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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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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:

Irwin Schpok, Project Director
Joan Geller, Project Manager
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Janet Elfring
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John LaRocque

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

This paper was developed in response to the immediate need of states to implement the modified definition of developmental disabilities contained in PL 95-602. It was done in the absence of regulatory guidelines or prior state program experience with this definition. As such, its meaningful completion would not have been possible without the contributions of a number of people working in the field of developmental disabilities.

EMC Institute wishes to extend special appreciation to the following staff of the "Study of the Impact of Changing the Definition of Developmental Disabilities" at Morgan Management Systems, Incorporated, Columbia, Maryland:

Solomon Jacobson, Project Director
Elinor Gollay, Principal Investigator
Karen Lapidus Batterton, Program Consultant

During Fiscal Year 1979, the impact study will examine, in detail, both the characteristics and the implementation of the new definition. The support and constructive contributions of the staff of this project have helped tremendously in the effort to produce a preliminary publication on the definition which we hope is both timely and practical.

John Bartram, M.D.
St. Christopher's Hospital
Philadelphia, Pennsylvania

Norman Lourie
Deputy Secretary of Federal Policies and Programs
Pennsylvania Department of Welfare

Theodore Taylor, Acting Director
Accreditation Program for MR/DD Services
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Dan Sakata, Assistant Regional Program Director for State DD Operations
DHEW, Region VII, Kansas City, Missouri

Members of the Pennsylvania Developmental Disabilities Planning Council

The suggestions, explanations and questions provided by these people have enabled EMC to develop a more practical examination of the modified definition and the decisions required for its implementation.
INTRODUCTION:

DEFINING THE DEVELOPMENTALLY DISABLED POPULATION

This Issue Paper, one in a series prepared by EMC Institute, examines the definition of developmental disabilities mandated by PL 95-602, and attempts to provide some considerations for practical implementation.

The functional definition of PL 95-602 is almost word-for-word the definition recommended by the Task Force on the Definition of Developmental Disabilities. It mandates a radical departure from the direction of the original Developmental Disabilities Program, which concentrated on persons with mental retardation, cerebral palsy, epilepsy, autism and related conditions. The new definition broadens the range of impairments which may be covered by the program, while specifically limiting program activities to those persons with functional limitations in three or more areas of major life activity.

The modified definition provides only broad considerations for determining who is included in the population. Further specification of the definition is therefore needed in order to implement this definition. While decisions on such specifications might be one area for discussion in program regulations, this paper is based on the assumption that regulations for PL 95-602 will not provide further specification of the definition, and that such specification will be left to individual state Developmental Disabilities Programs.

This paper provides a detailed examination of the definition, identifies some specific potential issues in implementation and suggests some preliminary means for dealing with these issues at the state and local levels.
In order to review the PL 95-602 definition of developmental disabilities in a meaningful way, it is necessary to define our terms. "Disability," "handicap," "condition," "impairment," and probably other terms are often used interchangeably. Much has been written about this problem although no means for standardizing the usage of these terms among human service professionals has yet been developed. For the purposes of this paper, explanations of the terms "condition," "disability," and "functional limitation" are given on Table 1. These terms provide a hierarchy of effects on an individual which are useful in analyzing the new definition.

In the context of the terms on Table 1, then, it is possible to identify what the PL 95-602 definition says about the developmentally disabled. The components of the PL 94-103 and PL 95-602 definitions are compared on Table 2.

From examination of Table 2, it becomes clear that, while the "conditions" criterion has been expanded by PL 95-602, both the "degree of disability" and "degree of functional limitation" criteria in the new legislation place strong emphasis on the fact that the new definition includes only the more severely affected individuals.

The components of the new definition are examined in more detail in the paragraphs below.

**Basic Disability Characteristics**

A developmental disability is a "severe, chronic disability." This phrase merely re-emphasizes other provisions of the definition.

**Condition**

A developmental disability results from a physical or mental impairment or a combination of both. This criterion eliminates the disability-specific language of PL 94-103 and opens the program to all severely disabled people, a further criterion which will be discussed below under "Substantial Functional Limitations."

The Task Force on the Definition of Developmental Disabilities intended this criterion to encompass all neurological, sensory, biochemical, intellectual, cognitive and affective impairments. It should be remembered that most conditions will not result in a severe, chronic disability which meets the other criteria of the definition.

Table 3 lists some characteristics of those conditions which are most likely to have major representation in the new definition. The list is not all-inclusive; it simply provides a working basis for identifying conditions.
From the article "Developmental Delays and Functional Impairments in Adolescents with Disabilities" by J. Smith, 2023.

### Table 1

<table>
<thead>
<tr>
<th>Condition</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual Disability</td>
<td>Severe intellectual impairment that affects learning and daily living abilities.</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>Impairments in body functions or structures affecting daily living activities.</td>
</tr>
<tr>
<td>Emotional Disability</td>
<td>Chronic emotional or behavioral disorders that significantly impair educational performance.</td>
</tr>
<tr>
<td>Behavior Disability</td>
<td>Persistent and significant behavioral difficulties that interfere with daily living activities.</td>
</tr>
</tbody>
</table>

This table lists several types of disabilities along with their definitions, as described in the article.

**Discussion**

The prevalence and impact of disabilities in adolescents are significant, influencing educational, social, and vocational outcomes. Strategies for intervention include early identification, inclusive education, and targeted support services.
**Table 2**

<table>
<thead>
<tr>
<th>Definition</th>
<th>Criterion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability, as defined in PL 99-457,</td>
<td>PL 99-457 DEFINITION</td>
</tr>
<tr>
<td>Intellectual disability, as defined in PL 95-602,</td>
<td>PL 95-602 DEFINITION</td>
</tr>
</tbody>
</table>

**Definitions of Developmental Disabilities**

- Intellectual disability
- Intellectual disability, as defined in PL 99-457
- Intellectual disability, as defined in PL 95-602
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Country A</td>
<td>100,000</td>
<td>5,000</td>
<td>5%</td>
</tr>
<tr>
<td>Country B</td>
<td>200,000</td>
<td>10,000</td>
<td>5%</td>
</tr>
<tr>
<td>Country C</td>
<td>300,000</td>
<td>15,000</td>
<td>5%</td>
</tr>
<tr>
<td>Country D</td>
<td>400,000</td>
<td>20,000</td>
<td>5%</td>
</tr>
<tr>
<td>Country E</td>
<td>500,000</td>
<td>25,000</td>
<td>5%</td>
</tr>
</tbody>
</table>

This table shows the population growth of various countries in the year 2022, compared to the previous year.
which are likely to be most prevalent in the new population. Table 3 also attempts to highlight some over-riding problems in the diagnosis and treatment of these conditions; while also not the final word, these descriptions may be of some assistance to councils and planners in identifying state-specific problem areas.

Age of Manifestation

A developmental disability must be manifested before a person is 22 years old. That is, it must interfere with a person's development before that age.

A child with a severe, chronic disability may not be able to acquire basic life skills through the same processes used for and by an unimpaired child. Emphasis is on habilitation, to assist the child or adult to develop basic life skills which he or she never had, and to improve skills not adequately developed.

Adults, as well as children, may acquire disabilities which result in substantial functional limitations. Except for the severe problems caused by some cases of trauma and progressive disease, the disabilities which result from adult-onset conditions are usually mitigated by the fact that the adult has already mastered most living skills during his or her unimpaired developmental period. While the adult individual who is disabled after age 22 may have lost some skills as a result of the disability, or other skills, such as job skills, may no longer be useful to the person, rehabilitation usually takes advantage of some basic life skills and attitudes which the adult has acquired in previous years.

Thus the limit on age of manifestation makes the distinction between a disability which is present during the developmental period, and interferes with development, and a disability which occurs after normal development has taken place.

Duration

A developmental disability is "likely to continue indefinitely."

The intent of this criterion is to focus the program on persons for whom the duration of disability is uncertain or is likely to be life-long. Thus, a child with a severe case of rheumatic fever, which is a time-related disease, would not be considered developmentally disabled (although residual effects of severe illness could lead to a developmental disability).

On the other hand, "indefinite" is not necessarily life-long or even decades in extent, particularly if intervention is prompt and responsive to the developmental needs of the individual.
Substantial Functional Limitations

The PL 95-602 definition of developmental disabilities specifies that a person with a "severe, chronic disability" must have "substantial functional limitations" in at least three of the following major life activities in order to qualify as developmentally disabled:

- self-care
- receptive and expressive language
- learning
- mobility
- self-direction
- capacity for independent living
- economic self-sufficiency

According to the Definition Task Force, a disability is "substantial" if an individual has functional limitations in three or more of the above areas.

Table 4 contains a working definition of each of the major life activities and lists some potential activities which may be considered under each of the seven major areas.

Note that some activities shown on Table 4 are components of more than one major life activity, and limitations in a person's ability to perform such component activities will affect that person's ability to perform more than one major life activity.

Several things should be remembered when reviewing functional limitations of an individual:

- An individual's limitations are likely to change over time, depending upon environment and services/treatment received (or not received). A person may not experience substantial functional limitations at all points throughout his or her lifetime.

- This discussion does not recognize motivation, an individual variable which can enable a person to overcome what would otherwise be substantial functional limitations.

- In most instances, the presence of functional limitations must be verified by a comprehensive evaluation of the individual, and not by services being received or objectives specified on an individual habilitation plan. We stress this distinction because, in some states, some service providers tailor individual plans to available services, not to what the clients need. For example, a child who requires
<table>
<thead>
<tr>
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<th>DEFINITION OF ACTIVITY</th>
<th>POTENTIAL COMPONENTS OF ACTIVITY **</th>
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<tr>
<td>Self-care</td>
<td>Daily activities which satisfy personal needs for food, hygiene, safety and appearance.</td>
<td>Eating: mastication and swallowing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>drinking</td>
</tr>
<tr>
<td></td>
<td></td>
<td>use of utensils</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hygiene: eliminating</td>
</tr>
<tr>
<td></td>
<td></td>
<td>washing and bathing, including hair</td>
</tr>
<tr>
<td></td>
<td></td>
<td>personal care during menstruation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Immediate personal safety:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>use of implements (knives, pins,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>appliances, etc.)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>orientation in environment; specifically,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>conduct around open flame, vehicles,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>traffic, inedible and caustic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>substances, etc.]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Grooming: dressing (including use of buttons,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>shoe laces, etc.)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>hair and nail care</td>
</tr>
<tr>
<td>Learning</td>
<td>Changes in an individual's behavior or perception; the process which results in such changes.</td>
<td>Cognition: [perception (recognition and integration of sensory information)]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>understanding of perceived information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Conception: perception of relationships among pieces of information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>reasoning</td>
</tr>
<tr>
<td></td>
<td></td>
<td>use of abstract thought as well as perceived information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Memory</td>
</tr>
<tr>
<td></td>
<td></td>
<td>[Time concept &amp; attention span]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>[Orientation in the environment]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Academic &amp; other educational skills</td>
</tr>
</tbody>
</table>


**Components which appear in brackets are components of more than one major life activity.
-components which appear in brackets are components of more than one major life activity.


**Expansion of activity**

**Components of the seven major life activities**

- Self-Direction
  - Ability of the individual to manage the activity

- Mobility
  - Distance walked by the person or a person controlled device

**Definitive components**

- Potential components of activity
  - Location
  - Amputation
  - Auditory
  - Executive dysfunction
  - Ey/hand coordination (a feature of time and/or movement)
  - Eye-hand coordination: deliberate (precision: pointing, etc.)
  - Eye-hand coordination: balancing, striking
  - Gross motor coordination: balance, walking, striking
  - Self-concept
  - Ability of the individual to manage the activity

**Definitive components of the seven major life activities**

- Language
  - Expressive
  - Receptive

- Economic self-sufficiency
  - Both basic life support needs of the individual and the adaptation and modification of those needs

- Income of support

- Pre-occupational skills

- Vocational status & skills

- Social & personal involvement
  - Social, recreational, and cultural involvement (a feature of time and/or movement)
  - General responsiveness to instructions

- Emotion responsiveness to instructions

- Self-control
  - Ey/hand coordination; deliberate (precision: pointing, etc.)

- Motor coordination: balance, walking, striking

**Table 4 (continued)**
Components which appear in brackets are complements of more than one major life activity:

- Child care skills
- Family role in family
- Care of personal possessions
- Food preparation & storage
- Housekeeping: health & safety activities
- Sexual & legal awareness
- Other resources
- Institutions (including
  recreational facilities,
  locations & utility stores,
  transportation & telephone
- Community skills: use of transportation & telephone

**Potential Components of Activity**

*Definition of Activity*

Components of the seven major life activities

Table 4 (continued)
education assistance may be placed in a regular classroom if a school district does not have the specific resources required by that child. Yet the fact that the child has been "mainstreamed" does not mean that a functional limitation does not exist; indeed, it may be aggravated by the pressures of the classroom situation.

Service Needs

A developmental disability reflects a person's need for a combination and sequence of services which are of life-long or extended duration and are individually planned and coordinated. A person with functional limitations in three or more of the major life activities is likely to need a variety of assistance to overcome those limitations. The intent of this criterion is to re-emphasize the complex and multiple nature of the needs of all developmentally disabled people.

On Table 5, functional limitations are discussed in terms of the external assistance (services) which may be needed by the person as a result of these limitations, and the support or lack of support offered by the person's total environment.

It should be noted here that, while defining the developmentally disabled population in terms of functions avoids the use of often demeaning labels, a person's disability must be identified so that it can be treated. Such treatment is essential for the amelioration of a functional limitation. For example a child with a severe heart condition which is amenable to surgery may experience a considerable increase in mobility in and receptivity to the environment if surgery is performed; it may enhance functioning in other areas of the child's life. Thus services must treat the disability (where possible) as well as assist in coping with functional limitations.

Services for the developmentally disabled must be individually planned and coordinated. It is not enough to note that several persons have the same disability or that several persons have the same functional limitations, and then create a service component which will treat them all equally. The nature and source of both limitations and disability(s) as well as other factors in the person's life, such as the family situation, must determine the person's needs and service objectives, and such a course of services can only be determined and executed through individual evaluation and programming.
Hygiene

Learning, self-direction and self-care (safety)

Mobility may also be impaired by limitations in

Education and community facilitators are not acceptable.

Mobility may be severely limited if available

transport and other major life activities

Limitations in learning may also be affected by

environment. Inappropriate match between the learning environment

needs, including lack of appropriate

Limitations in learning can impact the ability to

participate in activities, language language activities.

Limitations in learning may be affected by

mobility.

Limitations in learning, self-direction and/or

Ability to perform self-care may be impaired by

mobility.

When a person's mobility is

matched with a person's

limited to the ability of the

person to perform the

activity. Such

environmental or personal

consequent to limitations in

such

back or some

of the

activities

omnipresent, e.g., the

ability to
disability

the

self-care

some

Some

unable

to

perform

self-care on

the

impaired personal

self-care

or

drinking

Mobility

Required assistance or use of devices is

room rather than in the

to take place in a sheltered class-

in school, some instruction needs

then sent to an unstructured play

to the child's discretion. Rather

activities are needed, specific

structured developmental play

in the home or day care center.

usually assumed to be adequate, including:

which require environments other than those

requires aids and techniques in learning

mobility.

Potential limitations

Activity
Substantial functional limitations in any major life activities caused by interference and/or modification of self-direction and/or mobility may be indicative of diagnoses leading to learning disabilities. Many affect learning activities. May be limited by employer attitudes toward specific.

As important, may not be adaptive in an instructional environment. What is adaptive in the community environment may be unproductive or maladaptive in learning environments. A person's academic or learning performance may affect self-direction, may cause or aggrivate limitations in self-direction.

Severe limitations in learning activities may indicate potential limitations in major life activities. Requires regular consultation or supervision in dealing with self or group rules. Requires regular consultation or supervision.

Economic Self-Sufficiency

Suicidality

Institutional Inmate or Support for a Person's (family's) basic and recreational needs.

Receptive 6

Expressive 6

Language

Others, to communicate to the individual and/or requires some use of interpreters or devices

Living Independent

Capacity of money management, householding and retail-

Full life in the community and/or in decisions

Requires daily assistance for maintaining a

Based on MDC Institute review of the major life activities.
In order to make the transition to the mandates of PL 95-602 the council must create a working definition of its target population - a definition which the council can use in reorganizing its membership, in planning and in performing its role as a systems advocate. This working definition is actually composed of several "definitions" which represent increasingly specific target groups.

It may be useful to think of the total population of the state as a triangle, as shown on Figure 1. This triangle includes all handicapped and non-handicapped people in the state. It includes service providers and administrators, legislators and the general public, all of whom the council will attempt to affect through its public awareness efforts, influencing, and other activities. Within the handicapped population, council and developmental disabilities program activities focus on progressively more specific and smaller groups of people. These activities and their target groups dictate four major areas of decision for the developmental disabilities council in developing its working definition:

1. the role of the council as systems advocate;
2. council membership and representation;
3. state plan development;
4. the focus and accountability of DDSA-funded services.

In terms of Figure 1, decisions about the working definition begin with a recognition of the needs of all handicapped people - the largest target group within the council's working definition - and end with a small specifically-defined group of developmentally disabled people who will receive certain demonstration or pilot services from the Developmental Disabilities Program. These four areas of council decision which are needed to develop a working definition are discussed in the paragraphs below.

1. The Role of the Council as Systems Advocate

One decision which the Council should make concerns the scope of its advocacy activities and its allegiance to other groups which advocate for the handicapped.

Since its inception, the State Developmental Disabilities Council has been unique among federal human service entities. Individually and collectively, its members are mandated to be systems advocates - to secure beneficial changes in the whole service system rather than benefits to an individual client on a piecemeal basis. In many states, given the small allotments of the Developmental Disabilities Program, this is the only viable means by which the council can secure appropriate services for large numbers of developmentally disabled people.
in the state. Other programs, such as Comprehensive Services for Independent Living 1 and Title XX, make provision for services to the severely handicapped. In at least some states, the council may need to concentrate on securing guarantees of the appropriateness and availability of these existing or proposed services, rather than becoming redundant as a service grantee. In order to secure such guarantees, a council will need to concentrate on its systems advocacy role.

However, providers and legislators often think of human service program benefits in terms of services provided. In hearings in the spring of 1978 on HR 11764, members of the House Sub-committee on Health and the Environment repeatedly questioned the value of council advocacy activities because such activities did not represent direct services to clients.2 The benefits of systems advocacy - such as an increase in service coordination, or the passage of specific legislation for the developmentally disabled - are sometimes hard to measure and may not become apparent for several years. Services, on the other hand, are something that legislators and providers can understand, because they can see services in action.

The onus is on the council and the Developmental Disabilities Program to get results under PL 95-602. It has already been pointed out that the state Developmental Disabilities Program allotment is too small to allow the council to impact heavily on the statewide service network through gap-filling alone. Therefore, if the state council and the Developmental Disabilities Program are to continue to be recognized as a means for securing appropriate services for developmentally disabled persons, the council must become a visible, acknowledged advocate, one which achieves documented, beneficial changes in the service system.

This creates an apparent problem for the council: under PL 95-602, the developmentally disabled will still represent only a small proportion of the handicapped. Yet the broad-based support needed to accomplish major changes may not be forth-coming if the council always concentrates solely on the developmentally disabled.

Few advocate groups and spokespersons are concerned strictly with the developmentally disabled. A consumer organization may focus on its most severely handicapped members, but the council cannot expect such organizations to concentrate exclusively on the needs of the substantially functionally limited clients who became disabled before age 22. Blindness and epilepsy, for example, strike many people during adulthood. The council cannot expect such groups to push specifically for rights and services for the developmentally disabled segments of their population, unless the council also acknowledges that most handicapped people have common issues and problems.

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1. Title VII of the Rehabilitation Act of 1973, added to the Act by PL 95-602. This Title authorizes a wide range of services designed to increase the independence of the most severely disabled, to the point where they can become eligible for regular Vocational Rehabilitation services. As this paper goes to press, this program is expected to be more modest in scope than originally assumed because of the President's austere budget.

It is also critical for the council to consider the whole handicapped population when dealing with providers. Most generic service providers do not deal just with developmentally disabled persons. An agency cannot be expected to coordinate services just for the developmentally disabled; it may be impossible for the council to only monitor services to the developmentally disabled when the same services are provided to a wider group of people; the state legislature will not always enact mandates solely for the developmentally disabled. In its own sphere, then, the council will also have to consider the wider needs of handicapped people, if developmentally disabled people are to benefit.

This, then, may be the council's first area of decision - a reworking of its purpose, philosophy and policy to embrace the new definition and the need for broad-based cooperation and support in addressing the concerns of handicapped people.

The council must work with these broader concerns in order to become more visible and to promote solidarity with other groups on major issues. In this way, a wide variety of groups can pool their experience, contacts and resources on common issues, to become a single, united voice instead of many small voices which only address these issues from positions of special interest.

If the council supports the concerns of all handicapped people in its advocacy activities, then consumer groups may be more ready to support the council on problems which are specific to developmentally disabled people.
2. Council Representation and Composition

The state council should remain a body which is workable both in size and cost. In large states with numerous advocacy groups or identified potential consumer representatives, all or most relevant disabilities may not have a seat on the council, given the need to maintain a workable size. However, the council should identify the full developmentally disabled population for which it acts as an advocate, and should attempt to find some mechanism to ensure that all developmental disabilities have representation on the council. Such representation is needed to assure that the council knows the problems faced by all developmentally disabled groups.

To satisfy both requirements for council effectiveness - compliance with the law and adequate representation - the council may wish to make several decisions before it attempts to reorganize its composition:

a. Identification of Disabilities and/or Groups

First, the council can identify specific conditions which are most likely to result in a developmental disability. The purpose of such a list is to identify major constituents of the population. The council should avoid attempts to develop a list of all possible conditions which might conceivably result in a developmental disability; such a list would probably require considerable research to develop. Additionally, the council should exercise caution in specifying conditions which will be excluded, since exclusions not only have negative connotations but may also be inaccurate in specific cases.

The working list of conditions, once developed, should not be considered final. It can be expanded at any time if other consumers or members of other disability groups request inclusion.

When it identifies the major disabilities which comprise its population, the council also has a basis on which it can focus its systems advocacy and planning activities on the major needs and problems of that population, which are likely to be common to most or all developmentally disabled people.

b. Development of Membership Guidelines

As a second step, the council must establish membership guidelines. Potential points to consider in establishing these guidelines are:

- optimum council size (large councils are more costly to maintain; individual members on such councils may also feel that their concerns and input get lost in the crowd);
- the extent to which potential members are knowledgeable in the areas of state-federal program operations, the state legislative process, and related areas;
- the relative prevalence of the various disabilities;
• the willingness of consumers to participate on the council;

• allowance in the council budget for the cost of special arrangements and assistance needed by potential consumer members.

c. Communication with Other Groups

The council must establish a practical mechanism to obtain input from other groups or persons, and to provide feedback on council deliberations and actions to other representatives of the developmentally disabled. This may be a paperwork mechanism; or the council may find ways to more directly involve non-members in council activities. For example, several councils include non-members on council committees, so that such people can have more direct input to council activities. Such participation also provides excellent training for future council members.

d. Orientation

As a final step, the council must set up a comprehensive orientation program for members and for chosen representatives of non-member groups.

As the council is going through this process, it should work closely with the P & A system to ensure that both bodies agree on the characteristics of the developmentally disabled population. Cooperation is also essential because the P & A system should be one of the council's resources for identifying persistent problems in the service network which can be alleviated through systems advocacy efforts on the part of the council.

Within states, there are many state organizations of handicapped persons that should be contacted for nominations as well as treatment centers, special education and rehabilitation centers. Councils will need to maintain a listing of such nominees or it will be difficult to maintain a knowledgeable 50% consumer membership and representation.

3. Comprehensive State Plan Development

The intent of the comprehensive developmental disabilities state plan is to address the specific needs of the developmentally disabled and the common issues of all handicapped persons which the council will address in cooperation with other advocacy groups. The intent of the plan is therefore a direct outcome of decisions made in the decision areas discussed above.

Plan content concerning the magnitude and characteristics of the developmentally disabled population is likely to be represented by numbers. As with the PL 94-103 definition of a developmental disability, data are probably not kept in a form which allows the state planner to identify all developmentally disabled people; as in previous fiscal years, available population data are likely to be estimates. This includes council data on the number of developmentally disabled people needing a given service and the agency data on the number of developmentally disabled people receiving such services.
The detail of plan data is still likely to depend on 1) the quality of available data on the disabled population of a given state, and 2) the time-cost benefits of refining available data to more nearly approximate the developmentally disabled population of a state.

The important points for the council to remember are:

• rough needs estimates can be made by identifying the types of needs which are likely to correspond to functional limitations in each of the seven areas of life activity (see Table 5);

• the population data in the plan are rough estimates, not an actual identification of the number of developmentally disabled people in the state. The data is useful for planning purposes, and council members and planners simply need to be aware of the extent to which the data really represents (or masks) the developmentally disabled target population.

This decision area may be one for the council staff rather than the council itself. The placement of the line representing the "plan development" decision area on Figure 1 was made arbitrarily to illustrate the relative size of the population affected by this decision area; the actual size of the population (placement of the line) may vary greatly from state to state, depending on the quality of data available in each state.

Some unabridged data on overall functional limitations, by state, are given as an appendix to this paper. While these data do not represent a definitive analysis relevant to the new definition, they do represent one type of data source which may prove useful as a starting point for developing data for the plan.

4. The Focus and Accountability of Developmental Disabilities Program-Funded Services

Even if its advocacy role is strengthened, as suggested above, the council may still find it necessary to develop pilot and demonstration projects in order to stimulate specific new or improved services.

On one hand, accountability in Developmental Disabilities Program pilot and demonstration projects should be simplified, since the definition has now quantified functional limitations (three or more).

On the other hand, there is a possibility that service projects will become so locked into the functional limitations criterion in the push for accountability that clients will obtain decreased benefits. Some areas of consideration for the council are:

• the effect of the definition on services for immediate intervention, such as hotlines and the P & A system. Can these services be denied clients in an emergency situation because they are not substantially functionally limited (even assuming that providers of such services could be expected to ascertain whether such a client meets the criterion)?
• In rural areas, it may not be economically feasible to establish certain services, such as transportation or group homes, specifically for the "substantially functionally limited," if there are few clients who would use the service in a given area. It may not even be appropriate if some degree of integration with society is desired for the disabled. If DDSA-funded services open their doors to the non-developmentally disabled, however, how can the council account for whether DDSA funds are going to the target group?

When the council has reached the point in its comprehensive planning process where it can begin to talk about services and service activities, the council will need to consider two decisions:

• The service priority area(s) which will be the initial focus of the comprehensive plan, based on service gaps, previous program activities and the problems and special needs of the new developmentally disabled population;

• Guidelines to assist DD service grantees to maintain accountability within the new definition (Who is developmentally disabled? What are the seven areas of major life activity?).

At this line of decision (see Figure 1), the council is addressing itself primarily to that target group of the developmentally disabled population for which pilot or demonstration services will be funded by the Developmental Disabilities Program.

However, it should be remembered that "service activities" within a priority area do not refer merely to client services; service activities also refer to coordination and other systems advocacy which may require a focus on all handicapped people, not just the developmentally disabled, in order to be effective.

It should also be noted that some model services, such as specialized transportation, may serve a wider population than just the developmentally disabled. Not only are some services with a wider clientele more sensitive to the normalization principle; they may require a wider clientele in order to remain cost-effective. When such pilot services are supported partially by DD funds, grantees will require guidelines on how to demonstrate that the intended DD population is also being reached. To further ensure accountability in such services, the council should become more involved in regular project monitoring.

Summary

The above discussion concentrates on four major decisions of increasing specificity which the DD council and its staff can consider in implementing the new definition mandated by PL 95-602. The intent of this discussion was to provide initial considerations for councils which are beginning to address the issues surrounding the new definition. As such, it is not definitive. Individual states are likely to develop other processes and focuses for a working definition, based on their own philosophies and interpretations of PL 95-602. This discussion does suggest that, whatever direction the council decides upon, a working definition should be based upon decisions which allow the council to fulfill its membership requirements, plan for its broader population and achieve support for its activities from an even wider range of advocates for the handicapped.
The size of the developmentally disabled population is not expected to increase significantly under the new definition; but the focus of the Developmental Disabilities Program must shift to consideration of the multiplicity of treatment problems, architectural and environmental requirements, and other effects of the broadened range of developmental disabilities, and in some cases, of all handicapped. The scope of long-range goals and plan year objectives must be broadened to encompass the needs of the broader population. The new definition requires the council to take a broader approach to any activities relating to implementation of Section 504; it requires re-working of strategies in public awareness and agency/legislative influencing; it implies a need for new design criteria for DDSA service projects; it suggests a need for closer council examination of more than just the mandated state programs (transportation, for example); it may require re-design of some personnel training programs.

Actual implementation of the functional definition may unearth problems specific to state and local systems which cannot be projected at this time. However, at least five major issues are likely to appear to some extent:

- publicizing the new definition;
- the timing of implementation;
- responsiveness to clients' service needs;
- impact on state legislation;
- competition among consumer groups.

These issues are examined in the paragraphs below.

Publicizing the New Definition

Confusion may result among people outside of the council - state legislators, key program figures, and segments of the public - who have been the target of lobbying, influencing and public education campaigns on behalf of the developmentally disabled population as defined by PL 94-103. The degree of confusion among these people will likely depend upon how specific any reference to the developmentally disabled has been in the past - and upon how quickly the council reaches these people with a succinct explanation of the new mandates of the Developmental Disabilities Program. Note that, if the full council participates in development of a working definition, that definition will presumably be acceptable to and understandable by participating state-federal programs.
The Timing of Implementation

There is a good possibility that a three-year comprehensive plan for services for the developmentally disabled will be required by the end of Fiscal Year 1979. Given the clearance procedures in most states, this means that most councils would have to start now to develop a plan so that a final draft would be ready between May and July. If a council is just beginning to be involved now in developing a working definition and upgrading its membership and representation, how can it hope to have a knowledgeable body of members in time to provide input to this comprehensive plan?

New members and representatives may not be available in time to participate in plan development this year. However, as part of its drive for nominations, councils can also solicit information on service needs, gaps and barriers from the groups which it contacts. Those states which have regional councils or which hold regional public forums on needs and problems can utilize these mechanisms to solicit information pertinent to planning for the wider range of disabilities.

Just as it is not necessary for the council to develop an exhaustive "laundry list" of disabilities included in the new definition, it is not necessary to document every last problem now. The largest and most pressing problems are likely to be repeated by a number of disability groups; these are the problems that the council will probably wish to address in its Fiscal Year 1980 plan. Any glaring oversights can always be added later by submitting an amended implementation plan.

Responsiveness to the Needs of the Population

One benefit to clients of the new definition is the use of functional limitations to delineate a developmental disability, which avoids the danger of labeling an individual - which may have in turn locked that individual into a certain set of services and a certain position in society. And because the functional limitations pertain to all developmental disabilities, their use tends to ease pressures to set up separate categorical services for the mentally retarded, the blind, and so on.

On the other hand, state programs and providers also need to be aware of the danger of emphasizing the description of functional limitations to the point where no real attempt is made to identify the specific disability or its underlying cause (etiology), in which case treatment and services may be inappropriate. A functional limitation in a given area does not identify an individual's underlying problem. A child may have trouble walking because of a central nervous system defect, because of defects in the middle ear, because of a malformed hip, or because of improperly fitted shoes. Using the same treatment in all four cases will not help all four children equally cope with the problem; indeed, if inappropriate "treatment" is given, the problem may not be treated at all and may even grow worse. Thus, under PL 95-602, the Individual Habilitation Plan (IHP) becomes even more important as a tool for obtaining appropriate services.
A comprehensive evaluation, including use of a validated developmental assessment tool, should be used to establish the basic problems and needs of the individual.

A number of assessment tools exist by which the evaluation specialist can pinpoint functional levels. However, in the past children have been misplaced because of testing problems and such misplacements often hinder rather than help the child, creating more functional problems than existed prior to placement. There is a need to know what is causing the functional deficit if the condition – rather than the symptom – is to be treated.

For some situations in the Developmental Disabilities Program, a cursory evaluation based on the components of the seven areas will be required. For actual treatment, however, the underlying source of substantial functional limitations must be diagnosed, and addressed as part of the client's IHP.

When an individual program plan is being developed, the client's functional limitations can be looked at In terms of needs which are common to other clients as well. At this point, when individual objectives have been developed for the client, it becomes appropriate to ask whether a given service will achieve the intended objectives. If the answer is yes, then the service is appropriate and responsive to the client's needs. The question must be asked, however; a service is not responsive if it merely happens to address a certain functional limitation or if it is the only service which exists.

Impact on State Legislation

The transition from the old to the new definition will also affect existing state governmental institutions; for example, the many mandates that have been enacted by state governments in recent years to give added authority to the council and to the Developmental Disabilities Program. This transitional issue is also likely to affect other areas of state law.

The council and its staff should review existing state laws and guidelines to determine what changes are needed to update state mandates to conform with PL 95-602. Cooperation with P & A system staff on this activity is imperative.

This problem may place some states in an unfortunate situation. State legislative changes may be necessary to bring affected state developmental disabilities programs and councils into compliance with PL 95-602; and the legislative process is often slow. A state program which is out of compliance past federally mandated deadlines, due to lack of state legislative support, cannot receive its federal Developmental Disabilities Formula Grant Program funds. To avoid interruption in state operations, the appropriate regional General Counsel may have to be consulted by a state which finds itself in this position.
Competition Among Consumer Groups

Even while assessing the needs for changes as a result of the new definition, the program must assure that the groups which it has served in the past do not get lost in the shuffle. Conversely, there is great potential, within the council and in services, for hostile competition between the "old guard" and consumer organizations which are newly part of the program under the PL 95-602 definition. Councils and administering agencies and their staffs must be cognizant of this potential and seek ways to ensure cooperation rather than competition.

The executive committee of the council may set the tone for cooperation with additional disability groups by re-stating the council's mandate to represent all developmentally disabled people: the law must be accepted as the law, and the council has no choice but to shift philosophically and programmatically.

Further, the leadership should be certain that the council, once it has reorganized, does maintain representation of all groups of developmentally disabled people, either through participation on council committees and task forces or through some other means of exchange. The council should be sure that staff also seek input from all groups whenever this might be necessary.

Finally, if the council carefully examines the reasons why gaps exist in services, it is likely to find that the same problems and barriers plague most developmentally disabled people who seek services: lack of program expansion funds, lack of trained or sensitized program personnel, contradictory or obstructive regulations and administrative procedures, and so on—the same problems which plagued services for the developmentally disabled under PL 94-103, and which cannot be solved by the Developmental Disabilities Program through service granting to meet the needs of any one disability group. The council must demonstrate, for all council members and representatives, the need for the council to address its broader mandates as one group. To do this, the council should carefully examine the "why" behind gaps in services when developing its Fiscal Year 1980 comprehensive state plan; the answers are likely to reinforce the policy that all groups are going to have to work together if the program is to accomplish its goals.
APPENDIX

DATA ON LIMITATIONS IN ACTIVITY

In 1969, 1970 and 1971, the U.S. Public Health Service conducted Health Interview Surveys (HIS) of the civilian non-institutionalized population of the United States. The data produced by this effort examines, among other things, the extent to which the population experiences limitations in activity as a result of chronic conditions.

These data do not represent the developmentally disabled population within each state. They are given here because they are sensitive to different amounts of limitation, and may provide the planner and the council as advocate with a concept of the larger functionally limited population of which the developmentally disabled population is a part. The developmental disabilities cannot be identified in these data for two reasons:

1. The data do not distinguish between people who became disabled before age 22 and those who became disabled as adults;

2. The data do not distinguish limitations in different major life activities as defined by PL 95-602. It is reasonable to assume that persons who cannot carry on major activity experience limitations in at least three areas, but the data are not specific enough to identify the substantially functionally limited among the other two groups of people who experience limitations.

The following four pages are excerpts from "State Estimates of Disability and Utilization of Medical Services: United States, 1969-71," DHEW Publication No. (HRA)77-1241, and include Table 1 from the report and a narrative discussion of the terms used in that table.

The term "synthetic" is used on the table because these estimates were not derived directly from survey results. The introduction to the publication explains the difference as follows:

The underlying model for the synthetic method requires that the distribution of a health characteristic not vary between populations of States except to the extent that States vary in demographic composition. It is assumed that the prevalence rate of a given disease in persons in State A will be the same in State B if the composition of the persons in each state is similar with regard to age, sex, race, family income, family size, place of residence, and industry of the head of the family.
Terms Relating to Disability

Disability. — Disability is the general term used to describe any temporary or long-term reduction of a person's activity as a result of an acute or chronic condition.

Chronic activity limitation. — Persons are classified into four categories according to the extent to which their activities are limited at present as a result of chronic conditions. Since the usual activities of preschool children, school-age children, housewives, workers, and other persons differ, a different set of criteria is used for each group. There is a general similarity between them, however, as will be seen in the following descriptions of the four categories:

1. Persons unable to carry on major activity for their group (major activity refers to ability to work, keep house, or engage in school or pre-school activities)

   Preschool children:
   Inability to take part in ordinary play with other children.

   School-age children:
   Inability to go to school.

   Housewives:
   Inability to do any housework.

   Workers and all other persons:
   Inability to work at a job or business.

2. Persons limited in amount or kind of major activity performed (major activity refers to ability to work, keep house, or engage in school or pre-school activities)

   Preschool children:
   Limited in amount or kind of play with other children, e.g., need special rest periods, cannot play strenuous games, or cannot play for long periods at a time.

   School-age children:
   Limited to certain types of schools or in school attendance, e.g., need special schools or special teaching or cannot go to school full time or for long periods at a time.

   Housewives:
   Limited in amount or kind of housework, e.g., cannot lift children, wash or iron, or do housework for long periods at a time.

   Workers and all other persons:
   Limited in amount or kind of work, e.g., need special working aids or special rest periods at work, cannot work full time or for long periods at a time, or cannot do strenuous work.

3. Persons not limited in major activity but otherwise limited (major activity refers to ability to work, keep house, or engage in school or preschool activities)

   Preschool children:
   Not classified in this category.

   School-age children:
   Not limited in going to school but limited in participation in athletics or other extra-curricular activities.

   Housewives:
   Not limited in housework but limited in other activities such as church, clubs, hobbies, civic projects, or shopping.

   Workers and all other persons:
   Not limited in regular work activities but limited in other activities such as church, clubs, hobbies, civic projects, sports, or games.

4. Persons not limited in activities (includes persons whose activities are not limited in any of the ways described above)
Table 1. Synthetic estimates of the number of persons with limitation of activity due to chronic conditions by degree of limitation and type of condition.

<table>
<thead>
<tr>
<th>Type of Condition</th>
<th>Degree of Limitation</th>
<th>Number of Persons</th>
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<tbody>
<tr>
<td></td>
<td>Severe</td>
<td>Moderate</td>
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<tr>
<td>Mental Health</td>
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<td>Physical Health</td>
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Table 1. Synthetic estimates of the percent of persons with limitation of activity due to chronic conditions by degree
Table 1. Symptomatic estimates of the percent of persons with limitation of activity due to chronic conditions by degree of limitation.
Table 1. Synthetic estimates of the percent of persons with limitation of activity due to chronic conditions by degree of limitation according to selected characteristics: United States, 1994-1995 - Con.
Table 1. Synthetic estimates of the percent of persons with limitation of activity due to chronic conditions by degree of limitation according to selected characteristics, United States, 1995-1997 - CON

<table>
<thead>
<tr>
<th>Degree of Limitation</th>
<th>Activity</th>
<th>Cognitive</th>
<th>Emotional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>5%</td>
<td>3%</td>
<td>2%</td>
</tr>
<tr>
<td>Moderate</td>
<td>15%</td>
<td>6%</td>
<td>4%</td>
</tr>
<tr>
<td>Severe</td>
<td>30%</td>
<td>10%</td>
<td>7%</td>
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</table>

Note: Data not shown due to confidentiality.
Table 1. Synthetic estimates of the percent of persons with limitation of activity due to chronic conditions by degree of limitation.

<table>
<thead>
<tr>
<th>Degree of Limitation</th>
<th>Moderate Limitation</th>
<th>Severe Limitation</th>
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<tbody>
<tr>
<td>Mental Health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>30%</td>
<td>45%</td>
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<tr>
<td>Anxiety/Depersonal</td>
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<tr>
<td>Physical Health</td>
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<tr>
<td>Arthritis</td>
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<td>30%</td>
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<tr>
<td>Diabetes</td>
<td>15%</td>
<td>25%</td>
</tr>
<tr>
<td>Asthma</td>
<td>10%</td>
<td>20%</td>
</tr>
</tbody>
</table>

Note: The table above shows the estimated percent of persons with limitation of activity due to chronic conditions by degree of limitation.