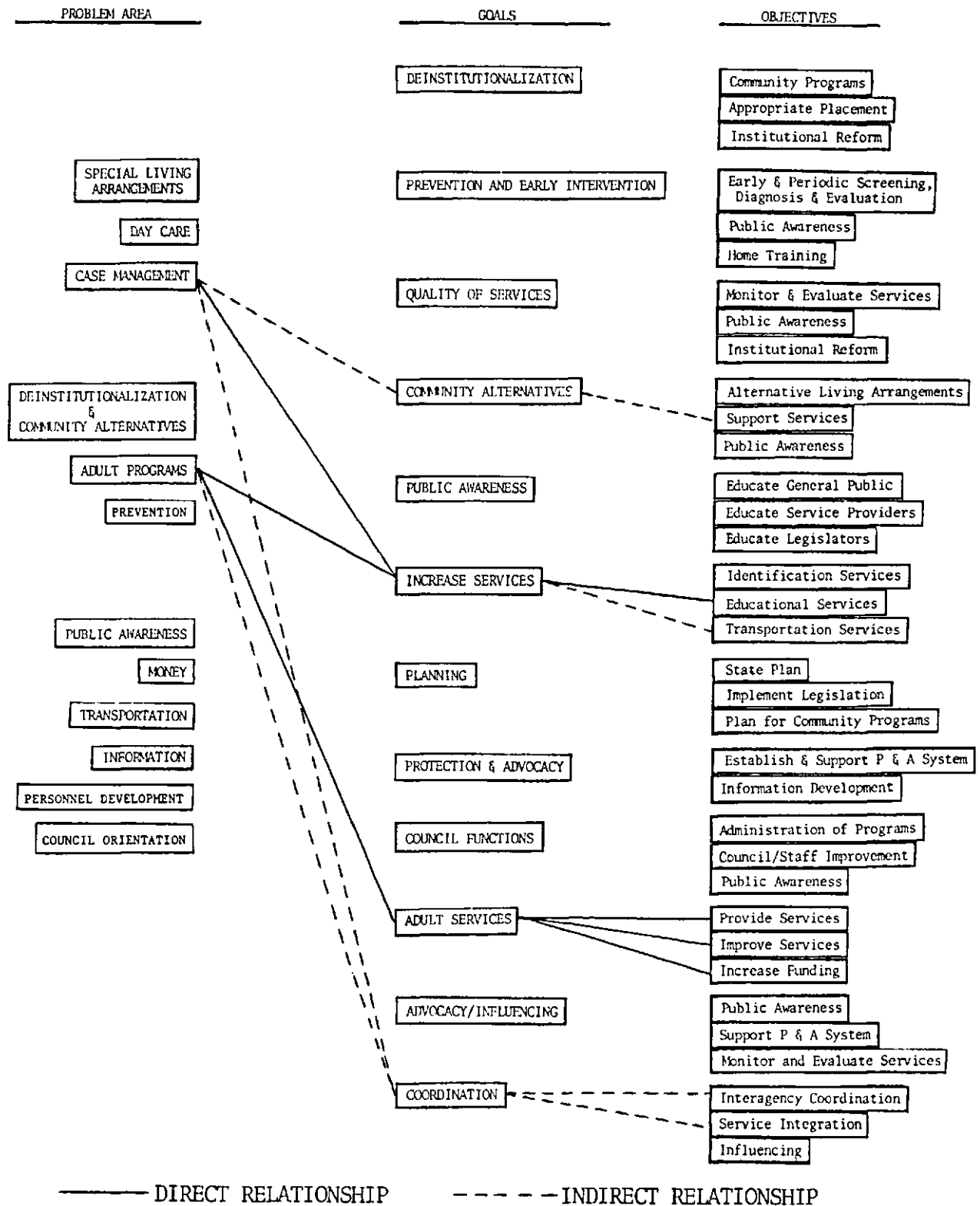
Fiscal Year 1978 funds in thirty-six states going to these areas are as follows:

DDSA allocations	\$1.188 million
Non-DDSA contributions	0.801 million
Total Funds	1.989 million

Once again, additional funds going toward "Increase Services" and toward "Deinstitutionalization" and "Community Alternatives" are also likely to impact on coordination and the adult services continuum.

FIGURE 4

GOALS & OBJECTIVES RELATING TO CASE MANAGEMENT
& ADULT PROGRAMS



Problem Area: Prevention & Early Intervention

Thirty-six (36) states cited needs in the area of Prevention and Early Intervention; seventy-five percent (75%) of these states addressed this area broadly, without mention of specific needs; thirty-nine percent (39%) cited a need for the expansion or improvement of early screening, diagnosis and evaluation; nearly seventeen percent (17%) cited a need for parent training. In addition, major gaps in identification services were identified by over fifty percent (50%) of the states which identified service gaps. This places early intervention as a justified major goal area as shown on Figure 5. Note that "Public Awareness," a problem that affects most program areas, is the second most frequent objective used to address this goal area. Public awareness of services and of the rights and abilities of the developmentally disabled are an essential factor in the success of early intervention and prevention services.

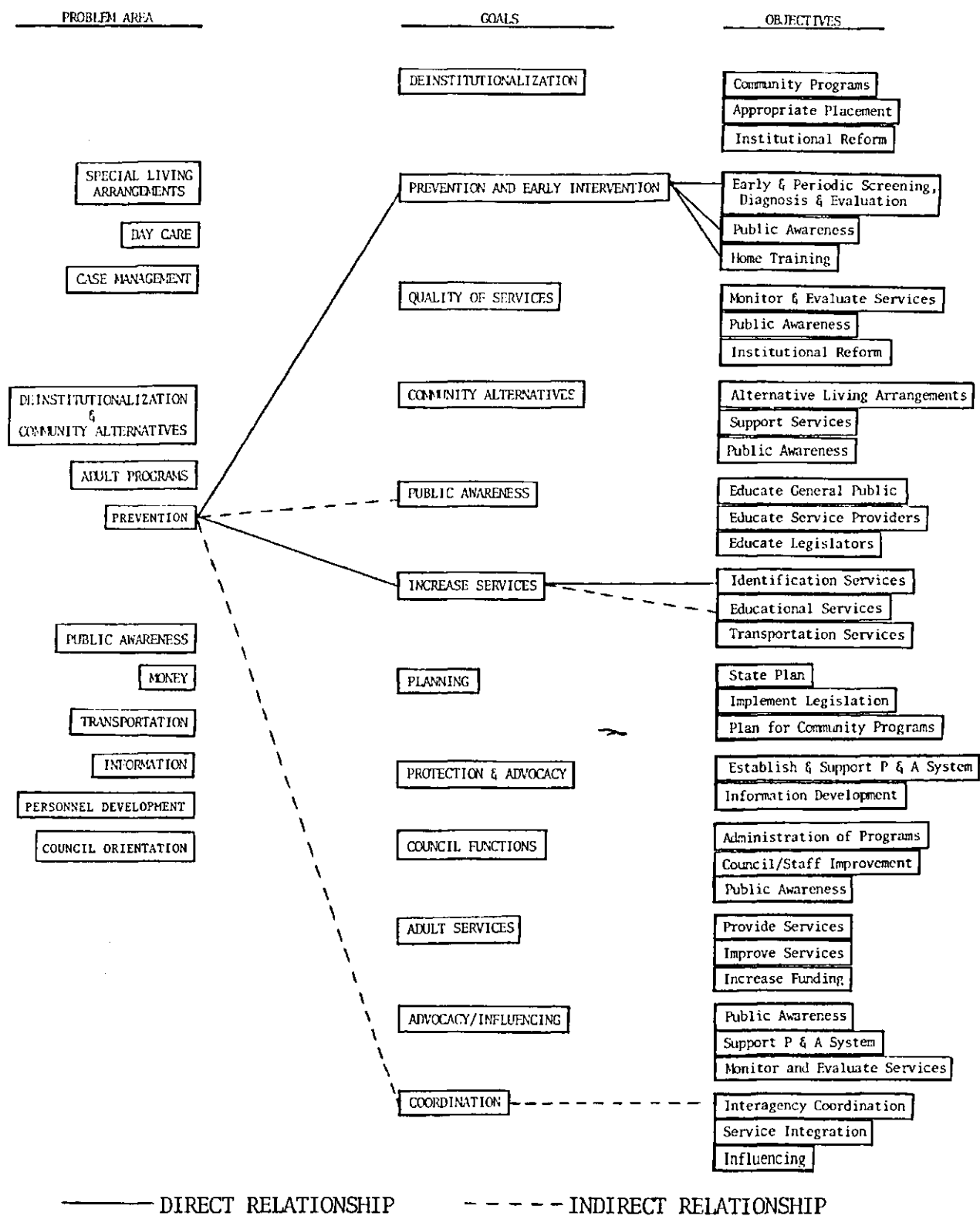
The majority of Fiscal Year 1978 funds going to these services are probably under "Prevention and Early Intervention" objectives:

DDSA allocation	\$0.274 million
Non-DDSA contributions	0.561 million
Total Funds	0.835 million

Note that over two-thirds of the money earmarked for this problem area is from non-DDSA sources; most of these contributions are state monies.

FIGURE 5

GOALS & OBJECTIVES RELATING TO "PREVENTION"



Problem Area: Public Awareness

Sixty-two percent (62%) of the states cited needs for public awareness and education and for protection and advocacy. Figure 6 shows the wide impact of public awareness on other program areas. Appropriate education is essential to get public and legislative support for program funding, to get cooperation of service providers, to break down the barriers to acceptance of the institutionalized developmentally disabled in the community, and to the comprehensive outreach function of early intervention. As such it forms a major strategy for a number of problem areas.

Funds going to "Public Awareness" objectives are as follows:

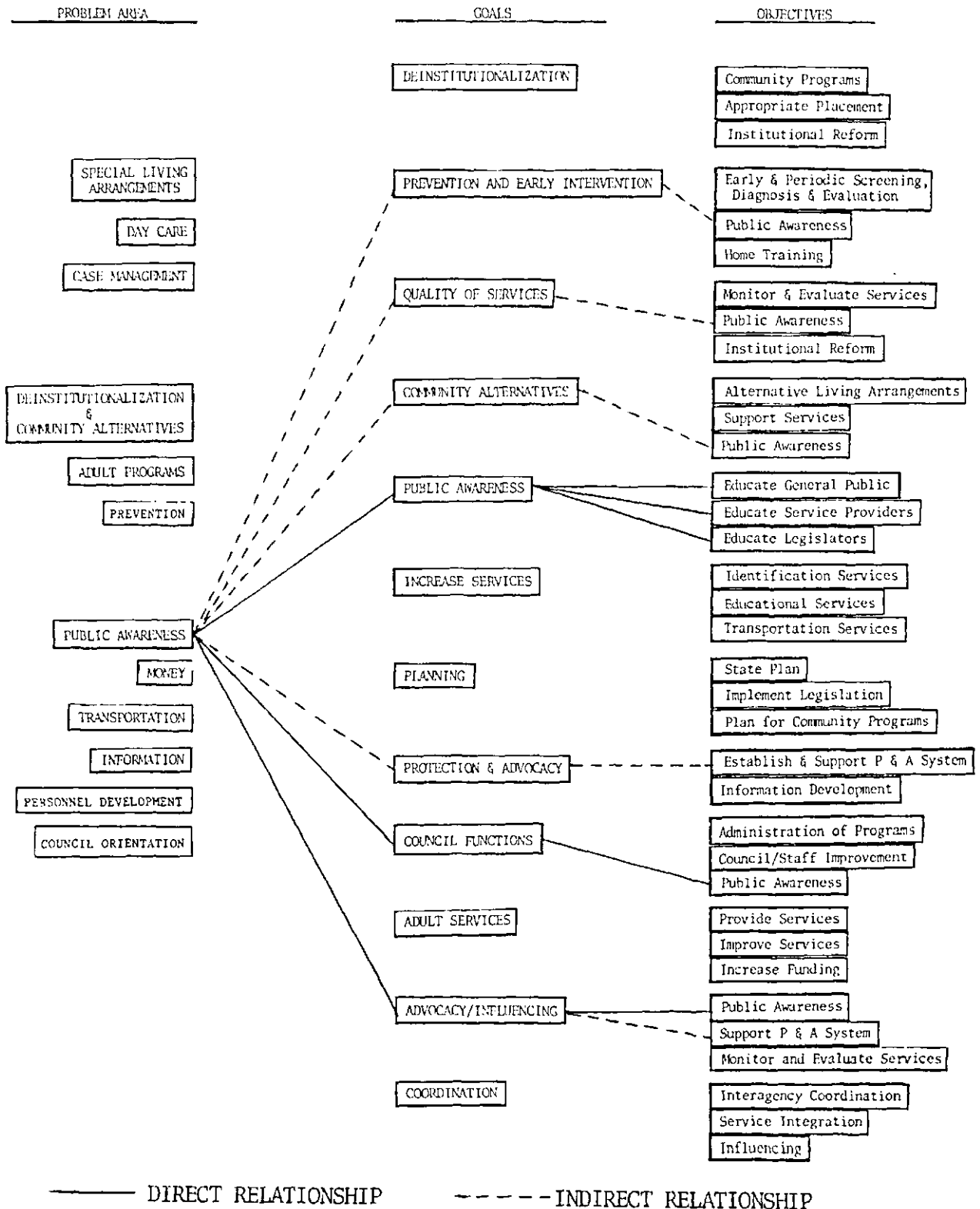
DDSA allocations	\$0.890 million
Non-DDSA contributions	0.163 million
Total funds	1.053 million

It is likely that at least some objectives categorized as "Advocacy" and "Influencing" actually involve public awareness activities. If so, then some of the \$1.359 million in "Advocacy/Influencing" funds should also be added to the above total.

In addition, public awareness strategies are particularly susceptible to augmentation by in-kind contributions. While the council may spend initial funds to develop films, radio spots, newsletters and so on, most media and public utilities offer low or no-cost strategies for disseminating information over large areas of the state. Thus, the total dollar value of the activities being carried out under "Public Awareness" may be much larger than can be shown by an analysis of implementation plan allocations.

FIGURE 6

GOALS & OBJECTIVES RELATING TO PUBLIC AWARENESS



Problem Area: Money

Twenty-six (26) of fifty-three (53) states, or fifty-four percent (54%), cited lack of funds to expand services as a major barrier in the Developmental Disabilities Program. While funds from various programs are actually available to provide additional services, dollars are often available only as reimbursement for services provided. This problem impacts heavily on the development of community alternatives.

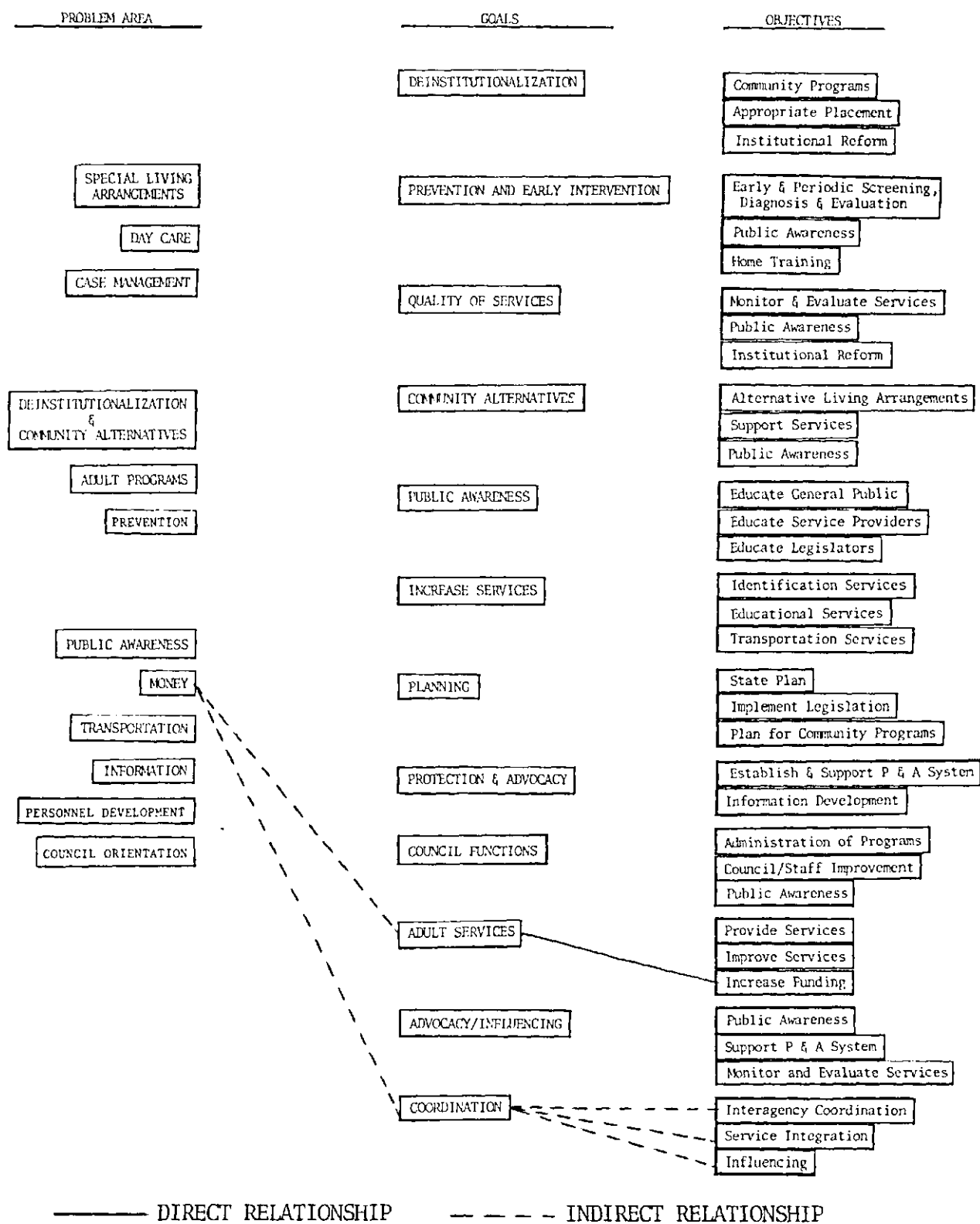
A number of state councils have expressed success in accessing Title XX Training and other funds; yet, in many cases, the most feasible way to implement new services is to use DDSA funds as seed monies to cover start-up and initial operations costs.

The relationships in this problem area are shown on Figure 7. The only obvious connection is with the adult services programs objectives to "Increase Funding." Yet, the largest share of all Developmental Disabilities Program funds - thirty-two percent (32%) in thirty-six (36) states - has gone to objectives relating to "Service Expansion & Improvement:"

DDSA allocation	\$3.190 million
Non-DDSA contributions	\$4.635 million
Total funds	\$7.825 million

It may appear to be a contradiction that the largest proportion of funds is going to a problem area that takes second place to a comprehensive problem like public awareness. However, the planning and influencing activities that make up the strategies for public awareness, advocacy, coordination, and even deinstitutionalization and community alternatives, are much less costly and can utilize far more in-kind contributions, such as time. The provision or upgrading of services requires hard capital outlay.

GOALS & OBJECTIVES RELATING TO MONEY



Problem Area: Transportation

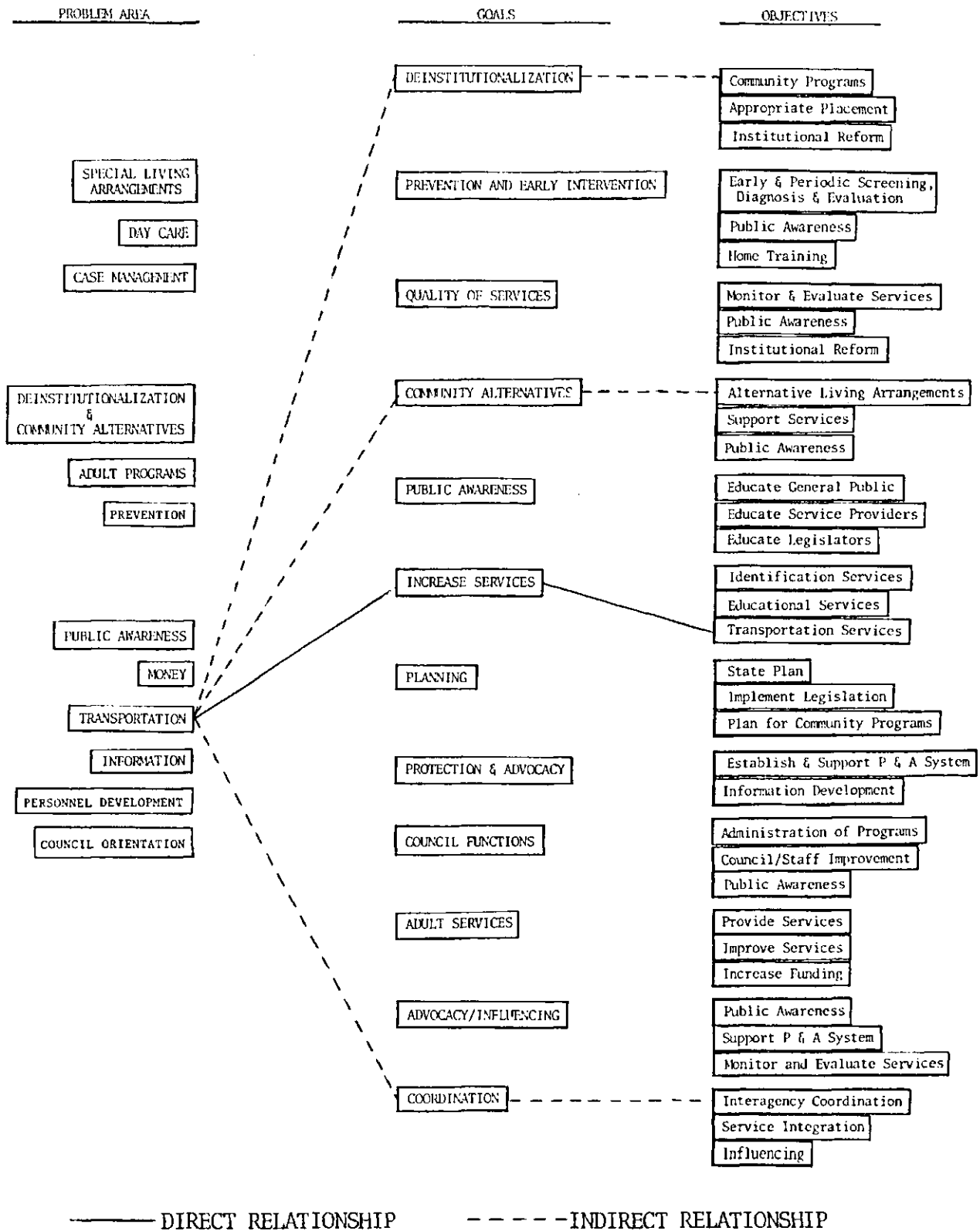
Transportation was reported as a major service gap by only twenty-four percent (24%) of the states which identified gaps, but as a barrier to the use of other services it was identified by at least thirty-one percent (31%). Considering those other states which specified "rural problems" as a barrier to service accessing, transportation may figure as a major barrier in at least forty-six percent (46%) of the states, and severely hinder deinstitutionalization. Understandably, then, transportation figures as a major objective under "Increase Services." These relationships are shown on Figure 8.

Some states are attempting to do coordinated planning for use of existing transportation systems in order to overcome these gaps and barriers. In many rural areas, however, no such systems exist and outlays are required for vans or other vehicles. Thus funds being used to address transportation barriers in thirty-six (36) states form the third largest amount of funds going to one type of problem in Fiscal Year 1978:

DDSA allocations	\$0.355 million
Non-DDSA contributions	\$2.067 million
Total Funds	\$2.422 million

FIGURE 8

GOALS & OBJECTIVES RELATING TO TRANSPORTATION



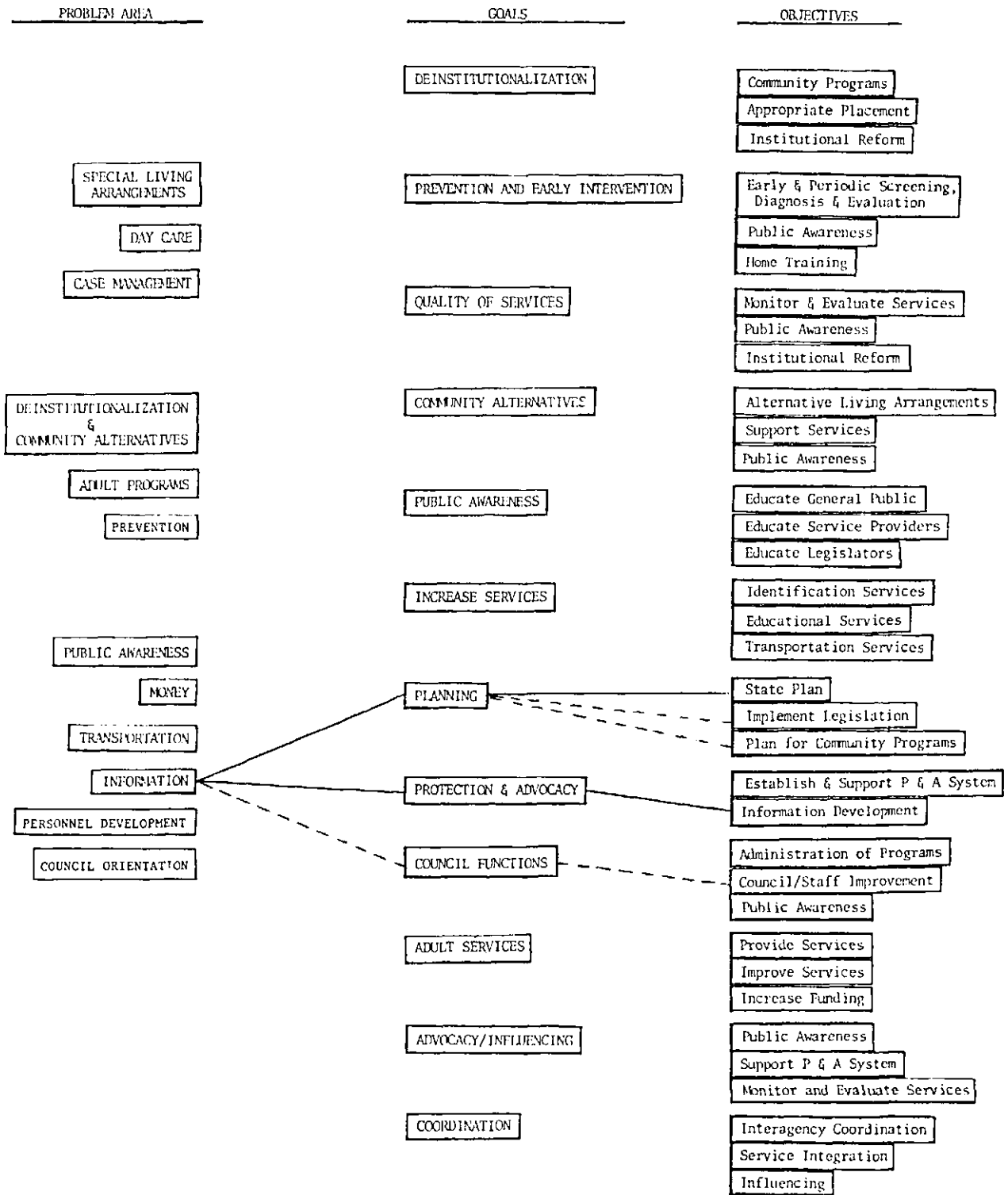
Problem Area: Information

Forty-eight percent (48%) of forty-eight states identified information development as a state program need. Needs for information exist in state plan development, information and referral services (a major service gap in at least fifteen percent of the states which identified gaps), client tracking and needs assessment. Note that the Protection and Advocacy System also has objectives for Information Development on Figure 9.

Funds going into this problem area are scattered under other objectives and goal areas. Information development is a planning and research function likely to be carried out by program staff or council members or staff. Any funds going for information development are likely to be for service needs and other special surveys.

FIGURE 9

GOALS & OBJECTIVES RELATING TO INFORMATION



———— DIRECT RELATIONSHIP

- - - - - INDIRECT RELATIONSHIP

Problem Area: Personnel Development

Forty-two percent (42%) of forty-eight (48) states reported a need for personnel development, which relates directly to the quality of existing services. Note on Figure 10 that activities relating to this problem area are probably hidden in such broader objective categories as "Institutional Reform," "Quality of Services," "Improve Services," "Home Training," and so on.

At least the following funds are going toward personnel development in thirty-six (36) states in Fiscal Year 1978:

DDSA allocations	\$0.257 million
Non-DDSA contributions	\$0.120 million
Total Funds	\$0.377 million

Problem Area: Council Functions

One-third of the states identified general needs in the mandated functions of the council: planning, monitoring and evaluation, influencing, and organization and administration. Fully eighty percent (80%) of the states cited a need for council orientation, training and technical assistance.

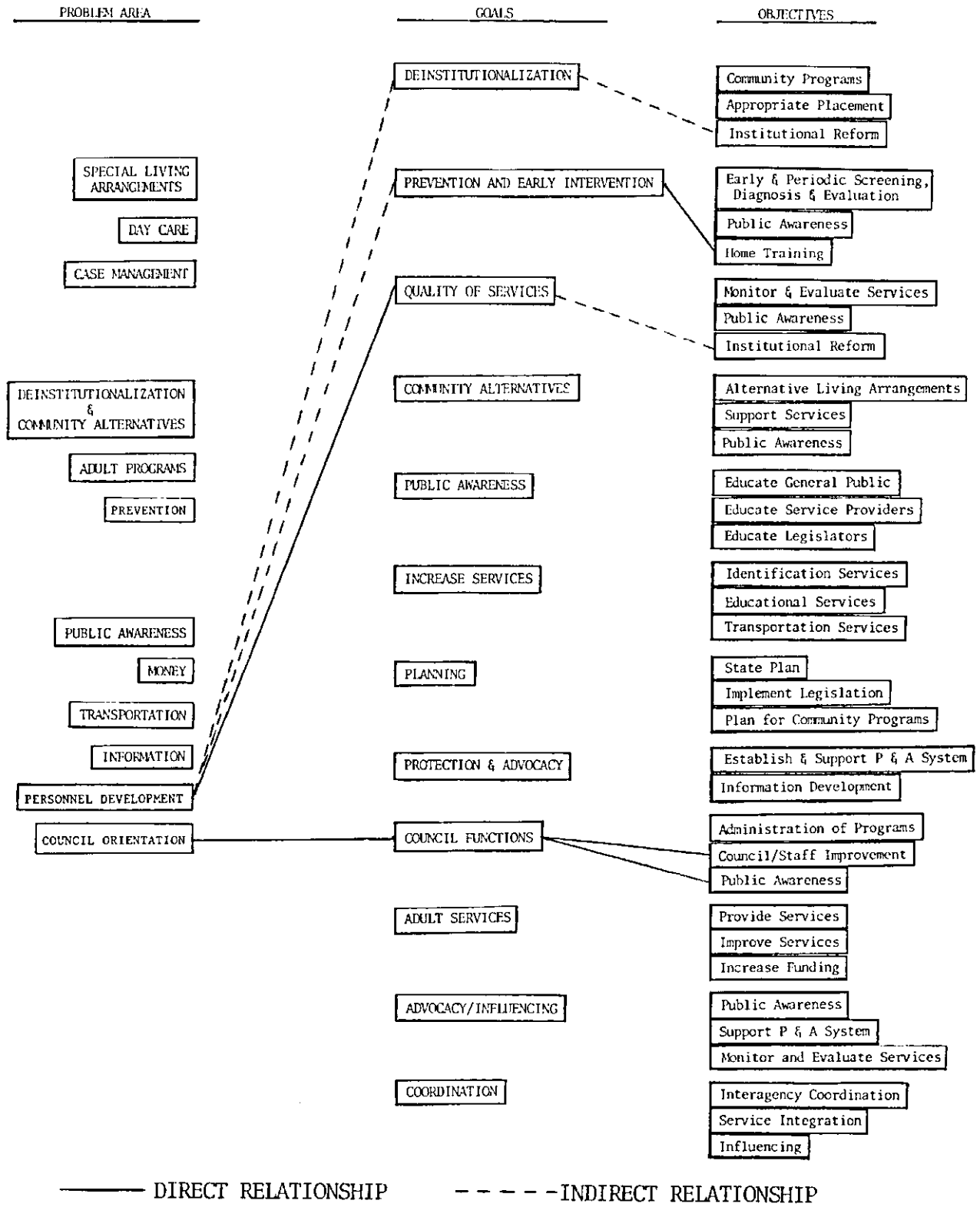
Fiscal Year 1978 response to these needs is shown on Figure 10. Funds going to council improvement are as follows:

DDSA allocations	\$0.318 million
Non-DDSA contributions	\$0.164 million
Total Funds	\$0.482 million

Note on Figure 10 that some activities are being directed to public awareness to increase the visibility of councils.

FIGURE 10

GOALS & OBJECTIVES RELATED TO PERSONNEL DEVELOPMENT &
COUNCIL ORIENTATION



METHODOLOGY AND LIMITATIONS:

THE RELATIONSHIP OF DEVELOPMENTAL DISABILITIES PROGRAM ACTIVITIES TO GAPS AND BARRIERS

Methodology

Data for this analysis were collected from Section IV, "Developmental Disabilities Program Gaps" and Section VI, "DD Program Plan" from fifty-three (53) Fiscal Year 1978 developmental disabilities state plans. The original analysis was done for three other Issue Papers in this series, "Gaps and Barriers in the Developmental Disabilities Service Network," "Goals and Objectives of the Developmental Disabilities Program" and "Designs for Implementation." These data and analyses were combined for the purposes of this paper. More detailed methodologies and limitations for these original analyses are given in the above papers.

The following data were examined:

- o the five most critical gaps identified in specific types of services in each state plan;
- o special program needs, council needs and other state needs and barriers to service delivery identified in each state plan;
- o types of goals given high priority in each state plan;
- o targets of plan year objectives;
- o sources and amounts of funds designated to achieve the objectives.

Analysis for this paper involved reviewing the most frequently mentioned objectives and high priority gaps, needs and goals to determine the extent to which states are addressing major problem areas through short- and long-range planning.

Limitations of the Data and Analysis

The limitations of both the data collection methodology and of the analysis center around the judgment required of the analyst:

- o Since State Plan Guidelines require the identification of gaps in all services, judgment was required to decide which gaps imposed the worst problems on the state service network; this was accomplished through careful reading of paragraphs 4.1 and 4.2 of the state plans.

The analysis was to be based on the five highest priority goals in each state, but few states actually prioritized goals; therefore, it was assumed that the first five goals mentioned in Section VI of the state plans were of higher priority, unless other information in the plans indicated otherwise.

Some states wrote vague objectives worded more like long-range goals than like measurable objectives, i.e., "to develop appropriate placements." Whenever possible, the analyst inferred the true nature of the objective and activity from the wording of the associated Design for Implementation. Because of some incomplete Designs for Implementation, this process may have caused misinterpretation of the true nature of some of the objectives.

Only thirty-six (36) states included cost figures in their Designs for Implementation. Because the Designs are keyed to the plan-year objectives, and fifty-three (53) states were included in the objective analysis, the proportions of funds going to problem areas cited in this analysis are probably not very different from those cited here. The absolute dollar figures, however, are different.

Because of time constraints on data collections and analysis, this paper does not contain data from state plan amendments submitted on or after October 1, 1977. Data in such amendments may have increased the dollar figures noted above.

Because of the gross nature of this analysis and the need to categorize the data, the often complex and occasionally exemplary combinations of goals and objectives being used by states are not apparent in the data; for the same reason, it has not been possible to trace all funding directly to the cited problem areas.