



DEVELOPMENT AND CONCEPTUAL FRAMEWORK
OF THE
PERFORMANCE STANDARDS
FOR THE
DEVELOPMENTAL DISABILITIES PROGRAM

Task 1.2.2

Contract

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INTRODUCTION

The Performance Standards for the Developmental Disabilities Program is the last in a series of program documentation written to develop, implement and assess the State Developmental Disabilities Programs. The program was initiated with the passage of the Developmentally Disabled Services and Facilities Construction Act (PL 91-517) in 1970 and amended by PL 94-103 in 1975. The Act gave federal support to states for a wide range of activities to promote the provision of services to meet the life long needs of persons with developmental disabilities. The Developmental Disabilities Program regulations were issued by the Department of Health, Education and Welfare in February of 1977 giving the department's interpretation of the legislation. Subsequently the Developmental Disabilities Office has issued several program guidelines including the State Plan guidelines in response to issues arising from interpretation of the legislation and regulations. Finally, Performance Standards have been developed to assess the State Developmental Disabilities Program operations.

The development of standards for operation of the Developmental Disabilities Program poses complex problems at this point in time. The specter of organizational and legislative change looms ahead creating uncertainties at all levels of the program. The current Developmental Disabilities legislation may be rewritten. The National and Regional Developmental Disabilities Offices are being reorganized. Both of these circumstances may have strong impact on future directions of the program. The question may be raised as to the purpose of developing Performance Standards at this time.

The original purpose of the Performance Standards was to provide a means of assessing effectiveness of the State Developmental Disabilities Program in carrying out its mandate to advocate for persons with developmental disabilities. In the present uncertain climate an additional purpose emerges. At all levels of the program the original intent of the legislation is being debated. Sweeping changes might eradicate some advances which have been made on behalf of developmentally disabled persons under the current legislation. A statement of the intent and requirements of the program according to current legislation and state practice is very timely. Such a statement has been attempted within the Performance Standards.

Regardless of imminent change it remains important for program managers and evaluators to be able to assess the efficacy of the Developmental Disabilities Program. The Performance Standards provide the guidance for achieving this purpose. Additionally, the program evaluator, the program manager and the program participant can find in the standards guidance about what ought to be done in the program, who should do it and how to judge if it has been done.

It is hoped that the standards will add stability to the program in the present uncertain climate and will be a reminder of the considerable progress already made at the state level in carrying out the original intent of the legislation. The Developmental Disabilities Program is an innovator among federal programs. Its potential for future impact should not be lost.

This paper is a link between the requirements for the development of the Performance Standards and the actual Standards document. It's purpose is to describe the conceptual framework and the methods of developing the Performance Standards. The discussion in the following sections of this paper will describe the development of the conceptual framework for Standard design (intent model), the rationale for the Performance Standards, and the design of the Performance Standards document.

The Standards appear in a separate document entitled Developmental Disabilities Program Performance Standards.

I. THE INTENT MODEL: A FRAMEWORK FOR DEVELOPMENT OF THE PERFORMANCE STANDARDS

The development of the Performance Standards required considerable research and discussion about the requirements and intent of the Developmental Disabilities Program. Legislation, regulations, program guidelines, FY 1978 state plans and related developmental disabilities reports were reviewed. Staff field experience at state, regional and national levels of the program was analyzed. Attempts were made to build the Performance Standards synthetically from specific legislative directives. However, the laws, regulations and other program documents do not provide a consistent direction to program operations. A broader statement of the intent of the Developmental Disabilities Program was needed.

The intent model, conceptual framework of the Performance Standards, is a statement of the purposes of the Developmental Disabilities Program. Its development required a step back from the detail of program documentation in order to see the intent of the legislation. The standards which resulted are based on both specific legislative directives and interpretations of legislative intent including state practice. ...

The development processes of the intent model and Performance Standards are described in this section.

1.1 Literature Review

The Developmental Disabilities legislation, regulations, state plan guidelines and other program guidelines were reviewed to determine the requirements of the program. Related Developmental Disabilities Program service standards such as Intermediate Care Facilities for the Mentally Retarded (ICF/MR), Commission for Accreditation of Residential Facilities

(CARF), and Program Analysis of Service Systems (PASS) and the Developmental Disabilities Office study on Quality Assurance Mechanisms (QAM) were reviewed to determine how other standards were developed and implemented.

Familiarity with other performance standards in Office of Human Development programs was gained by a review of the standards of the Head Start Program, Runaway Youth Program, and Regional OHD Programs. In addition, current Health Systems Agency (HSA) standards were reviewed. Many developmental disabilities related reports were also reviewed to gain a broad perspective on interpretations of the intent of the program. The FY 1978 Developmental Disabilities State Plans provided valuable information on how states are carrying out the requirements and intent of the Developmental Disabilities Program.

A complete list of the literature reviewed appears in Appendix A.

1.2 Definitions and Design Criteria

The definitions adopted for the design of the Developmental Disabilities Performance Standards are similar to those used in other Office of Human Development programs.

Standard - a general principle against which performance can be assessed.

Criterion -a specific aspect of a standard which helps define a standard and against which the standard can be tested. Several criteria may be needed to define a standard.

Indicator- a specific activity or process which is amenable to direct observation or measurement and which documents whether a particular aspect of a criterion is met.

Within these definitions a set of design criteria for the Performance Standards was specified:

1. Standards should reflect all aspects (implied and specific) related to state operations formula grant of the Developmental Disabilities Program.
2. Standards, criteria and indicators should be justified in the program documentation, state practice or sound management practice.
3. To the extent possible, indicators should be observable, and measurable as program outcomes.
4. The standards, criteria and indicators should be universally acceptable.

1.3 Functional Model

In the beginning of the search for a useful conceptual basis a matrix* was developed as a framework in which to develop the information from the program documentation. This matrix, called the functional model, appears in Figure 1. The column variables of the matrix contain five major program operational areas - planning, influencing, evaluation, administration and implementation. Each area was subdivided into four parts. The row variables of the matrix contain each of the "major actors" in the Developmental Disabilities Program: the council, council staff, administering agency and implementing agency.

The literature (including FY 1978 Developmental Disabilities State Plans) was reviewed to determine the roles or functions of each of the "actors" in each of the specific program areas. The matrix was completed with extensive information from this review. The results include:

* Webster defines a matrix as "something within which something else originates or develops."

Figure 1

THE FUNCTIONAL MODEL
FOR DERIVING PERFORMANCE STANDARDS
Roles of Developmental Disabilities Program Constituents

<u>CONSTITUENTS</u>	<u>PLANNING</u>	<u>INFLUENCING/ COORDINATING</u>	<u>MONITORING/ EVALUATION</u>	<u>ADMINISTRATION</u>	<u>IMPLEMENTATION</u>
Developmental Disabilities State Planning Council (Whole)					
State Agency Representatives Consumer Representatives Local Agency Representatives					
Developmental Disabilities State Planning Council Staff					
Administering Agency Program Unit Staff					
Implementing Agency*					

* If not covered by agencies listed above

1. Functions are seldom clearly described. Many of the requirements are not actually functions, i.e. "the state plan must have... a deinstitutionalization plan" is a requirement. It is also an implied function since someone has to do it. But even in the program guidelines, the direct responsibility for the deinstitutionalization plan is vague. The responsibility for implied functions were often difficult for the reviewers to interpret.
2. State planning council staff functions as separate from the council functions are not specified in the Law and regulations and only briefly addressed in the program guidelines.....
3. Implementing agencies have many functions in the Developmental Disabilities Program including those of the construction agency, service providers, and Individual Habilitation Planning (IHP) coordinators. These functions should be understood and monitored by council as part of the total Developmental Disabilities Program.
4. In order to accomodate the different type of variables the model frequently became multidimensional including the "actor," the "function," and the "output," thus rendering it too complex for organizing the standards.

It should be understood that the described lack of clarity as to who shall accomplish program functions is an expected condition of program guidance documents. In the concept of such documents, particularly program guidelines, the emphasis is what should be done rather than "who" should do it. The implied philosophy is that the assignment of responsibility within state operations is a state prerogative and is clearly outside the domain of the federal regulatory and guidance process. This posture is clearly an advantage since state operations are rarely organized in the same manner as federal operations. Never-the-less this circumstance poses a problem to the development of specific monitoring tools for state level operations.

Although the work on the functional model familiarized the design team with program documentation and clarified information about functions, it was not an adequate conceptual basis for development of the standards.

1.4 Requirement Model

The second model that was tried as a conceptual framework for the standards was called the requirement model. It was decided that the review of functions required too many assumptions about responsibility. The basic concept behind the requirement model was to base the standards solely on documented program requirements. The program documentation was reviewed again to extract direct quotations of program requirements. Each quote was recorded on an index card so that it could be organized into different categories.

The results of the analyses included the following findings:

1. The detail of the laws, regulations and program guidelines often obscure the intent.
2. Much of the specific information in the program documentation is repetitive and involves administrative detail while broader missions are largely unspecified.
3. Standards based only on current documentation would have the same scope as the program guidelines and as a result would potentially and improperly limit the scope of the standards.

Although the requirement model work resulted in excellent source material it, too, was not a workable conceptual basis for the Performance Standards.

1.5 Development of the Intent Model

The need to step back from the details of the program documentation was apparent. All available literature was studied and extensive field experience was reviewed to probe the underlying intent of the program. Through this process an intent model evolved. Three major "intent areas" emerged as basic parts of the program:

1. The Developmental Disabilities Program shall be an advocate for recognition of the needs and rights of persons with developmental disabilities.
2. The Developmental Disabilities Program shall have a comprehensive and continuing plan for meeting the needs of persons with developmental disabilities.
3. The state shall have an administrative structure which promotes the intent of and implements the Developmental Disabilities Program.

The entire set of Performance Standards for the Developmental Disabilities Program are organized around these intent areas.

Once the intent areas were identified, the amount of support each received in the laws, regulations and program guidelines and state practice was determined. The requirement statements on the index cards developed as a part of the requirement model were organized into the intent areas. The

set of requirements clustered for each intent area was analyzed for potential standard areas. Explicit criteria and indicators were identified within each standard area by their relative specificity.

Further analysis and refinement of the standard requirement clusters and intent areas resulted in the set of standards, criteria, and indicators. The basis for the majority of the standards and criteria is a specific legislative directive. Others are based on interpretation of legislative or regulatory intent. In some areas state or sound management practice is the basis for the standard criteria. These areas represent gaps in current program documentation.

1.5.1 The Systems Advocacy Intent

Section 137 of the Legislation clearly states that the role of the council is to "serve as an advocate for persons with developmental disabilities." Webster defines an advocate as one who pleads in favor of. Additionally, advocacy usually implies that a change is needed and usually occurs for someone who is not able to advocate for himself/herself. The central concept of the Program is that through advocacy the current service system can be changed to meet the needs of a previously neglected population. The concern of each state Program is fulfilling the advocacy role.

Systems advocacy implies "pleading" for change within the features and policies of the program as differentiated from individual advocacy*. The Legislation implies two aspects of the systems advocacy role. One part is focused on influencing the system to recognize the needs and rights of the developmentally disabled, the other on the development and maintenance of appropriate services within the service system.

* Advocacy for individuals as distinct from systems advocacy is in domain of the Protection and Advocacy System.

The Law identifies the Individualized Habilitation Plan (IHP) as the principle mechanism for promoting the recognition of the needs of persons with developmental disabilities . By encouraging the development, review and implementation of the IHP, the Developmental Disabilities Program can help to ensure that persons with developmental disabilities will receive services appropriate to their needs.

The "Rights of the Developmentally Disabled," described in the legislation and the Protection and Advocacy guidelines emphasize that persons with developmental disabilities have the right to appropriate treatment, services and habilitation which should be designed to maximize their developmental potential. Basically the law guarantees any legal or other rights which other citizens enjoy to persons with developmental disabilities. The Program has the responsibility to encourage the system to provide these rights.

The Developmental Disabilities Program also has the mission to ensure that services needed by persons with a developmental disability are obtained from the generic service system. The Law implies several functions related to systems advocacy for the development and maintenance of appropriate service programs such as : coordinating services and programs, expanding services, developing demonstration services and programs, promoting deinstitutionalization, and monitoring and evaluating services and programs.

1.5.2 The Comprehensive Planning Intent

Of equal importance to the systems advocacy intent is the clear charge to the Developmental Disabilities Program to develop and maintain a comprehensive plan for the provision of appropriate services to the developmentally disabled.

The Law directs that the state plan must:

- **Identify a state planning council.**
- Describe how other federally assisted/state programs provide services for persons with developmental disabilities and **the** relationship of the Developmental Disabilities Program to these other programs.
- Identify gaps and barriers to service availability and use.
- Show how needed services for the developmentally disabled will be provided including addressing the national goals of the Program.
- Provide for the maintenance of standards for facilities and services.
- Set forth the policies or organizational procedures for expenditures of funds designed to assure effective and continuing planning, evaluation, and delivery of services to the developmentally disabled population.
- Describe methods to be used to assess the effectiveness and accomplishments of the state in meeting the needs of persons with developmental disabilities.
- Provide for the determination of goals and priorities for meeting needs for services and facility construction.
- Develop implementation plans (DFI) **for** each objective.

The state plan guidelines have organized these requirements into a format for identifying the service needs of persons with developmental disabilities, identifying all service program resources available to meet the needs, identifying gaps and barriers to the provision of services, specifying goals, objectives and priorities for the state's service network, specifying strategies for funding and implementation, and assuring proper administration of the program. In short, the comprehensive state plan is to be the blueprint for the state's effort on behalf of the developmentally disabled.

1.5.3 The Administrative Intent

It is the intent of the Act that an administrative structure is established which will promote the intent of and implement the Program. Moreover, the administrative structure must ensure that the Developmental Disabilities Program is operated within the constraints of the applicable rules and regulations of federal and state statute.

Unlike many programs the Developmental Disabilities Program creates an organizational partnership between the state planning council and the administering agency(ies). Both entities have unique requirements for their organizational structure. The council must be comprised of at least one third consumers (or consumer representatives) and service agency representatives with authority to speak in behalf of their agencies. The administering agency must have an organizational unit that will provide administrative support to council operations as well as implement the state plan. Together their missions require access to the executive branch of state government and cut across Program jurisdictional lines. The placement of the council and administering agency in the executive branch should foster the needed access to other agencies in the state. Maintenance of this organizational structure which joins consumers, state agency representatives and service providers in a partnership for policy deliberation on behalf of persons with developmental disabilities is one of the key concerns of the Developmental Disabilities Program administration.

1.5.4 The Intent Model

Figure 2 displays the intent model for the developmental disabilities Performance Standards. Each intent area of the Program has been developed into standards and criteria. The standards in the second column are defined as general principles against which performance can be assessed. There are twenty-one standards in all, eight relating to systems advocacy, seven related to planning and six to administration.

The criteria for each standard (third column in Figure 2) are defined as specific aspects of the standards from which the standards can be tested. For example, the first standard relates to ensuring that persons with developmental disabilities receive services appropriate to their needs. The three criteria for this standard are based on the ways implied in the Developmental Disabilities Program documentation for ensuring that individual service needs are met. The criteria in this example are:

- 1.1 Persons with developmental disabilities receiving services sponsored by Program funds shall have an individualized habilitation plan (IHP).
- 1.2 Services to each individual which are provided through Program funds are in accordance with his or her IHP.
- 1.3 The Program advocates for an individualized plan for services for persons with developmental disabilities receiving services sponsored by other programs.

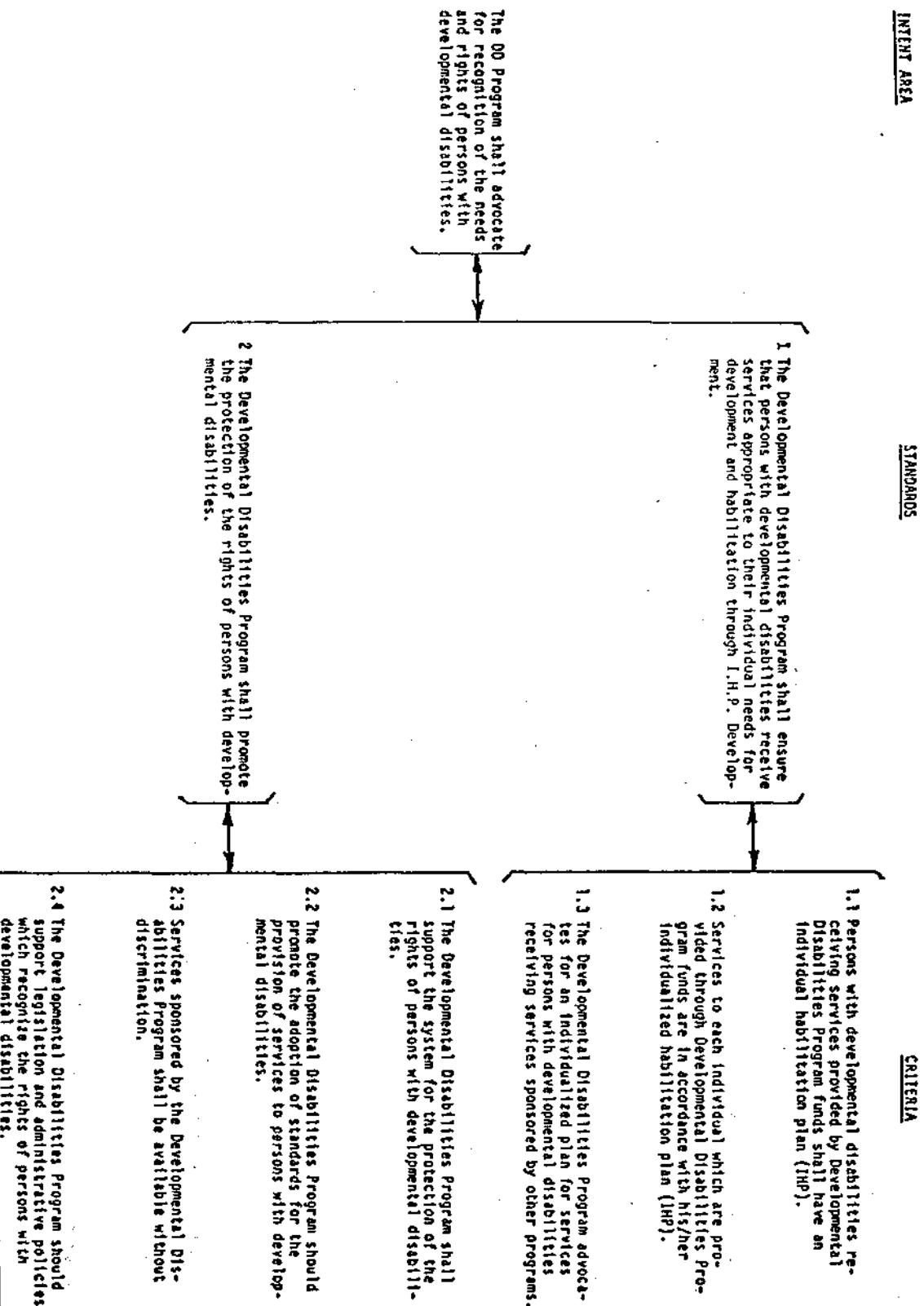
There are a total of sixty criteria for the twenty-one performance standards; twenty-seven related to systems advocacy standards, seventeen related to comprehensive planning standards, and sixteen related to administrative standards.

A further level of specificity exists in the Performance Standards which is not shown on the intent model. Each criterion has several indicators defined as specific activities or processes which are amenable to direct observation or measurement and which document whether a specific aspect of the criteria is met.

The intent model has several advantages not found in the other approaches:

1. It was possible to identify and further develop areas missing in current documentation but needed for state level operational monitoring.
2. Areas of Program responsibility can be organized in a simplified way.
3. Specific requirements can be seen from the perspective of their intent in Program operations.

Figure 2
INTENT MODEL FOR THE DD PERFORMANCE STANDARDS
SYSTEMS ADVOCACY



A diagram of a horizontal beam supported by a central vertical post. A downward-pointing arrow is located at the center of the beam, representing a force.

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Figure 1

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INTENT MODEL FOR THE OO PERFORMANCE STANDARDS
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Figure 2 (Con't)

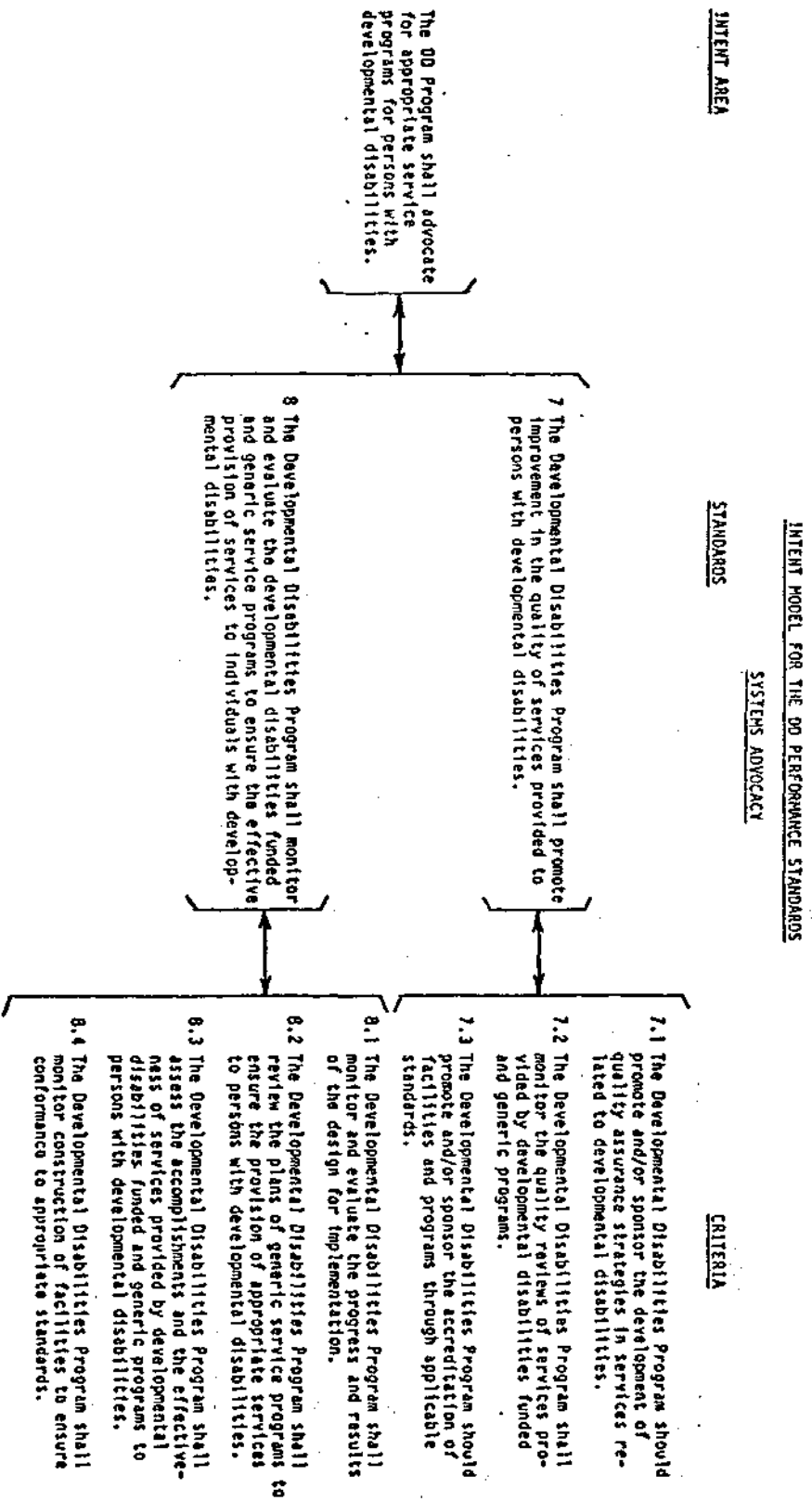


Figure 2 (Con't)

INTENT MODEL FOR THE DD PERFORMANCE STANDARDS

PLANNING

INTENT AREA

STANDARDS

CRITERIA

The DD Program shall have a comprehensive and continuing plan for meeting the needs of persons with developmental disabilities

9 The service needs of the developmentally disabled population shall be assessed.

9.1 The developmentally disabled population of the state shall be identified.
9.2 The type and extent of service needs of the developmentally disabled population of the state shall be assessed.

10 The scope and extent of services available to persons with developmental disabilities shall be assessed.

10.1 The services available to persons with developmental disabilities shall be identified.
10.2 The utilization of available services by persons with developmental disabilities shall be assessed.

11 Gaps in provision of services to persons with developmental disabilities shall be assessed.

11.1 Gaps in the utilization of available services shall be identified.
11.2 Gaps in availability of services to persons with developmental disabilities shall be identified.

12 The goals and objectives of the Developmental Disabilities Program shall be developed.

12.1 Long range goals for the Developmental Disabilities Program shall be established.
12.2 Plan year objectives for the Developmental Disabilities Program shall be established.

13 The strategies and manner by which the Developmental Disabilities Program will be implemented shall be determined.

13.1 An implementation plan for each plan year objectives shall be determined.
13.2 A plan for desinstitutionalization shall be developed.
13.3 The allocation and use of Developmental Disabilities Program funds shall be determined.

14 The organization and functions of the Developmental Disabilities Program shall be reviewed and described.

14.1 The organization of the state planning council shall be reviewed and described.
14.2 The functions and activities of the state planning council shall be reviewed and described.
14.3 The organization of the identified administering agency shall be described.

15 Construction projects funded by the Developmental Disabilities Program shall be developed and conducted within the federal Developmental Disabilities Program policies.

14.4 The methods of administration of the Developmental Disabilities Program shall be described.
15.1 The need for construction using Developmental Disabilities Program funds shall be determined.
15.2 The development of plans for construction/renovation projects using Developmental Disabilities Program funds shall be in accordance with Developmental Disabilities Program policies.

Figure 2 (Con't)

INTENT MODEL FOR DD PERFORMANCE STANDARDS

ADMINISTRATION

INTENT AREA

STANDARDS

CRITERIA

The State shall have an administrative structure which promotes the intent of and implements the DD program.

16 The state planning council and staff shall be established, organized and maintained according to Developmental Disabilities Program policies.

17 The program unit of the administering agency(ies) shall be maintained according to Developmental Disabilities Program regulations.

18 The council and administering agency should be placed in the state structure to optimize the effective implementation of the Developmental Disabilities Program.

19 Functions and responsibilities of the Developmental Disabilities Program shall be defined and assigned in accordance with Developmental Disabilities Program policy.

16.1 The council shall be composed of appropriate numbers of representatives of groups, agencies and individuals according to legislative, regulatory and program guidelines.

16.2 Council members should have sufficient knowledge, experience and/or authority to advocate effectively for persons with developmental disabilities.

16.3 Council staff shall be adequate in number and qualifications to meet responsibilities of the council.

16.4 The established organization and procedures of the state planning council and staff are maintained.

17.1 A unit within the organization of the administering agency shall be designated to administer the Developmental Disabilities Program.

17.2 The program unit staff shall be adequate in number and qualifications to meet the responsibilities of the administering agency.

18.1 The council and administering agency should be located at an organizational level within the state system to advocate effectively for services for persons with developmental disabilities.

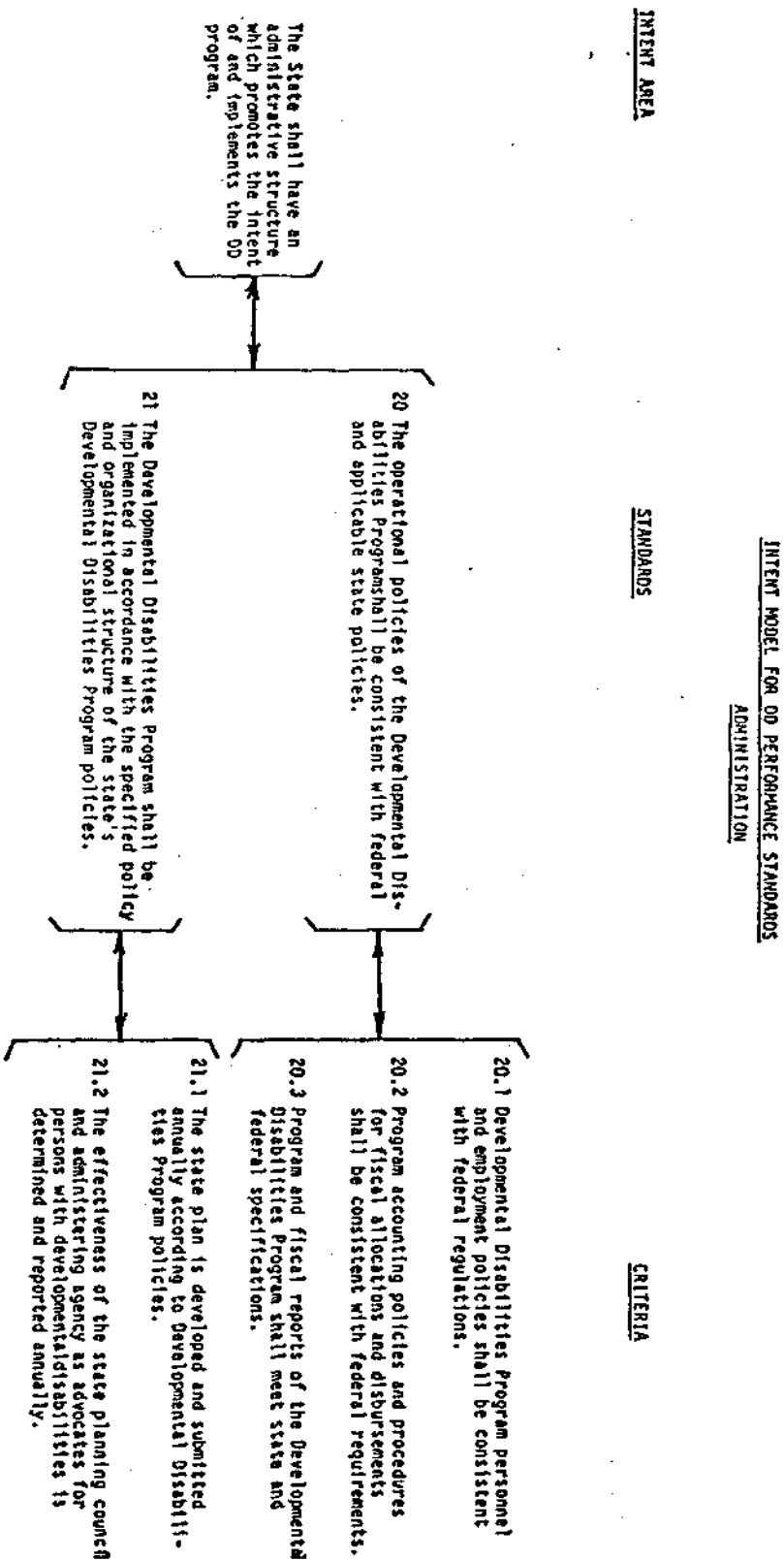
18.2 In order to influence state policy, the council should have access to the Governor and other appropriate state authorities.

19.1 Developmental disabilities state plan development responsibilities shall be assigned for the most effective outcomes.

19.2 The responsibilities for administration of the Developmental Disabilities Program and state plan implementation shall be assigned to the administering agency.

19.3 Monitoring and evaluation activities shall be assigned for efficient and effective implementation of program responsibilities.

Figure 2 (Con't)



1.6. The Relationship of the Performance Standards to the Law

The Performance Standards link the intent areas of the Developmental Disabilities Program to its statutory, regulatory and guidance basis. It is important to understand that while Program intent is the major organizing scheme, the Performance Standards, criteria and indicators are firmly justified in the Developmental Disabilities Program documentation. Of the 21 standards, 19 (90%) are statements directly derived from the Law and regulations and only 2 (10%) are implied from a variety of regulatory language. Similarly, of the 60 criteria, 48 (81%) directly reflect the Law and regulations, 11 (18%) are implied and only 1 (1%) reflect state practice.

Finally, there are 291 indicators of which 170 (65%) are direct reflections of Program regulations and guidance, while 22 (8%) are implied by these documents, 27 (9%) are reflected in state practice only and 52 (18%) reflect "sound management principles" added to fill gaps in the Program documentation.

Table 1 shows the distribution of the sources of standards, criteria and indicators by intent area.

Table 1

SOURCES OF STANDARDS, CRITERIA & INDICATORS
BY INTENT AREA

SYSTEMS ADVOCACY		COMPREHENSIVE PLANNING		ADMINISTRATION		TOTAL	
#	%	#	%	#	%	#	%

STANDARDS

DIRECT (LAW/REG)	8	100	6	86	5	83	19	90
IMPLIED (LAW/REG)			1	14	1	17	2	10
STATE PRACTICE								
SOUND MGT. PRACTICE								
TOTAL	8	100	7	100	6	100	21	100

CRITERIA

DIRECT	20	74	16	94	12	75	48	81
IMPLIED	7	26	1	6	3	19	11	18
STATE PRACTICE					1	6	1	1
SOUND MGT. PRACTICE								
TOTAL	27	100	17	100	16	100	60	100

INDICATORS

DIRECT	50	39	78	98	62	73	190	65
IMPLIED	16	13	1	1	5	6	22	8
STATE PRACTICE	19	15			8	10	27	9
SOUND MGT. PRACTICE	42	33	1	1	9	11	52	18
TOTAL	127	100	80	100	84	100	291	100

II. RATIONALE FOR THE PERFORMANCE STANDARDS

In this section the rationale for each of the standards is discussed. The standards themselves appear in the intent model in Figure 2.

2.1 Rationale for Systems Advocacy Standards

Developmental Disabilities Performance Standards numbers one through eight are directed toward the systems advocacy intent of PL 91-517 (as amended by PL 94-103). Performance Standards one and two address the advocacy role of the Developmental Disabilities Program as it relates to persons with developmental disabilities. Although individual advocacy is the special domain of the Developmental Disabilities Protection and Advocacy System, the Law indicates at least two areas where the requirements relate to persons with developmental disabilities as a class. These two areas are access to services which are appropriate to the individual's needs and promotion of the human, civil and treatment rights of the developmentally disabled. Criteria relating to the access of appropriate services are embedded in the individualized habilitation plan (IHP) requirements of the Act. The rights for individuals are strongly suggested by the "bill of rights" section of the Act and further defined as a council area of concern in guidelines for the Protection and Advocacy System.

The remaining six standards, three through eight, in the systems advocacy area are directed at the advocacy role in the service network. These include coordination of services and programs, gap filling in the generic service program, demonstration of new service techniques, promotion of the least restrictive environment in programs (deinstitutionalization), promotion of improved quality of services and the monitoring and evaluative functions of the Developmental Disabilities Program.

Rationale for Performance Standard 1

A key element of the systems advocacy role is the individualized approach to treatment and habilitation. The intent is that all persons with developmental disabilities receiving services, Developmental Disabilities sponsored or otherwise, receive the kinds and types of service that are most likely to address his/her specific manifestations of the disabling condition. A conceptual leap is made in PL 94-103 that the intent will likely be met if the services needed for each person with a developmental disability are specified in an IHP. The responsibility of the Program in ensuring appropriate services is addressed by the requirements of the IHP development and use.

Rationale for Performance Standard 2

The systems advocacy role includes the charge to promote human, civil and treatment rights of persons with developmental disabilities. The protection and advocacy focus is reinforced by the Federal mandate to establish the state's Protection and Advocacy (P&A) System. Program documents emphasize the cooperative, complimentary relationship between the P&A System and the council, notwithstanding the separateness of the P&A System administration. Such support is an integral part of the criterion for the standard.

Almost all government and other service standards mandate treatment and civil rights in service programs. Thus, the promotion of standards and certification activities in service providing agencies is a method of assuring that these rights have been upheld.

Closely linked to every federally aided (and often state sponsored) program is the charge that discriminatory practices based on race, sex or income status are prohibited. Assurances and operational procedures must reflect full accessibility of services without regard to race, sex and financial status.

One principal method of effecting the affirmative action needed to protect rights of persons with developmental disabilities is to have the basic rights appear as agency policy.

Rationale for Performance Standard 3

One of the principles of PL 94-103 is that already existing service programs are the first source of appropriate services to persons with developmental disabilities. PL 94-103 further indicates that generic service programs, although categorical in nature, can be coordinated to meet the needs of persons with developmental disabilities. This coordination mandate is another key element in the systems advocacy role of the Program. However, authority to implement the coordination is limited to the following: identification of gaps in service/program policies; the study and identification of ways in which to achieve the optimal use of funds of other programs to address service needs of persons with developmental disabilities; the promotion of information exchange among agencies, consumers and providers; the promotion of agreements among agencies to meet the state plan's goals and objectives; and the contribution to a general awareness of the need for availability of resources for persons with developmental disabilities.

PL 94-103 stipulates that at least nine other federal programs be coordinated including but not limited to: education for the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, crippled children's services, comprehensive health and mental health.

Rationale for Performance Standard 4

The Developmental Disabilities Program allows for the distribution of limited funds for filling identified gaps in services. Based on the identified gaps and priorities, funds may be directed to augment current services/programs or establish new demonstration programs. Augmentation of current services/programs is the key to expanding the availability of services/programs deemed appropriate to persons with developmental disabilities. Through its funds, the Program can complement services or programs or assist in the construction and renovation of facilities designed to serve persons with developmental disabilities. The Program is to access resources from the generic service network to meet the special needs of the persons with developmental disabilities.

Rationale for Performance Standard 5

The demonstration of new or improved techniques of serving persons with developmental disabilities is another method for service gap filling provided by the Program. This feature allows program operation to be directed at extending the scope, extent, and quality of services for the developmentally disabled population by establishing demonstrations of yet untried or previously unavailable service modalities. The range of techniques indicated in the Act include specialized training programs, establishment of demonstration programs and/or facilities and some special attention to early intervention programs. The demonstration of new service delivery methods is one of the central elements of the systems advocacy role of the Developmental Disabilities Program.

Rationale for Performance Standard 6

The systems advocacy role is clearly intended to enhance the principle of "least restrictive environment" in the provision of services to persons with developmental disabilities. Deinstitutionalization is the national high priority as stated in PL 94-103. The intent of deinstitutionalization is to reduce reliance on institutionally based services through increasing the availability of community based alternatives and reforming the institutional service environment itself. Treatment and habilitation should be provided in the setting which is the least restrictive of a person's liberty. The establishment of community alternatives is a central element in accomplishing deinstitutionalization.

Rationale for Performance Standard 7

A mandate is given to the Developmental Disabilities Program to promote the provision of quality services to persons with developmental disabilities. The Program can achieve this through 1) the promotion of quality assurance strategies in the service providing agencies, 2) the monitoring and evaluation of developmental disabilities funded and generic services, and 3) the promotion of accreditation of service programs via appropriate standards. The promotion of accreditation and other quality assurance mechanisms represent methods indicated in the Act for improving generic service provision, particularly since the council has no authority to impose quality standards on generic service providers. Monitoring and evaluation responsibilities are the methods provided to the council to ensure quality service provision.

Rationale for Performance Standard 8

Monitoring and evaluation of generic service programs and Developmental Disabilities funded services is a key responsibility in the advocacy role. The scope of monitoring and evaluation activities outlined in Program documentation is broad. Within the Program, the funded services and all other specified activities are the focus of the monitoring and evaluation activities. Systems advocacy objectives are to be met by the monitoring of the activities of the Program. Moreover, the necessary assessment of the effectiveness of strategies implemented by the Program is achieved by monitoring and evaluation of the implementation of the designs for implementation (DFI) of the Developmental Disabilities State Plan. Generic services/programs related to persons with developmental disabilities are to be evaluated to determine the effectiveness of the state in meeting the needs of persons with developmental disabilities. Review of other agency state plans as well as direct and indirect evaluation of services/programs is the basic method suggested in the Act for accomplishing its systems advocacy role.

2.2 Rationale for Comprehensive Planning Standards

In order to participate in the Developmental Disabilities Program a state must have a state plan submitted to and approved by the Secretary of Health, Education, and Welfare.

Performance Standards nine through fifteen relate to the development of a comprehensive state plan in the following manner: standards nine and ten to the description of needs and available resources; standard eleven to gap identification; twelve to establishing goals and objectives; thirteen to the design for implementation (DFI); fourteen to a description of the organization and operation of the program; and standard sixteen to construction activities.

Rationale for Performance Standard 9

The Developmental Disabilities Program is required to determine the number, characteristics and needs of the developmentally disabled persons in it's state. This is a fundamental step in planning for resource development and utilization. Determining service needs is to be based on estimates of the developmentally disabled population. Specifically, a developmental disability is defined as a disability which

is attributable to mental retardation, cerebral palsy, epilepsy or autism;

- is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons; or
- is attributable to dyslexia resulting from a disability described above.

Rationale for Performance Standard 10

As part of its comprehensive planning charge, the Program must identify the scope, extent, availability and use of current services in the state. The assessment of services available in the service network for persons with developmental disabilities is important to the identification of gaps in services/programs to be addressed by the Program.

Rationale for Performance Standard 11

The Program has the responsibility to identify the gaps and barriers to the provision of services to persons with developmental disabilities. The assessment of gaps is a prerequisite to establishing attainable goals and objectives and the strategies for reducing and/or eliminating such gaps.

Rationale for Performance Standard 12

Establishing and prioritizing goals and objectives focuses the attention and resources of the Program on specific areas of need of the developmentally disabled population. PL 94-103 sets forth priorities and procedures for expenditure of funds under the state plan which "...are designed to assure effective state planning, evaluation and service delivery for persons with developmental disabilities." In addition, specific national program goals must be addressed. Section VI of the state plan is designed to provide for the description of long range goals and objectives, plan year objectives and activities for both the service network agencies and the council.

Rationale for Performance Standard 13

The Program must develop a strategy to be followed in meeting its goals and objectives. The development of such strategies allows for the orderly accomplishment of tasks and provides a mechanism to monitor the progress made towards meeting goals and objectives. Implementation plans for each objective are key elements of bringing the plan into an action phase. These plans include deinstitutionalization and the allocation of Developmental Disabilities Program funds.

Rationale for Performance Standard 14

The comprehensive planning role of the Developmental Disabilities Program includes a description of the organization and operation of the Program. Within constraints of council membership and administering agency/council roles and functions laid out by Program documents, there are broad discretionary possibilities for organizational and operational roles and functions. These roles and functions must be described to clarify and enhance the operation of the Program.

Rationale for Performance Standard 15

The Developmental Disabilities Program is allowed to participate in renovation and construction activities. However, the type and extent of the involvement of the program is regulated and monitored by federal requirements. The need for such activities must be documented by the program before resources are made available. If resources are allocated, their use must be carefully monitored through the definition and descriptions of the projects in the state plan. If no construction activities are being funded, examination of this standard is not applicable.

2.3 Rationale for Administrative Standards

Performance Standards sixteen through twenty-one cover the organizational structure, staffing and administrative operations of the Developmental Disabilities Program. Standards sixteen, seventeen, and eighteen are focused on the organization of the council, council staff and administering agency.

Responsibilities of the council and administering agency are often interlaced. The Program provides considerable flexibility within general functional areas of program operations. Performance Standard nineteen relates to the administration of the functional relationship of the council and the administering agency.

Standard twenty brings attention to the administrative rules of the federal legislation such as employment, fiscal, and program practices.

Standard twenty-one emphasizes the administrative (as opposed to the substantive) requirements of the state plan development and evaluation function of the Developmental Disabilities Program.

Rationale for Performance Standard 16

One of the central intents of the Developmental Disabilities Program is that the advocacy and planning functions of the Program be carried out by a partnership of consumers, service providers and state agencies responsible for providing services to the developmentally disabled population. PL 94-103 calls for the establishment of a state planning council, appointed by the Governor, consisting of persons concerned with the provision of services to persons with developmental disabilities. This group of persons is intended to be knowledgeable of the needs of persons with developmental disabilities and influential in meeting those needs.

The Act requires the identification of a state administering agency which will ensure the council operations and the state plan will be implemented within the framework of PL 94-103.

Rationale for Performance Standard 17

The Program requires that the administering agency carry out the administrative functions of the council (particularly fiscal) including the implementation of the state plan. A program unit within the administering agency must have adequate staff to fulfill the functions assigned to the administering agency.

Rationale for Performance Standard 18

The Governor has the responsibility to establish the Developmental Disabilities Program at such a level in state government that the program's ability to advocate for the developmentally disabled population will be enhanced. Both the council and the administering agency, through established relationships, should have access to state officials whose operational authority is relevant to the service network for persons with developmental disabilities.

Rationale for Performance Standard 19

Although some responsibilities for operation of the Developmental Disabilities Program are specifically assigned in the Legislation or Program guidelines, in other areas there is room for flexibility in the division of responsibilities between the council and the administering agency. The bulk of the "day to day" administration is definitely assigned to the administering agency. Evaluation is clearly a council responsibility. Planning and monitoring are carried out by both, requiring cooperation between the two groups. The missions of the Program will only be met through an efficient and cooperative relationship between the council and the administering agency. Ultimately the division of responsibility and authority in the Developmental Disabilities Program operations should suit the peculiarities of the state.

Rationale for Performance Standard 20

The Developmental Disabilities Program operations related to personnel, fiscal and program reporting must be consistent with the federal and state requirements and procedures. These requirements are designed to ensure proper accountability in the management of the program.

Rationale for Performance Standard 21

The Developmental Disabilities Program not only develops the state plan but also submits it to the appropriate authorities according to requirements. Finally, the Program should conduct an annual assessment of its effectiveness in meeting the needs of persons with developmental disabilities.

III. THE DESIGN OF THE PERFORMANCE STANDARDS DOCUMENT

Standards, criteria and indicators are organized in the Performance Standards document according to the intent model.

The Performance Standards document contains three forms related to each standard, the Rationale form, the Standard/Criteria form, and the Criterion/Indicator form. The components of each form are discussed below. Examples of the forms appear in Figures 3 through 5. They are coded with letters in parenthesis "(a)" which relate to the discussion below.

3.1 The Rationale Form (Figure 3)

The Rationale/Assessment form consists of a statement of the rationale of the standards and how to assess the standard. The rationale is a statement that clarifies the association between the standard and the intent area. The statement on assessing the standard is intended to clarify the relationship between the criteria and the standard. Special instructions for determining if the standard is met are included here.

3.2 The Standard/Criteria Form (Figure 4)

The Standard/Criteria form consists of a listing of the standard (a) and associated criteria (b). Each statement has been referenced in the Law, regulations and Program guidelines, as noted in the "Reference" column (d). In the reference column "L" stands for PL 94-103 followed by a section reference. "R" stands for the regulations and is followed by a regulation reference number. "PG" stands for Developmental Disabilities Office Program Guidelines and is followed by the transmittal number. Sometimes a Program Guideline is referenced by letters only such as SPG for state plan guideline, due to the incomplete status in the official documentation review cycle. The "Results" column (c) is used to indicate, by a check mark, if the standard and/or criteria

are met. Yes or no is indicated by a check in the appropriate column. The "Assessment Notes" column (e), is to be used by the review team to explain the results of standard and criteria assessment. The type code (TC) column, (f) identified the source of each indicator, criteria or standard. Codes are as follows:

- 1: required ("shall") in the Law, regulations or Program guidelines.
- 2: strongly suggested ("should") in the Law, regulations or Program guidelines.
- 3: suggested ("may") in the Law, regulations or Program guidelines.
- 4: implied by the Law, regulations or Program guidelines.
- 5: state practice
- 6: sound management practice

3.3 The Criterion/Indicator Form (Figure 5)

The Criterion/Indicator form contains a repetition of the criterion under consideration (b). Under the criterion are its associated indicators (g). The Results column (c), Reference column (d), Assessment Notes (e), and Type Codes (TC) columns (f) are identical to those on the Standard/Criteria form and serve the same function.

Two additional elements are added to the Criterion/Indicator form to aid in the assessment process. The Primary Source column shows the primary Document sources column (h) for verifying indicators and the primary Respondent column (i) for identifying persons to be interviewed to verify indicators. The Guidance part of the form (j) provides some special instructions to the review team.

It should be noted that indicators have been written to identify the responsible agent in the Developmental Disabilities Program to the extent possible. When there is clear instruction in the Program documents as to the assignment of responsibility, the responsible agent is identified in the indicator statement. For example, such an indicator would read "...a report is prepared by the council." Where no agent is clearly identified, a code for the suggested responsible agency appears in parentheses after the indicator. For example, see indicator 1.. 1.1 where (AA) designates the suggested agent. There are three codes for the suggested responsible agents:

AA administering agency of the Developmental Disabilities
 Program

SPC state planning council

SIA service implementing agency

Information on the use of the standards for self assessment or third party review appears in the introduction to the Performance Standards.

3.4 Further Development of the Performance Standards

Phase two of the project involves a pilot test on eight (8) states and independent review by many experts in the field. Results of this review phase will lead to modification of the performance standards. Finally, training sessions will be conducted in each region for council and a council staff on the use of the standards.

Figure 3
Rationale Form

DEVELOPMENTAL DISABILITIES PROGRAM PERFORMANCE STANDARDS	
<u>Rationale</u>	<p>A mandate is given to the Developmental Disabilities Program to promote the provision of quality services to persons with developmental disabilities. The Developmental Disabilities Program can achieve this through 1) the promotion of quality assurance strategies in the service providing agencies, 2) the monitoring and evaluation of developmental disabilities funded and generic services and 3) the promotion of accreditation of service programs via appropriate standards. The promotion of accreditation and other quality assurance mechanisms represent methods indicated in the Act for improving generic service provision. Particularly since the council has no authority to impose quality standards on generic service providers monitoring and evaluation responsibilities are the methods provided to the council to ensure quality service provision.</p>
<u>How is the standard met?</u>	<p>The methodology for determining if standards have been met is not included in this review draft. Information gathered through the review process must be considered in completing this component of the Performance Standards.</p>

Rationale Statement

Assessment Statement

Figure 4
Standard/Criteria Form

DEVELOPMENTAL DISABILITIES PROGRAM PERFORMANCE STANDARDS			Assessment Notes
STANDARD AREA: SYSTEMS ADVOCACY		Final Y/N	Reference
<p>(a) →</p> <p>Standard</p> <p>7 The Developmental Disabilities Program shall promote improvement in the quality of services provided to persons with developmental disabilities.</p>			<p>TC</p> <p>1</p> <p>L 5111</p> <p>L 5133(b) 6</p>
<p>(b) →</p> <p>7.1</p> <p>Criterion</p> <p>The Developmental Disabilities Program should promote and/or sponsor the development of quality assurance strategies in services related to developmental disabilities.</p>			<p>TC</p> <p>4</p> <p>L 5111</p>
<p>7.2</p> <p>Criterion</p> <p>The Developmental Disabilities Program shall monitor the quality reviews of services provided by developmental disabilities funded and Genetic Programs.</p>			<p>TC</p> <p>1</p> <p>L 5133(b) 2</p> <p>L 5137(b)</p>
<p>7.3</p> <p>Criterion</p> <p>The Developmental Disabilities Program should promote and/or sponsor the accreditation of facilities and programs through applicable standards.</p>			<p>TC</p> <p>2</p> <p>L 5133(b) 6</p> <p>L 5114</p>
<p>Criterion</p>			<p>TC</p>
<p>Criterion</p>			<p>TC</p>
<p>Criterion</p>			<p>TC</p>

(c) (d) (e) (f)

70

(d)

$$\underline{z}(f)$$

Guidance:

BIBLIOGRAPHY

LEGISLATION

Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L. 91-517).

Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103).

A Compilation of Developmental Disabilities Legislation, Developmental Disabilities/Technical Assistance System, 1975.

Hearing before the Subcommittee on the Handicapped, Ninety Third Congress, Second Session on S. 3378, Developmentally Disabled Assistance and Bill of Rights Act of 1974, Washington, Government Printing Office, 1974.

Compilation of the Developmental Disability Legislation, Developmental Disabilities Office.

REGULATIONS

Federal Regulations for the Developmental Disabilities Program, (45CFR) Federal Register, Vol.42, No. 18, Thursday, January 27, 1977.

GUIDELINES

From:

Developmental Disabilities Office,
Office of Human Development
U.S. Department of Health, Education, and
Welfare; September, 1977.

Guidelines for:

Construction Program, TN-77-007.

Design for Implementation of the State Plan
(DFI) TN-77-005.

Individualized Habilitation Plans (IHP).
TN-77-009.

State Administering Agency(ies) and Program
Unit Functions and Responsibilities TN-77-008.

State Planning Councils Functions and
Responsibilities, TN-77-010.

Volunteer Services, TN-77-006.

Deinstitutionalization (DRAFT) .

Employee's Protection (DRAFT).

Guidelines and Instructions for Developing and Preparing
the Comprehensive State Plan for the Developmental
Disabilities Program, March, 1977.

PERFORMANCE STANDARDS

Head Start Program Performance Standards, Office of Human Development, July 1975.

Regional Management Performance Standards (DRAFT)
Office of Human Development, April, 1976.

Vocational Rehabilitation Performance Evaluation Standards Study, Part II Guidance Materials.

Program Performance Standards Self-Assessment and Program Monitoring Instrument and Instructions: Projects for Runaway Youths, Office of Human Development, March 1977.

STANDARDS

Joint Commission on Accreditation of Hospitals.
Standards for Community Agencies Serving Persons with Mental Retardation and Other Developmental Disabilities.
Accreditation Council for Facilities for the Mentally Retarded, July 25, 1973.

Joint Commission on Accreditation of Hospitals.
Standards for Residential Facilities for the Mentally Retarded
Accreditation Council for Facilities for the Mentally Retarded — May, 1971'.

Wolf Wolfensberger and Linda Glenn.
Program Analysis of Service Systems, A Method for the Quantitative Evaluation of Human Services, Third Edition, 1975.

Standards for Services for Developmentally Disabled Persons,
Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons, January, 1977.

ADDITIONAL DOCUMENTS

"A Report on Implementing Georgia's Program Under the Developmental Disabilities Services and Facilities Construction Act as Amended"
The Georgia Council on Developmental Disabilities, September 30, 1977.

ADDITIONAL DOCUMENTS (CONT'D)

Edmund Ricci, Kathryn Greever, William Hall and Dennis Parrucci
Guidelines for the Evaluation of State Developmental
Disabilities Planning Councils, Council Supported Projects
and Other Projects Funded through PL 94-103, University
Affiliated Center, West Virginia University, Morgantown,
West Virginia. April, 1977.

Program Administration Review, Region IV, Developmental
Disabilities Division

Review and Evaluate Standards and Quality Assurance Mechanisms
for Programs and Services to Persons with Developmental
Disabilities. Government Studies and Systems, Philadelphia,
Pennsylvania, April, 1977.

Wolf Wolfensberger. The Principal of Normalization in
Human Services. National Institute on Mental
Retardation, Toronto, 1972.

Ned Vitalis. Monitoring and Evaluation Overview. Social
Planning Services Inc., Watertown, Mass. 1977.

_____. Monitoring and Evaluation of the State Plan,
Social Planning Services Inc., Watertown, Mass. 1977.

_____. Monitoring and Evaluation of the Design for
Implementation, Social Planning Services Inc.,
Watertown, Mass. 1977.

_____. Roles and Options for Monitoring and Evaluation
under the DP Act (PL 91-517 as amended by PL 94-103)
Social Planning Services Inc., 1977.

_____, and Carolyn Cherington. The Two Dimensions of
Evaluation. Social Planning Services Inc., Watertown, Mass.
1977.

OFFICE OF HUMAN DEVELOPMENT POLICIES

Operational Planning System Manual - April, 1975

Policy Paper for Human Services - June, 1977
(Not for Publication)

Memorandum Zero Based Budgeting DDO - April, 1977