

Definition of Developmental Disabilities

National Task Force
On the Definition of
Developmental Disabilities

Chairperson:
Norman V. Lourie

FINAL REPORT
OF THE
NATIONAL TASK FORCE
ON THE
DEFINITION
OF
DEVELOPMENTAL DISABILITIES

Submitted to

The Committee on Interstate
and Foreign Commerce
of the House of Representatives

and

The Committee on Human Resources
of the Senate

ABT ASSOCIATES INC.
55 WHEELER STREET, CAMBRIDGE, MASSACHUSETTS 02138
TELEPHONE : AREA 617-492-7100
TELEX: 710-3201326

November 3, 1977

Hon. Harrison Williams, Jr.
Chairman
Senate Committee on Human Resources
4230 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Senator Williams:

Enclosed are fifty (50) copies of the Final Report of the Special Study on the Definition of Developmental Disabilities which was conducted in accordance with Section 301 (b) of Public Law 93-104.

As you are probably aware, the Developmental Disabilities Office of the Department of Health, Education and Welfare awarded a contract to Abt Associates Inc. to conduct the Independent Study of the Definition of Developmental Disabilities through the project. A National Task Force on the Definition of Developmental Disabilities was established under the Chairmanship of Mr. Norman V. Lourie of Pennsylvania. The entire Task Force, as well as many individuals and organizations throughout the country, worked hard to contribute to the enclosed report. The final recommendations are those agreed upon by the National Task Force.

My staff and I, as well as members of the National Task Force are available to meet with you, members of your staff, or with the appropriate subcommittees to discuss the recommendations or to answer any questions which you may have regarding the study.

It was our pleasure to be able to work on this study and we hope that you will find the enclosed report helpful.

Sincerely,



Elinor Gollay, Ph.D.
Project Director

EG/cp

Enclosures

cc: Ms. Patria Forsyth

ABT ASSOCIATES INC.
55 WHEELER STREET, CAMBRIDGE, MASSACHUSETTS 02138
TELEPHONE • AREA 617-492-7100
TELEX: 710-3201328

November 3, 1977

Hon. Paul Rogers
Subcommittee on Health and Environment
of the House Committee on Interstate and Foreign Commerce
2415 Rayburn House Office Building
Washington, D.C. 20515

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Elinor Gollay, Ph.D.
Project Director

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Enclosures

cc: George E. Hardy, Jr., M.D.

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DEDICATION

The attached report is dedicated to developmentally disabled individuals who, however defined, were the primary concern of all participants in the Study.

We hope sincerely that developmentally disabled persons will be better served as a result of the recommendations and by considerations of the issues addressed in the study. Task Force members, staff and many other contributors gave their time and energy to produce this report with the hope that a better effort will be made to identify those most in need of service.

ACKNOWLEDGEMENTS

Many individuals and organizations made this report possible. All who will benefit from this report will appreciate their work. We thank them strongly and warmly. All members of the National Task Force on the Definition of Developmental Disabilities participated vigorously at meetings and between meetings when materials needed to be reviewed. Task Force members spent considerable time discussing pertinent issues. They brought to the meetings not only their own views and perspectives, but those of the many individuals and organizations who were not participating directly in the process.

Following a Congressional mandate, the Developmental Disabilities Office in the Office of Human Development services of HEW, funded the project which resulted in the following report. Thanks are due to Frank Leonard, who was the first Project Officer for the Study, and particularly to Ann Queen, who assumed the responsibilities of Project Officer midway in the project. The Developmental Disabilities Office throughout played a supportive role, without attempting to influence the final outcome. The recommendations reflect the opinions of the Task Force. Every possible effort was made to ensure the objectivity of the Study and to provide opportunity for all concerned to register views and react to issues as they arose.

Large numbers of individuals and organizations throughout the country took the time to respond to letters and documents sent to them. They wrote careful responses, provided much useful information and offered their support to the effort even when they were not necessarily pleased with particular recommendations. Throughout the Study they shared with the Task Force the primary concern that the ultimate benefits to be derived should be for disabled individuals.

Finally, there were many skilled and dedicated persons who worked as staff for the Study. The core staff of Carolyn Cherington, Donald Freedman, Ruth Freedman, John Doucette, and Suzanne Simenson worked on all

aspects of the substantive work and on the process of conducting successful meetings of the Task Force. Donald Freedman, in addition, served as a legal consultant to the Project. Geoffrey Bock, Thomas Carva, Paula Hammer, and Kenneth Livingston contributed papers. Karen Tropeano made sure that all meetings went smoothly and that all materials were produced. Alwina Bennett was the budget monitor, James Hoell was a research assistant for the project, Karen Keefe and Karen Schneiderman copy edited many of the materials in Volume II of this report.

Special thanks are due to Barbara Sampson who acted in a very special role: Technical Quality Reviewer, substantive staff person, and supportive friend to the project and all of the participants.

Norman Lourie
Chairman

Elinor Gollay
Project Director

MEMBERS OF THE NATIONAL TASK FORCE ON
THE DEFINITION OF DEVELOPMENTAL DISABILITIES

Mary Akerley Silver Spring, Maryland	Loy Golladay Rochester, New York	Evelyn Provitt Lansing, Michigan
* William Bean Washington, D.C.	Leon Greenspan New York, New York	Lloyd E. Rader, Sr. Oklahoma City, Oklahoma
Gerard Bensberg Lubbock, Texas	* Lawrence D. Haber Washington, D.C.	Raymond Ramiriz Springfield, Illinois
Elizabeth Boggs Hampton, New Jersey	Dennis Haggerty Philadelphia, Pennsylvania	Lee Rubin Harrisburg, Pennsylvania
* James Burr Washington, D.C.	Elsie Helsel Athens, Ohio	Janice E. Ryan Burlington, Vermont
Geraldine Clark Salt Lake City, Utah	* Lawrence Platt Rockville, Maryland	* Herman Saettler Washington, D.C.
Betty J. Cleckley Knoxville, Tennessee	* Rudolph P. Hormuth Rockville, Maryland	Lee E. Schacht Minneapolis, Minnesota
James D. Clements Chamblee, Georgia	* Richard K. Johnson Washington, D.C.	Thomas Scheinost Pierre, South Dakota
Louis Cooper New York, New York	Charles V. Keeran, Jr. Los Angeles, California	Hilde S. Schlesinger San Francisco, California
William M. Cruickshank Ann Arbor, Michigan	Maurice G. Kott Trenton, New Jersey	Sally L. Smith Washington, D.C.
* John Dempsey Washington, D.C.	Norman V. Lourie - Chairman Harrisberg, Pennsylvania	Lawrence T. Taft Piscataway, New Jersey
Floyd Dennis Nashville, Tennessee	Dorothy MacConkey Fairfax, Virginia	Eli Tash Milwaukee, Wisconsin
* Joseph Drage Bethesda, Maryland	Jack McAllister Washington, D.C.	Rita Varela Zephyrhills, Florida
Gunnar Dybwad Waltham, Massachusetts	James Moss Seattle, Washington	Richard Verville Washington, D.C.
Eunice Fiorito New York, New York	Mary Lou Munts Madison, Wisconsin	James MacDonald Watson Portland, Oregon
Robert M. Gettings Arlington, Virginia	Paul Pearson Omaha, Nebraska	

* federal members of the Task Force

In addition, the following groups had a representative at each meeting but no consistent member of the Task Force:

American Federation of State, County and Municipal Employees
(AFSCME)/AFL-CIO
Washington, D.C.

Social Security Administration
Baltimore, Maryland

- Extensive knowledge of or experience with a range of specific disability categories (including major disability groups included as well as some not included in the current definition of developmental disabilities);
- Geographic distribution, including all regions of the nation, both urban and rural perspectives;
- Experience at different levels of the government;
- Different professions and academic specialities (e.g., physicians, educators, psychologists, etc.);
- Direct knowledge of different types of services and programs (e.g., total service delivery systems, residential/institutional care, advocacy services, vocational rehabilitation, welfare, education, health);
- Different types of service providers (e.g., administrators, direct care personnel, planners);
- Extensive knowledge of the problems and service needs at different stages of life (e.g., neonatal, adolescent, adult, elderly);
- Primary and secondary consumers and advocates for consumers (e.g., disabled individuals, parents and volunteers).

The Task Force met for three working sessions in order to discuss the major question addressed by the study:

WHAT IS AN APPROPRIATE BASIS FOR A DEFINITION OF DEVELOPMENTAL DISABILITIES (I.E., WHAT CRITERIA SHOULD BE USED IN CHOOSING A DEFINITION)?

While the primary focus of the study was to determine an appropriate basis for a definition of developmental disabilities (part A of Section 301(b)), the concerns of disabled individuals to be excluded from the definition were kept in mind throughout the study. In addition, a number of specific efforts were made to determine the relationship between the definition of developmental disabilities and programs of federal and state agencies which serve this group and which serve other handicapped persons. A close examination of the issues raised by part B of Section 301(b) could not, however, be conducted within the scope of the present study.

For the working sessions a variety of research and background materials were prepared by staff for the Task Force members. Topics covered included:

1. Issues surrounding the nature of the target group; defining the criteria that should be applied in order to determine who is included within the rubric "developmental disabilities;"
2. Definitions of the main issues that derive from the nature of the current DD Program both as it is legislatively mandated and as it is actually operated, particularly at the state level;
3. Concerns deriving from the broader context in which the DD Program operates at the federal and the state levels; and
4. Implications for populations included or excluded from the definition.

Members reviewed these documents and consulted with a wide range of individuals and organizations to enhance their own understanding. They have worked together to ensure that ample consideration was given to the many factors bearing on decisions, or which were be affected by recommendations.

Efforts were made throughout the study to solicit opinions from the many individuals and organizations not directly represented on the Task Force. A project description, a newsletter, and a feedback document were mailed to over 500 persons and organizations. These materials were distributed to provide information, to solicit reactions to the alternative definitions under consideration by the Task Force and to obtain input on a variety of issues fundamental to the definition. In addition, staff and Task Force members attended a number of national meetings to provide information to people and obtain contributions to the effort.

This Report presents the final thinking and recommendations of the Task Force. It represents careful examination by Task Force members and staff of the complex issues involved.

2.0 RECOMMENDATION FOR THE APPROPRIATE BASIS FOR THE DEFINITION OF DEVELOPMENTAL DISABILITIES

This section contains the formal recommendation of the Task Force concerning the appropriate basis for the definition of developmental disabilities. These recommendations are explicated in Section 2.2. Section 2.3 indicates who would be included and excluded from the proposed definition. Section 2.4 gives a brief description of the steps the Task Force took leading to the recommendations included in this section. In Section 2.5 a minority recommendation of the Task Force is provided.

2.1 The Recommended Appropriate Basis for the Definition of Developmental Disabilities

The following is the recommendation of the Task Force for the appropriate basis of the definition:

For purposes of the Developmental Disabilities Act, a developmental disability is a severe, chronic disability of a person which:

- 1) *is attributable to a mental or physical impairment or combination of mental and physical impairments;*
- 2) *is manifest before age 22;*
- 3) *is likely to continue indefinitely;*
- 4) *results in substantial functional limitations in three or more of the following areas of major life activity:*
 - a) *self-care,*
 - b) *receptive and expressive language,*
 - c) *learning,*
 - d) *mobility,*
 - e) *self-direction,*
 - f) *capacity for independent living, or*
 - g) *economic self-sufficiency; and*
- 5) *reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are*
 - a) *of lifelong or extended duration and*
 - b) *individually planned and coordinated.*

2.2 Explication of the Recommended Definition

The following explication of the recommended appropriate basis for the definition of developmental disabilities provides a number of different perspectives and types of information concerning the recommendation. The purpose of the explication is to clarify the intent of the recommendation, as well as to point out some of the reasons why the specific recommendation was made and some of the concerns which were expressed.

The elements of the recommendation each reflect the majority opinion of the Task Force. In virtually no instances, however, was there unanimity on a recommendation. In all instances the Task Force members considered as many options as possible: during the course of the study they investigated many issues around each option, reviewed background materials designed to provide balanced perspectives on each issue, and finally made the decision which each felt was in the best interest of the developmentally disabled population.

This section discusses the concerns and different points of view which were expressed about each element in the definition in an effort to reflect some of the complexity of the decisions which the Task Force had to make, and to reflect true concerns which many members had even when they basically supported the total set of recommendations.

Some of the differences expressed were held more strongly than others. The difference which was expressed most strongly centered around the specification of impairments and categories of conditions. This view is reflected in the minority report, Section 2.5. It is hoped that this explication of the recommendations will provide readers with a better understanding of the intent, rationale, and concerns which the Task Force had about each element.

The explication takes each of the phrases in the recommendation in order.

"For purposes of the Developmental Disabilities Act..."

The first introductory clause delimits the legal scope of the definition. The definition was developed primarily to meet the specific purposes of this single federal/state program. The purposes of the Act, as stated in P.L. 94-103, were accepted as givens. It is intended to serve all aspects of that Program, as identified in the Act, including State Developmental Disabilities Planning Councils, the National Advisory Council on Developmental Disabilities, University Affiliated Facilities, Special Projects, and program standards. However, the definition is not intended exclusively for these purposes, and as a secondary consideration the definition is intended to be recognizable and usable in a variety of clinical, professional, and federal and state program contexts.

"...a developmental disability is..."

The definition of "disability" is that developed by Saad Nagi* and which is commonly understood in the professional literature. It is: a form of inability or limitation in performing roles and tasks expected of an individual within a social environment.

"...a substantial, chronic..."

These terms are used in a general, descriptive sense rather than as technical criteria. They are included for emphasis, with the specific criteria and qualifications listed in the following paragraphs.

"...disability of a person which..."

This phraseology is meant to convey the point that the term "developmental disability" is not a general catch-all for an arbitrary collection of existing labels attached to diseases, conditions, or syndromes, such as cerebral palsy or mental retardation. Mental retardation is not a developmental disability per se. Some people with mental retardation, on the other hand, have a developmental disability if their situation reflects all aspects of the definition. The "developmentally disabled" are a group of people with their experiences circumscribed by the definition. They are not defined by statistical probability or by inference drawn from a clinical label.

*"Definitions of Pathology, Impairment, Functional Limitations and Disability," based on a paper by Saad Z. Nagi, "Disability Concepts and Prevalence," excerpted from National Rehabilitation Association, Mary. E. Switzer Memorial Series No. 1, May 1975.

A developmental disability is characterized by the cumulative effect of meeting all of the following criteria:

"1) Is attributable to a mental or physical impairment or a combination of mental and physical impairments"

The term, "is attributable to" means that, broadly speaking, a physical or mental impairment must be shown to have caused or to be intrinsically bound up in the person's disability. No technical requirement of clinical etiology is intended. The specific terms, "mental" and "physical" were chosen because they are commonly used and accepted in the field--for example, in the Vocational Rehabilitation legislation and Social Security Act. The impairment requirement of the definition is intended to be very broad and non-technical, extending to all neurological, sensory, biochemical, intellectual, cognitive, perceptual and affective impairments. While the term, "impairment" is intended to have the broadest application possible in the mental and physical domains, it is not intended to include social problems such as juvenile delinquency or substance abuse which are unrelated to physical or mental impairment.

The language relating to combinations of physical and mental impairments is utilized to avoid the sterile debates of recent years over whether a particular impairment should be characterized as physical or mental. In many cases impairments are interrelated, falling into both domains.

The decision by the Task Force to describe developmental disabilities in terms of impairments is closely related to another majority decision of the Task Force not to list specific categories of disabling conditions in the definition as examples of requirements. Language referring to impairments as opposed to specific categories of conditions was used for the following reasons:

- Categories of conditions might be confusing, since people might wrongly assume that any person with a condition listed in the definition would have a developmental disability. Because the disability would have to meet all of the other criteria specified in the definition as well, no category of condition would be automatically included or excluded as a developmental disability.
- Categories might be divisive, potentially creating antagonisms between groups representing conditions included in the definition and groups representing excluded conditions. Such division would be contrary to the Developmental Disabilities Program's ecumenical approach to meeting the common needs of a subset of disabled people.

- Identifying all conditions which might result in developmental disabilities would have resulted in a very long, yet probably incomplete, list.
- The definition should lead to better access to services and the appropriate use of services relates to capacity for functioning rather than to diagnosis or other categorical labels.

On the other hand, by deciding not to list categories, some of the potential benefits of that approach are lost:

- Listing categories might help to clarify further for legislators the specific subset of the disabled population to whom the definition refers.
- Most federal, state, and voluntary programs for the disabled groups have traditionally been organized around specific categories of conditions. These groups might find it easier to use the proposed definition if it were based on a categorical approach.
- Listing categories would lend visibility and support to those groups of disabled persons so identified.
- Listing categories provides greater continuity with the current definition and could facilitate the implementation at the state level.

"2) Is manifest before age 22"

The critical limitation introduced through the use of the term "manifest" is that not only does the disability of the person have to have its origin in the developmental period, but its manifestation as well. Only persons who have a disability which in fact interferes with the person's development by objective manifestation of the disability during that time are intended to come within the scope of the definition.

The rationale for referring to manifestation rather than origination was:

- There are many medical conditions which are genetically determined or originate early in life, but are not manifest until adulthood, including diseases such as multiple sclerosis, Huntington's chorea, stroke, and certain types of diabetes. Persons with such conditions were considered to be significantly different in terms of their developmental experiences and service needs from those intended to be served by the Developmental Disabilities Program.
- If age of onset referred only to origin, then an "administrative nightmare" might occur--persons with various conditions manifest after the age specified in the definition would try to prove that their condition originated prior to the age cutoff point

in order to be covered under the Developmental Disabilities Program.

The major thrust of this component of the definition is on disabilities manifest during the developmental period. There is, however, great debate regarding what constitutes the developmental period. While there was extensive sentiment expressed for the notion that development and maturation are life-long processes, there was also a concern that the definition focus only on disabilities manifest in childhood. Most experts maintain that the needs of persons disabled in childhood are frequently quite different and more intensive than those of persons disabled in adulthood. Disabilities occurring in early childhood tend to interfere more with the individual's opportunities for education, employment, and social relations than disabilities occurring later in life.

In order to focus on the uniqueness of disabilities manifest in childhood, a specific age cutoff point was decided upon. It was recognized that the age cutoff would not dramatically influence the size of the population. The specific term, "before age 22" was selected for the following reasons:

- It represents a generally accepted end point of a primary maturational period, in that it is considered the age beyond which dependency is no longer generally considered acceptable or the norm.
- It is consistent with a broad variety of tax, Social Security, welfare, educational, and vocational programs which use this age as a critical point.

Task Force members realize that any specific age cutoff point is, by nature, arbitrary. Some Task Force members felt that the age cutoff should be lower in order to concentrate on those disabled earliest in life--at birth or in the first few years of life. A large number of those whom the Task Force intended to include would have manifestation early in life--for example, prior to age 12 or even 8. By using a cutoff point as late as age 22, certain types of disabilities might be included which are very different from those arising earlier in childhood--for example, disabilities arising in adolescence from emotional disturbances, sports, and car accidents. There was a feeling that individuals disabled in a substantial way very early in life, such that they never have an opportunity to develop certain skills, are qualitatively different from individuals becoming disabled later in life.

On the other hand, some persons argued that the cutoff point should be greatly broadened, or even eliminated, since the term "developmental" implies lifelong onset or manifestation and there are developmental issues throughout life. Also, persons disabled later in life have similar needs to those disabled earlier in life if the impairment and functional limitations are similar.

"3) Is likely to continue indefinitely"

The definition is intended to include disabilities the duration of which we do not know, and not only disabilities which have shown themselves to be of a chronic nature. The term, "likely" was selected to connote a general and non-technical sense of probability.

The main concern expressed was the potential danger in phrasing chronicity too negatively. Although Task Force members wanted to get across the concept of extended or lifelong duration, they did not want to convey thoughts of hopelessness or lack of potential for treatment and services. The Task Force, therefore, took great care in the wording of the phrases related to chronicity in order not to stigmatize those included in the definition. On the other hand, care was taken not to imply that there exists at the current time some panacea which could alleviate or eliminate a developmental disability.

"4) Results in substantial functional limitations in three or more of the following areas of major life activity:

- a) self-care,
- b) receptive and expressive language,
- c) learning,
- d) mobility,
- e) self-direction,
- f) capacity for independent living, or
- g) economic self-sufficiency."

One of the fundamental assumptions underlying this definition is that it should focus on substantially disabled persons. Since the term, "severe" might promote confusion because of its use as a classification or label in various tests and programs, the word "substantial" is suggested as a substitute. The requirement that the limitation be "substantial" is intended to be descriptive, not finely technical. However, the degree of functional limitation in various task areas can be established either by documenting significant variations from the norm on accepted measures of adaptive

behavior, or by informed observation. The thrust of this element in the definition is that the concept of substantiality is associated with a combination of limitations in function. If a person is limited in only a small number of areas, s/he should not be considered substantially disabled. Limitations in three or more areas of major life activity was suggested in order to assure that a person's limitations are, in fact, substantial.

It is difficult and somewhat arbitrary to specify the number of areas used to determine the substantiality of a disability. The question was raised whether the requirement of limitations in three or more areas was too stringent--would it screen out persons who should be included in the definition? For example, should limitations in two or more areas be more appropriate? It was decided, however, that a cutoff of two or more areas did not sufficiently emphasize the severe nature of the limitations of the population of concern. Too many mildly disabled people such as persons with mild hearing losses or mildly retarded persons might be covered under a two limitation requirement, which was not the intent of the Developmental Disabilities Program.

The overwhelming majority of Task Force members felt that functional limitations should be included as an element in the definition and specified in enough detail to help focus on the population of concern. "Functional limitations" are based on the individual's inability to meet age-specific expectations in certain performance areas. A three-year-old may not be proficient in many critical performance areas (capacity for independent living, for example) but if s/he is not substantially below the norm of the performance of three-year-olds for independent activity, then s/he is not "functionally limited" within the meaning of the definition.

It is the intent of the definition to emphasize limitations in a variety of broad areas of major life activity central to independent living. The term, "major life activity" has a generally accepted meaning in the disability field, and is specifically defined and utilized in other federal programs (Vocational Rehabilitation Act) and in typologies currently being developed by the National Center for Health Statistics.

It was important to select areas of limitation which were not only central to independent living but were also readily measurable by scales,

checklists, or other instruments in order to assist planners and administrators in identifying the population of concern. The specific domains of functions selected for the definition by Task Force members represent the major areas of adaptive behavior which have been measured in existing instruments in the field of developmental disabilities and related disciplines.

Additional concerns related to the selection of areas of major life activities include the following:

- The domains selected must be specific enough to help distinguish the limitations of developmentally disabled persons from the limitations of the broader set of all disabled persons;
- Even though the areas of functional limitation selected were intended to be measurable, the state-of-the-art in functional assessment is relatively new and unsophisticated; this might present problems for planners and practitioners faced with identifying, planning, and providing services for this population.

"5) Reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are
a) of lifelong or extended duration, and
b) individually planned and coordinated."

The intent of this element is to demonstrate the need for a wide array of services from a broad variety of providers in order to meet the needs of developmentally disabled persons. The term, "combination and sequence" is used to show that the nature of the disability being defined is such as to require both more than a single major service at any point in time and also services in an orderly progression over a long period of time. "Special services" are those provided specifically for disabled people, and typically only for disabled people. The services provided by a school for multiply-handicapped children would be an example. "Interdisciplinary services" are those which involve a blending of the approaches of a variety of professional disciplines.* "Generic services" are those available to the public at large which often through adaptation or training can be made fully capable of serving disabled people on an integrated basis. Probably the best example of a generic service which is more and more available to disabled people is our public schools.

*The related concept of interagency coordination was explicitly not used because the Task Force did not want the DD population defined by the nature of the existing service delivery system but only its needs for a certain pattern of care.

Services "of lifelong or extended duration" is intended to emphasize the long-term need for services. It is recognized that many, if not most of the people with developmental disabilities will have special needs throughout their lives. Concern was expressed about the negative, self-defeating effect of labeling an individual as in need of services for life. The use of the term, "extended" in addition to "lifelong" was to help avoid the negative implications of specifying only need for lifelong services. It is recognized that with proper service intervention, some developmentally disabled persons may not be in need of services for their entire lives.

The nature, number, and timing of the services needed by developmentally disabled persons is such as to require individualized planning and coordination. At the system level, individualized planning and coordination can be effected for a broad class of people only through planning and coordinating services on an interagency and intersystem basis, among the full range of education, health, welfare, housing, transportation, and allied services. At the client level there is a need for the development of an Individualized Habilitation Plan covering all service needs, as is specified in the DD Act.

The element referring to need for services was the most controversial and difficult to specify because the Task Force did not want to limit the definition of a population by the need for a specific set of services yet wanted to convey that inherent in the target population was difficulty in being served.

2.3 Who Is Included and Who Is Excluded from the Proposed Definition: A Comparison Between the Existing and the Proposed Definitions

The majority recommendation of the Task Force was that the appropriate basis for the definition should be the characteristics of the disability and its impact on the person's ability to function, not the specific conditions or diagnostic categories of the individual with a disability. The proposed definition, therefore, was intended to cut across a wide number of specific diagnostic conditions to include a subgroup of individuals within these categories of conditions who met certain criteria as spelled out in the recommended wording.

The proposed definition was intended to cover everyone currently covered under the definition and was also intended to add other individuals with similar characteristics. Under the proposed definition individuals

with the conditions currently listed in the law--autism, cerebral palsy, dyslexia, epilepsy or mental retardation (listed alphabetically)--would be included if they met the criteria of manifestation prior to age 22 (an expansion of four years), expectation of continuing indefinitely, resulting in a substantial functional limitation, and requiring multiple services for an extended period. The Task Force felt that it was making clearer the intent of the concept "developmental disability" by stressing the substantiality and chronic nature of the disability more strongly than it had been stressed in the present definition. It was not their intent, however, to exclude anyone who legitimately should have been included under the current definition. Rather, the feeling was that some individuals might have been inadvertently included under the present definition more because of their having one of the listed conditions than because of meeting the additional criteria enumerated in the definition. It was the Task Forces's understanding that the intent of the current definition was to include only the most severely handicapped within the categories of condition listed, but the application has not always been consistent with this intent.

Also included under the proposed definition would be individuals with physical or mental impairments or with specific diagnostic conditions not previously listed in the current definition if the individuals meet the criteria as listed. It is therefore reasonable to assume that a portion of the population with a variety of conditions would be added to the total developmentally disabled population. No people with a specific condition would automatically be excluded per se, just as no people with a specific condition would automatically be included in the developmentally disabled population.

The previous definition of developmental disabilities had a strong emphasis on limited mental abilities similar to mental retardation. The proposed definition of both the minority and majority recommendations allows more clearly for physical as well as mental causes for a developmental disability as long as it meets the other criteria as listed. There are three ways in which it is possible to look at the additional individuals who would be included:

1. Additional persons with mental impairments: Under the proposed definition, a small number of individuals with severe mental illness would be included. Specifically, a small number of persons so severely ill in childhood or adolescence (beginning prior to age 22) that they would have a poor prognosis for ever being able to function independently, would be included. This would include individuals with childhood psychosis.

definition a small number of individuals who have a severe physical impairment such as quadriplegia would be covered if that physical impairment were of such severity that it resulted in the type of functional limitations and need for services on a long-term basis which are described in the definition, and occurred prior to age 22.

3. Additional disease categories or conditions.* Under the proposed definition individuals who have any one of a number of specific conditions might be included if they meet the various criteria. For example, some individuals with spina bifida, muscular dystrophy, learning disabilities, deaf-blindness, etc. would be included. Once again it is important to emphasize that the proposed definition is intended to cut across specific categories of conditions, not automatically to include or exclude them.

The Task Force did intend, however, that certain groups of individuals be excluded from the definition. Individuals whose disabilities are manifest during adulthood or who are not substantially disabled or not expected to be disabled and in need of services for an extended period of time are excluded. Not that these individuals would be excluded from needed services provided outside the DD system per se. Indeed they are served by the same services as serve the DD population. Inclusion in the DD definition is in the spirit of focusing attention on the group; increasing potential for getting them served; getting them special attention because of their special needs; guaranteeing that they are not lost. In addition, the Task Force explicitly intended to exclude individuals whose impairments are primarily social in nature, such as juvenile delinquents and substance abusers. Persons who might have a physical or mental impairment as described in the above definition and also suffer from social or economic handicap would be included because of the other criteria in the definition.

An initial estimate of the size and characteristics of the developmentally disabled population according to the proposed definition is presented on the following page. It is purposefully listed according to the major categories in the current definition to facilitate a comparison. (NB: In this draft these are very rough estimates which will be validated for the final product.)

2.4 The Decision Process

At the third and final meeting of the Task Force a highly structured decision process was followed to facilitate the large number of difficult choices confronting the Task Force in making its final recommendation. This

*(These would be covered in the impairments mentioned above, but this is a different way of looking at the additions.)

ESTIMATE OF POPULATION TO BE SERVED WITHIN PROPOSED DEFINITION OF
DEVELOPMENTAL DISABILITIES

	Percent	Millions
Mentally retarded (profound, severe, moderate, a few mild)	.50	1
Cerebral Palsy	.30	.6
Epilepsy (See Commission Report)	.25	.5
Autism	.05	.1
Learning disabled (chronic, socially impaired)	.10	.2
Other severe chronic (e.g., deaf-blind, multiple handicapped, deaf, osteogenesis imperfecta, cystic fibrosis, spina bifida, muscular dystrophy)	.20	.4

1,400

+ two million
allowing for
overlaps

Proportion (%) of developmentally disabled among children will be somewhat higher* than among adults because of:

- 1) mortality;
- 2) "graduation" after extended intensive service
- 3) variability in risk--"likely to be" becomes more definitive as child grows older.

* maybe 50%

one of which brought the group closer to a picture of what the appropriate basis for the definition of developmental disabilities should be. Every effort was made to have binary decisions made by the Task Force: that is, it was hoped that by keeping the choices to two options whenever possible the problem of non-majority support for a specific recommendation could be minimized. The process was developed by the staff based upon the work which the Task Force had done during its first two working sessions. The process was designed to facilitate the ability of the Task Force to make decisions rapidly on points which had been discussed already at some length during the first two meetings. Although the process was quite structured, it was not imposed rigidly during the meeting, but was used flexibly.

The process began at the most general level with the Task Force deciding which elements or components of a definition should be included, and ended with a vote on a specific wording for the recommended definition. The discussions which took place around each vote afforded members of the Task Force an opportunity to express their reasons for or against a decision. In Section 2.2 of this report explications are provided of the actual elements of the final recommendation which provide expressions of intent, rationale, and concerns.

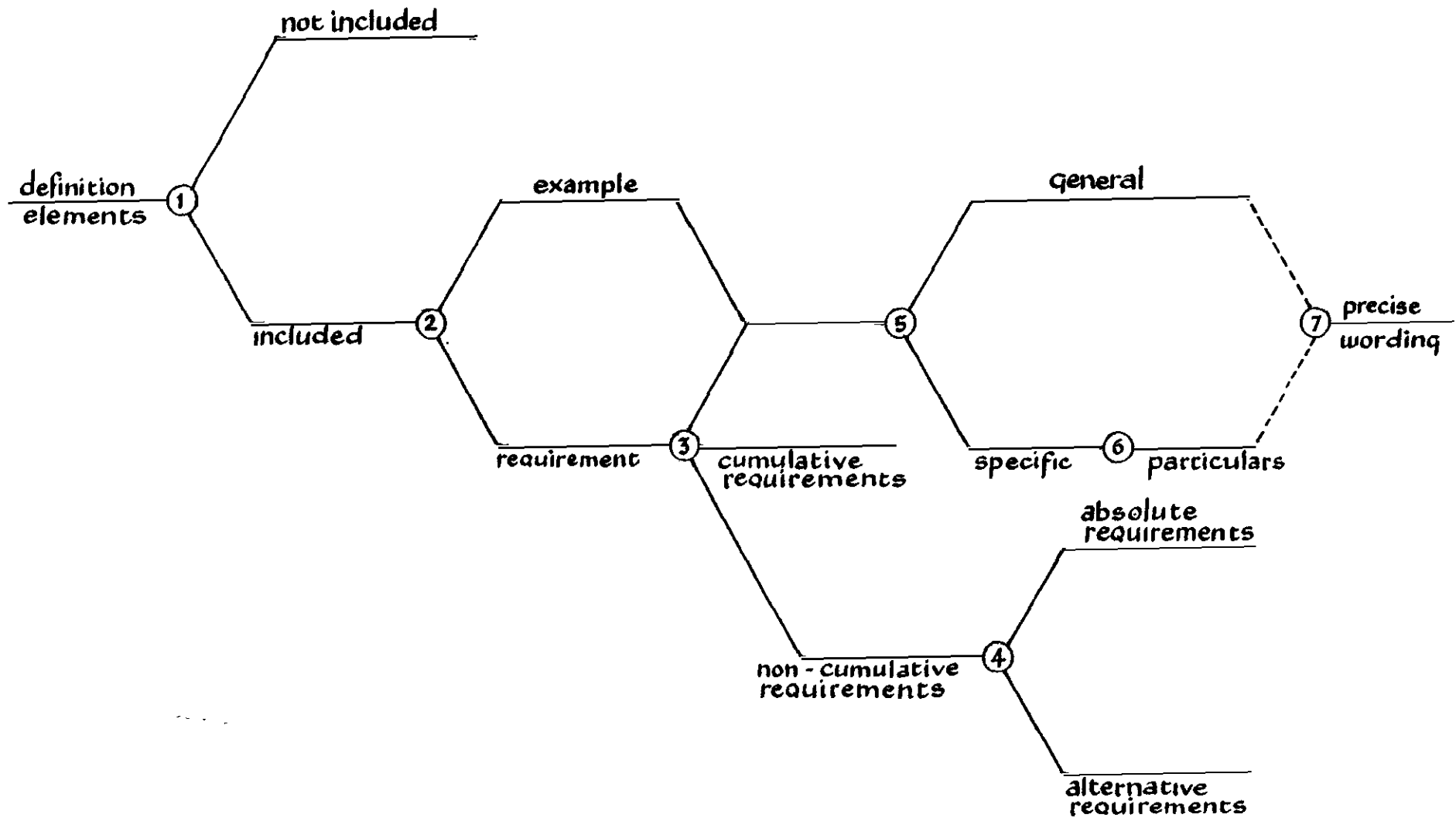
A flow chart showing the basic decision process is presented on the following page.

Seven major components of the definition had been identified and discussed throughout the project. These elements are:

- Age of onset
- Chronicity
- Severity
- Functional limitations
- Impairments
- Service need
- Categories of diagnostic conditions

The first step was to take each of the elements and decide if it would be included in the definition. Inclusion meant that the particular element would be mentioned as part of the appropriate basis for determining what is or is not a developmental disability. The Task Force decided that the

decisions leading to determining the appropriate basis for the definition of developmental disabilities



definition of developmental disabilities should mention as criteria for inclusion all the possible elements listed above except categories of conditions.

The second step was to take those elements which the Task Force voted to include in the definition and decide if each would be included as a requirement of a developmental disability or included as an example of a developmental disability. The Task Force decided that all the elements which were to be included should be requirements of a developmental disability. The element "age of onset" could only be included as a requirement. At this step the Task Force made a decision regarding whether onset should refer to origination only or manifestation only. The Task Force decided in favor of manifestation prior to a certain age as a requirement rather than origination only.

Step three involved deciding whether the required elements all needed to be present to constitute a developmental disability or whether it would be possible for a subset of the elements to constitute a developmental disability. The Task Force determined that a developmental disability is a result of the cumulative effects of all the elements.*

The next steps of the decision process involved determining how each element in the definition should be described and used. There were, at this point in the voting, six elements which had been determined to be cumulative requirements of a developmental disability: age of onset, chronicity, severity, impairments, functional limitations, and service needs. The Task Force decided that the concept of severity or substantiality should be conveyed in part through the cumulative nature of the elements in the disability and in part through the extent of a person's functional limitations and in the types of services required. The Task Force felt that chronicity or expectations of a long-term duration should be reflected both in the nature of the overall disability or impairment, and in the need for services. With the other four components of the definition, the Task Force decided that all references should be made to specific impairments (mental and physical), specific functional limitations and a specific age of manifestation (before age 22). However, the Task Force felt that it would be inappropriate to mention specific services within the definition.

As the final step, a small drafting committee then worked on the specific wording and the intent of the specific words chosen for the final

*This eliminated the need to go through Step 4 of the process, as displayed in the chart on the preceding page.

recommendation. They worked from the decisions discussed above which had produced an explicit set of elements which the majority of the Task Force agreed formed the appropriate basis for the definition of developmental disabilities. The entire Task Force discussed and voted to adopt with minor modifications the specific wording as recommended by the Drafting Committee. This is the wording provided in Section 2.1 of this report.

2.5 Minority Report of Members of the National Task Force on Definition of Developmental Disabilities*

The undersigned members of the National Task Force on the Definition of Developmental Disabilities agree with and support the proposed redefinition of "developmental disability" except Part #1 which states "is attributable to a mental or physical impairment or combination of such impairments." The wording in Part #1 has the effect of dropping all identifiable categories of disability from the definition. The twelve signers of the minority report, the majority of whom are or have been responsible for interpretation and implementation of the developmental disabilities program at the state and local levels, do not believe that the program can be successfully administered without identifiable categories of disability. A generic definition necessitates endless interpretation of who is or is not developmentally disabled and serves to increase the potential for not serving those most in need of services.

This minority report proposes the following substitution for Part #1:

"Is attributable to mental retardation, cerebral palsy, epilepsy, or autism; or is attributable to any other condition of a person similar to mental retardation, cerebral palsy, epilepsy, or autism because such condition results in similar impairment of general intellectual functioning and adaptive behavior and requires treatment and services similar to those required for such persons."

Therefore it is the position of the signers of this minority report that the definition not be based on the vague and all-inclusive phrase "mental or physical impairment," but rather that the existing categorical disabilities named in the act be retained with a strong emphasis on serving other individuals who meet the criteria of similar impairment requiring

*The Task Force agreed to the rule that at least 20% of the voting members present at the final meeting (eight people) were required for a minority report. There were specific votes on which a substantial minority disagreed with the Task Force vote but this report is the only one which dissenting members felt warranted a separate report. Concerns of members with other parts of the majority report are reflected in the explication given in Section 2.2

treatment similar to those required by categorical disabilities named in the definition.

Therefore, the definition recommended by the minority report signers reads as follows:

For purposes of the Developmental Disabilities Act, a developmental disability is a severe, chronic disability of a person which:

- 1) *is attributable to mental retardation, cerebral palsy, epilepsy, or autism; or is attributable to any other condition of a person similar to mental retardation, cerebral palsy, epilepsy, or autism because such condition results in similar impairment of general intellectual functioning or adaptive behavior and requires treatment and services similar to those required for such persons;*
- 2) *is manifest before age 22;*
- 3) *is likely to continue indefinitely;*
- 4) *results in substantial functional limitations in three or more of the following areas of major life activity:*
 - a) *self-care,*
 - b) *receptive and expressive language,*
 - c) *learning,*
 - d) *mobility,*
 - e) *self-direction,*
 - f) *capacity for independent living, or*
 - g) *economic self-sufficiency; and*
- 5) *reflects the need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are*
 - a) *of lifelong or extended duration, and*
 - b) *individually planned and coordinated.*

Signers of Minority Report

Geraldine Clark
Floyd Dennis
Joseph Drage
Dennis Haggerty

Dorothy MacConkey
Jack McAllister
Mary Lou Munts
Raymond Ramirez

Lee Rubin
Lee Schact
Thomas E. Scheinost
James MacDonald Watson

3.0 USES AND CRITERIA FOR THE DEFINITION

The recommendations described in Section 2.1 above were made by the Task Force based upon concepts which were discussed throughout the meetings and which form the context for the work of the Task Force. These were:

1. Concepts about the uses for the proposed definition of developmental disabilities.
2. Criteria for the definition itself.

These uses and criteria are discussed briefly in this section.

3.1 Uses of the Definition

In order to arrive at a decision about the appropriate basis for the definition of developmental disabilities, one of the most basic questions to which the Task Force addressed itself was, why define? How is the definition going to be used and by whom? To this end it was important to look at the major purposes of the Developmental Disabilities Program, since these different purposes may well imply somewhat different requirements for the definition. Indeed, considerable confusion prevails about the purpose or purposes of the DD Program (see Section 4.2. for more discussion of this issue). In the brief discussion which follows we have identified some of the primary purposes of the DD Program and the implied uses, users, and requirements for the definition.

The chart on the following page summarizes the various purposes of the DD Program and the implications of each purpose for a definition of developmental disabilities. These implications include the major uses which a definition might serve, the primary users of that definition, and some general requirements which the definition might meet. The information contained in this chart is intended to be illustrative of, not inclusive of, the various requirements for a definition of developmental disabilities.

The purposes of the Developmental Disabilities Program (as derived from the DD legislation and the perceptions of program staff) can be regarded as at least: 1) comprehensive planning; 2) systems advocacy; and 3) service delivery to individuals through many programs. The specific functions included in each of these purposes are described in the chart. As can be seen, the service delivery purpose implies very different uses/users than the comprehensive planning and advocacy purposes which are quite similar in scope.

MAIN USES OF THE DEFINITION

Program Purposes	Uses of Definition	Users of Definition	Requirement for Definition
<p>1) Comprehensive Planning</p> <ul style="list-style-type: none"> ● Defining and describing the target population ● Defining target population service needs ● Identifying/describing a service delivery network for the population ● Identifying gaps in the delivery network ● Setting priorities for action and financial allocation 	<p>Identification of Target Population</p> <p>Identification of Agencies Serving Target Population</p> <p>Identification of Constituencies</p>	<p>Planners</p> <p>Demographers</p> <p>Agency Administrators</p> <p>Service Providers</p> <p>DD Councils</p>	<p>Identifies broad group of persons with some common characteristics</p> <p>Offers broad statement of mission</p> <p>Compatible/congruent with other agencies' and legislation's definitions of disabled populations</p> <p>Flexible to ensure continued responsiveness to changing needs of target population</p>
<p>2) Service Delivery to Individuals</p> <ul style="list-style-type: none"> ● Individual Habilitation Plans (Section 112) ● Protective and Advocacy Services (Section 113) 	<p>Eligibility Determination</p> <p>Diagnosis and Evaluation</p>	<p>Clinicians</p> <p>Physicians</p> <p>Educators</p> <p>Psychologists</p> <p>Rehabilitation Counselors</p> <p>Social Workers</p> <p>Service Providers</p>	<p>Precise</p> <p>Measurable/Operational</p> <p>Appropriate to available resources</p>
<p>3) Systems Advocacy</p> <ul style="list-style-type: none"> ● Addressing interagency gaps in service ● Seeding/supplementing other agencies' efforts ● Reforming laws and administrative regulations ● Developing quality assurance standards 	<p>Identification of Target Population</p> <p>Identification of Agencies Serving Target Population</p> <p>Identification of Constituencies</p>	<p>Legislators</p> <p>Agency Administrators</p> <p>Service Providers</p>	<p>Identifies broad range of persons with some common characteristics</p> <p>Offers broad statement of mission</p> <p>Compatible/congruent with other agencies' and legislation's definitions of disabled populations</p> <p>Flexible to ensure continued responsiveness to changing needs of target population</p>

The information can be summarized as follows: different purposes of the DD Program imply different users and types of definitions. Identifying the appropriate bases and criteria for a definition is dependent upon the purposes and scope of the program and the intended uses of the definition. If the definition is intended for service delivery purposes, it must be very precise, measurable, compatible with existing resources, and related to the fact that services are provided to the defined population. If the definition, on the other hand, is intended to serve the Act's planning and advocacy function, different requirements should be considered. This definition can be broader and more flexible in its orientation than the definition for service delivery, serving more as a statement of mission than a mechanism for determining eligibility.

There are, in addition, a number of important potential users of a definition of developmental disabilities outside the "DD Program" per se. These include users of some of the other federal laws which have incorporated the term "developmental disabilities" either in the statute or in the regulations; state agencies which have changed their titles from "mental retardation" agencies to "developmental disabilities" agencies; and various private agencies such as the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons. In addition, when arriving at the appropriate basis for the definition, consideration must be given to the impact which inclusion or exclusion would have on the disabled person: will inclusion result in positive benefits of improved services or in greater stigmatization; will exclusion from the target population result in exclusion from needed services not available through any other source? (Sections 5.9 through 5.11 provide some additional thoughts on implications of alternative definitions.)

Changes Resulting from a New Definition

Thus, the users of the definition, primarily those within the DD Program but also those outside the program, need to be considered when arriving at the definition. In addition to exploring what type of definition each user might find most appropriate, it is also important to consider some of the implications brought about by simply a change in the definition--regardless of whether it is a change in a more or in a less "usable" direction from the perspective of the many actors in the field.

Some of the primary ways in which a change in the definition might have implications for all types of users and populations follow:

- The size of the target population. The total number of persons considered to be developmentally disabled may increase or decrease depending upon the final decisions of the Task Force.
- The service or programmatic needs of the population. As a result of changes in the definition it could be that additional services are seen to be required (either within the DD Program or outside it) or that services previously identified as needed no longer are needed.
- The number of identifiable constituencies. Regardless of whether the size of the target population is increased or decreased, it is possible that, for example, by either giving a "laundry list" of specific impairments or by identifying only one area of functional limitation, the number of organizations considering themselves to be part of the constituency of the program might change.
- The compatibility of the definition with other programs' definitions. Depending upon the particular approaches and/or qualifiers which are selected by the Task Force, the final definition can be either more or less compatible with definitions of other disabled groups used for other purposes.
- The potential availability of services for included and excluded populations. Changes in the target population could have direct impacts on the services available to the disabled individuals who are included or excluded within the term, both in terms of services provided directly through the DD Program and through services provided through related federal, state, and local programs.
- The potential stigmatization of individuals included in the definition. Inclusion within the term "DD" can be considered to increase or decrease the perceived or real stigma attached to disabled individuals, particularly if negative connotations are associated with any of the specific words used in the final definition.

To summarize, as each of the primary approaches and qualifiers is examined there are two main questions which need to be kept in mind:

- Who will be the primary users and what will be the primary uses of the definition, both within and outside the DD Program?
- What are some of the main changes which use of a particular approach, set of approaches, qualifier or set of qualifiers might bring about in terms of the DD Program, non-DD Program users, and the disabled population?

3.2 Criteria Which the Definition of Developmental Disabilities Should Meet

The Task Force worked within certain basic criteria which the definition of developmental disabilities needed to meet. These criteria derived from the belief that the recommendation of the Task Force, while not necessarily the final statutory language, should be designed as carefully as possible to ensure that its intent was clear and that it was appropriate for the uses to which it would be put, as discussed in 3.1 above.

The definition of developmental disabilities should be:

1. Appropriate for the mandated purposes of the Developmental Disabilities Program as understood by the Task Force. These purposes are primarily focused around planning and advocacy, but also include funding of some services in many states.
2. Appropriate for the development of sufficient constituency support such that the common interests of the group defined can be advocated and protected.
3. Technically sound in that it adequately and accurately describes a population primarily on the basis of their shared characteristics and common needs which are appropriate and meaningful outside of the immediate concerns of the Developmental Disabilities Program.
4. Potentially appropriate for use by programs outside the formal Developmental Disabilities Program which have adopted the concept of developmental disabilities for their own agencies.
5. Sufficiently clear in its wording and its intent that it can be readily understood, interpreted, and applied.

4.0 POLICY CONCERNS

The Task Force was, of necessity, concerned with many broad policy issues affecting the population which they were attempting to define. These issues fell into two broad categories: (1) issues related to the developmentally disabled population and (2) issues related to the disabled population excluded from the definition of developmental disabilities. A central concern for the Task Force throughout the study was that it draw a line around a group of disabled individuals who are, by virtue of certain characteristics identified as the basis for the definition, different from other disabled individuals.

Although it was not possible for the Task Force to consider these policy issues in depth, many were discussed as the members explored the pros and cons of including or excluding individuals with certain types of disabilities or certain characteristics. Throughout these deliberations there was an understanding that it was because of the extremity of their needs that the developmentally disabled population needed to be differentiated from other disabled individuals. The Task Force members realized that many individuals excluded from the proposed definition share certain needs with the developmentally disabled population and are indeed served by the same programs. However, the general consensus was that there was sufficient difference in needs as a result of the criteria listed in the recommended basis for the definition that, at least at the current time, separate attention within the federal and state service systems is warranted so that the most substantially severely handicapped persons are given such attention.

In this section brief discussions are provided of the underlying concept of developmental disabilities policy concerns for the developmentally disabled, and implications for the non-developmentally disabled population.

4.1 The Underlying Concept of Developmental Disabilities

The following statement indicates some of the basic precepts concerning the nature of the developmentally disabled population which underlie the work which the Task Force did as it determined the appropriate basis for the definition of developmental disabilities. Although there were areas of disagreement among Task Force members, there was general consensus about these underlying principles.

1. Target Population of the DD Program

a) The stated purposes of the Developmental Disabilities Act were taken as given, although not necessarily agreed upon or accepted as appropriate. The work of the Task Force took place within the limits of the current Developmental Disabilities Act and its implementation in the Federal system, although it was the hope of most Task Force members that the program as a whole would be benefited through clarification of the definition of developmental disabilities.

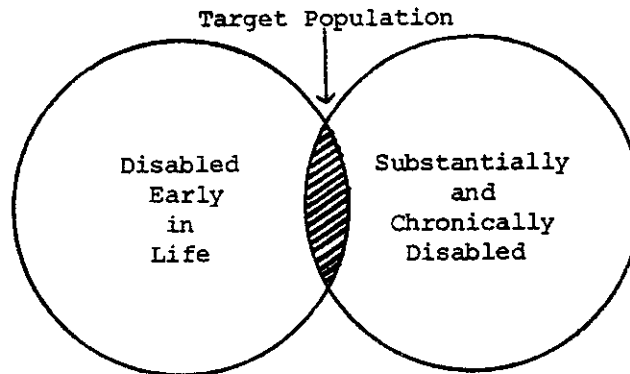
- The general intent of the Developmental Disabilities Program is to ensure that the developmentally disabled population is better served.
- The main mechanisms to this end are planning and coordination of services, individual and systems advocacy, and demonstration of model service programs.
- The DD Program is not intended to be a service program, but rather to be a mechanism through which the target population achieves better access to existing programs and through which new programs are developed where existing ones are inadequate.

b) The target population for the Developmental Disabilities Act was the focus of the efforts of the Task Force. This target population is a subset of the total population of individuals with disabilities. These are distinguished from the total population of handicapped individuals through certain common characteristics and needs which warrant special attention. It was precisely to the issue of determining which characteristics of the population warranted that the group of individuals be identified with each other and be identified separately from other disabled individuals that the Task Force devoted its energies.

The developmentally disabled population can be distinguished from other disabled individuals in part through characteristics of the individuals themselves and in part through the responses of the current service delivery system to them. There is evidence that they are not adequately served. The Task Force devoted its time to considering the common characteristics of the individuals. Both aspects are reviewed here briefly. Further elaboration of the characteristics of the population is provided in the explication of the definition itself.

2. Characteristics of the Population

The target population of concern to the Task Force was seen as being characterized by having the intensity of their impairment magnified by two sets of conditions: first, it is a group of individuals who are disabled early in life; second, it is a group of individuals who are substantially and chronically disabled. There are many individuals who are disabled early in life but who, because their disability is neither severe nor chronic are not the population which was the concern for the Task Force. Similarly, there are individuals who are severely and chronically disabled but who become disabled relatively late in life and who therefore were not the focus for the Task Force. The intersection of these two groups can be portrayed graphically:



(The diagram is not an indication of the size of either group.)

FOCUS OF THE DD PROGRAM AND TASK FORCE

a) The target population of developmentally disabled individuals are, in the broadest sense of the term, "developmentally" disabled in that their disabilities:

- Occur while an individual is maturing and can therefore be expected to have an impact on the individual's total development. In general the concept is not one of loss of abilities, but of never having had certain abilities.

Because of the occurrence during this period the disability

- Will impact on many other aspects of development so that what might start as a single impairment is likely to bring about difficulties in other areas. Thus, a mental impairment might also affect physical, social, and emotional as well as intellectual development.

As a result of the large potential for multiplying in magnitude and for affecting many aspects of functioning

- Early intervention in the area of the original impairment is required to impact both on the original disability and to reduce the possibility of other consequential disabilities.

b) The target population of developmentally disabled individuals are substantially and chronically disabled. The characteristics given above describe more individuals than are intended to be covered by the concept of developmental disabilities as articulated for the Developmental Disabilities Program. Within the group of individuals having disabilities described above, there is a small subset which is unique by virtue of there being present a combination of the following factors, all of which warrant being identified and advocated and planned for (if not necessarily served) separately:

- The substantiality of the handicap. That is, it is a disability which will have a major impact on the individual's ability to develop and function;
- The sustained nature of the impairment. That is, the impairment is not likely to disappear or be cured, but is likely to continue throughout the individual's lifetime;
- The likelihood of the need for a multiplicity of services over a prolonged period of time, not just the intervention of a single service or multiple services for a short period;
- The likelihood that it will result in the individual's having a limited ability to advocate for him or herself.

3. Characteristics of the Service Delivery System

Largely as a result of the characteristics described above, the current service delivery program does not do a very adequate job of meeting the needs of developmentally disabled individuals.

a) Service agencies' traditional approaches are not oriented towards meeting the unique needs of the target population. The traditional approaches either:

- Are organized around the needs of a single disability group (i.e., mentally retarded persons or persons with physical impairments) and provide either a total range of services for a total population meeting certain eligibility requirements or specialized services for a relatively small group of individuals narrowly defined by their specific need; OR

- Are organized around a single type of service for a diverse group of individuals (e.g., housing, health care payments, or education).

In either case, because of the relatively small size of the target population and because they tend to be the most difficult to serve with the least obvious measurable progress, the developmentally disabled tend to be overlooked or ignored within the total target populations for these agencies. In "deinstitutionalizing" and seeking least restrictive alternatives, the DD population is the most difficult to move and tend to remain behind.

As a result of this combination of individual characteristics and service delivery system characteristics, the following summary statement is presented.

4. Summary Statement

The developmentally disabled population of concern to the Task Force is:

- a) Substantially underserved, ill served, or unserved.
- b) Thus the following combination is required:
 - Comprehensive planning;
 - Improved leverage on existing monies;
 - Increased access to existing services;
 - Interdisciplinary services frequently across service systems;
 - Advocacy on their behalf to ensure the above.
 - Coordination of services at the delivery point to ensure that needs are met.

4.2 Policy Concerns for the Developmentally Disabled Population

The mandate of the Task Force was to examine the "appropriate basis" for the definition of developmental disabilities--that is, to determine the basis for including or excluding individuals from the category of developmental disabilities. It soon became clear that a unifying theme, indeed a primary reason, for grouping together individuals under the rubric "developmental disabilities" was their common needs. These common needs manifest themselves both as a result of the common characteristics of the individuals and as a result of the current service delivery system's response to their characteristics. Developmentally disabled persons represent, within the total group of persons with disabilities, those individuals who are in many ways the most difficult to serve, the easiest to overlook. The Developmental Disabilities Act seemed to be a response to this common need.

While the Task Force focused most of its energies on identifying a group of individuals whose common characteristics warranted their being grouped together, it also had to spend time considering the response of the current service delivery system to the population of concern. The Task Force members explored many aspects of the current problems in providing adequate service to the developmentally disabled population. Members drew upon their own varied experience and upon some of the background materials prepared as part of the Special Study. Making specific recommendations about the service delivery system or about broader policies for the developmentally disabled population was outside of their mandate and not possible to do within the time constraints. However, while the Task Force did not formally consider recommendations in these areas, they considered many policy issues. Some of the main issues which were raised by the Task Force in their deliberations are presented here. These issues represent areas which should be explored further, particularly by federal and state level policy makers who are concerned with the target population.

This section addresses briefly four major issues which were of concern to the Task Force and which were discussed throughout the study:

1. *There is a lack of clear responsibility at the state level for care of the developmentally disabled population and lack of a direct link between a state service program and a federal service agency for the total DD population and for its largest group, the mentally retarded.*
2. *There is a lack of clear responsibility at the individual client level for coordination and case management of the many services which developmentally disabled individuals require.*
3. *There is a lack of correspondence between the major missions of the Developmental Disabilities Program and its actual authority, both at the national and at the state levels.*
4. *There is a general lack of clarity concerning the purposes of the Development Disabilities Program.*

As can be seen, the first two issues have to do with the overall structure of services for developmentally disabled persons at the federal, state, and provider levels. The second two issues are concerned with problems with the current Developmental Disabilities Program.

1. There is a lack of clear responsibility at the state level for care of the developmentally disabled population and a lack of a direct link between a state service program and a federal service agency for the DD population and its largest group, the mentally retarded.

In most states there is no single state operating agency with the clear responsibility for the care of the developmentally disabled population. In some states the Mental Retardation Agency has been retitled a "Developmental Disabilities Agency." In a few of these states the change in title has represented an actual change in the target population for the agency: that is, the agency now serves individuals with epilepsy, cerebral palsy, or autism who are not retarded. However, in virtually all other states the mental retardation agency cannot legally serve this population. Individuals with epilepsy or cerebral palsy, for example, will unfortunately find that many retitled "developmental disabilities" programs in reality are agencies whose primary orientation is still towards mental retardation. Often non-mentally retarded persons are called mentally retarded in order to receive services

In states which have not changed the target population for their mental retardation program, individuals who have cerebral palsy but who are not retarded (for example) are virtually unable to locate any community residence programs comparable to those which are being established for mentally retarded persons. States which have changed their mandates are finding themselves faced with the problem of retraining staff, adding new staff with new skills, difficulties of changing the image and orientation of existing services while establishing new services for a previously unserved and frequently misunderstood population, expanding mandates but not necessarily expanding budgets, etc. As these agencies have expanded their target population to include developmental disabilities other than mental retardation, individuals with other similar disabilities exhibiting the need for similar services (such as spina bifida or muscular dystrophy) increase their demands for access to programs.

The state mental retardation agency comes closest in most states to being the main service provider for a large segment of the developmental disabilities population. It is interesting to note that the state mental retardation agency is the one major state service agency which does not have a direct counterpart at the federal level. There is no single federal agency which is the counterpart to the state mental retardation service system as there are, for example, for the state education, (including special education)

department, vocational rehabilitation, public assistance (including SSI), social service, health, mental health and housing programs. Increasingly the federal Title XIX (Social Security Act) program (for expenditure of monies under Medicaid for a wide range of health care including Intermediate Care Facilities for the mentally retarded and other developmentally disabled) is having an extremely strong influence on the shape of state mental retardation programs because many states are putting large amounts of their MR funds into institutions to bring them up to ICF/MR standards, and are therefore having a limiting effect on community programs.

In sum, there are many disabled individuals who cannot now turn to any single state agency as their primary source to provide or secure the total range of services which they need; as the case management link between them and an array of services from multiple agencies. Developmentally disabled persons, as those individuals frequently most in need of multiple services and advocacy, are in a particularly vulnerable position as a result.

2. There is a lack of clear responsibility at the individual client level for coordination and case management of the many services which developmentally disabled persons require.

The discussion so far has pointed out some inadequacies at the broad systems level in serving developmentally disabled persons. Task Force members expressed the concern that at the individual client level there tends to be a major case responsibility vacuum. Developmentally disabled persons require services from different agencies and from different disciplines. The lack of a single state agency with responsibility for their care manifests itself at the client level with a widespread lack of adequate case management. While many (federal) entitlements exist for the population (such as 94-142, the Education of All Handicapped Children Act, and Supplemental Security Income), individuals who have multiple needs on a long-term basis are likely to fall through the cracks. At the individual level some type of "placement" agency or case management structure is needed. This agency, in order to be effective, must have the capacity and authority to access services for the DD population. Some experiments in Pennsylvania and Wisconsin should be watched closely. The DD Program, through the DD Council's grants, could be used to fund model service integration projects on behalf of the developmentally disabled population. But this does not in the long run substitute for an operating level entitlement system. While the developmentally disabled population is far from being the only population

requiring such service integration, the DD population need for multiple services tends to be greater than for most populations and the ability to access these multiple services tends to be less.

3. There is a lack of correspondence between the major missions of the Developmental Disabilities Program under the present Act and its actual authority, both at the national and state levels.

Currently the intended focus of the DD Program (as articulated for example in the statement by Marjorie Kirkland, which appears at the end of Section 4.3) is planning and advocacy at the systems and individual levels.

Interest groups have maintained that only if the DD Councils have approval power over federal program expenditure and state planning will the DD Councils be effective in their systems advocacy and planning roles. However, existing agencies point out that it is not reasonable to expect a council of individuals serving in an advisory capacity outside of the State operating systems, to provide an adequate and effective review of a complex state plan such as that which is required in special education. This situation becomes even clearer when the target population of the DD Program is relatively narrowly defined and not necessarily seen as describing a population which warrants DD Council veto power over state plans intended for much larger groups of individuals.

It seems unrealistic and perhaps inappropriate to expect that the DD Councils as currently constructed will obtain approval power over all state plans for operating agencies affecting the developmentally disabled population. On the other hand, if the program is to be effective as a systems advocacy force, better mechanisms than currently exist will have to be developed and implemented.

In addition, at the individual level, the newly established Protection and Advocacy Systems could provide greatly enhanced access to services. If the Protection and Advocacy programs are truly effective, they will begin to accumulate a history of cases, the documentation of which could serve as a powerful tool for the systems advocacy undertaken by the DD Councils. However, the Protection and Advocacy system is currently inadequately funded and will need a few years of operations before its true potential can be realized. In addition, because it could be seen as threatening to existing generic agencies, special care will need to be taken to ensure that its

role is maintained and enhanced rather than dampened. Another major factor is that inherent in most Federal program mandates and in the charge to state operating agencies, there do exist other advocacy functions including those carried by public service and legal services corporations funded by Federal, state and local tax funds and by private funds.

4. There is a general lack of clarity concerning the purposes of the Developmental Disabilities Program.

A recurring theme throughout the conduct of the Special Study, both from Task Force members and other interested individuals, was the lack of clarity which exists concerning the purposes of the Developmental Disabilities Program as currently structured. A major confusion exists around the issue of service delivery: many persons see the primary mission of the DD Program as being the provision of services to the target population. For these persons, the small amount of money currently in the DD Program is being spread thin enough now and the potential addition of other groups would endanger those individuals currently covered. The belief that the DD Program is a major service program for the population is reinforced by the situation described above: despite the proliferation of funding sources at the federal level and of operating agencies at the state level, there generally is no single state agency responsible for delivery of services to the disabled population.

Other persons see the DD Program primarily as a planning and advocacy system. They see its primary mission as mobilizing the resources which exist in other state agencies towards meeting the needs of the target population. As an advocacy force within the state, the program could expand its target population without seriously jeopardizing its effectiveness. Indeed, it could be argued that with a larger constituency it could be more rather than less effective. Proponents of this position point out how small the total amount of money is within the DD Program, but how effective that money can be when used to leverage additional sources and to demonstrate the effectiveness of model programs which generic agencies are reluctant at first to try.

The DD Program, regardless of whether it is a service program or an advocacy and planning program, is not clearly understood. As a result, inappropriate expectations are widespread, with the resultant widespread dissatisfaction of unmet expectations. Many disabled individuals and groups of

individuals, as evidenced by their strong desire to be included as "developmental disabilities," see the DD Program as an important one for meeting their needs. Indeed, the program has been important in furthering the care of the individuals included both directly through the funding of specific programs and indirectly through increased visibility. Unfortunately, the precise benefits to be derived by inclusion are not clearly understood by many individuals.

In sum, an effort needs to be made to clarify the purpose of the DD Program. As this effort is made, careful consideration should be made of the various purposes which it could or should fulfill for a group of disabled individuals, and consideration should then perhaps be given to a new focus for the program. At the current time it is not adequately funded or structured to be a true service delivery program, yet it has not been successful at convincing people that it is primarily a planning and advocacy program primarily because all other programs have no legal instruction that the DD program is their coordinator.

A statement reflecting the official policy of the program, made to the Task Force by Marjorie Kirkland, Deputy Director of the DDO, is attached at the end of this chapter.

4.3 Implications of the Proposed Definition of Developmental Disabilities for Individuals with Other Disabilities

Part (B) of the section of the Developmental Disabilities Act which mandated the conduct of the study of the definition of developmental disabilities calls for an examination of "the nature and adequacy of the services provided under other federal programs for persons with disabilities not included in. . .[the recommended] definition."

Although it was not possible within the scope of the study to conduct an in-depth analysis of the services, a number of specific efforts were made to obtain information about the nature and scope of current federal efforts to serve persons with all types of disabilities. Until the final recommendation was made by the Task Force it was not possible to identify who was to be excluded from the proposed definition. The excluded population is discussed in Section 2.4 above. Some of the implications of changes in the definition of developmental disabilities as perceived by federal agencies for their programs are described briefly in Section 5.10 below. Key federal

programs serving disabled persons are analyzed in Section 5.2 which identifies who is covered.

Although no in-depth study was feasible, an effort was made within the Special Study to determine the extent to which disabled individuals not included in a potential definition of developmental disabilities are eligible for services similar to those which are provided through the Developmental Disabilities Program. It seemed most logical to focus on those specific benefits which disabled individuals are likely to receive through the DD Program:

1. *Comprehensive state planning which identifies the service needs of disabled individuals across all state agencies.*
2. *Review of state plans for use of federal monies to determine their utility to the developmentally disabled population.*
3. *Establishment of specialized protection and advocacy services within each state for the developmentally disabled population.*
4. *The development of individualized habilitation plans intended to identify the total range of an individual's needs across agencies and, potentially, throughout life.*
5. *Flexible monies for filling gaps and demonstrating innovative programs at the state and federal levels.*
6. *State councils with mandated consumer representation which are intended to be the main mechanism for ensuring that the above purposes are carried out at the state level.*

Virtually all these program elements are available in one form or another through other federal programs which serve non-developmentally disabled handicapped individuals. However, there are some unique aspects of the Developmental Disabilities Program which are not available through any other program. These unique aspects include:

1. *A focus on a specific population with an emphasis on an examination of the total needs both of specific individuals and of the total population. This focus on the total range of needs across agencies and across a specific set of services differentiates the DD Program from most of the other federal programs.*
2. *A focus on a specific population for its entire lifetime, not just for childhood, or for its employable years, or adulthood, as do most other federal programs aimed at serving handicapped individuals.*
3. *A focus on accessing generic services and filling gaps in these services rather than on the establishment of a specialized program providing a large amount of direct services.*

4. *A special mechanism for providing protection and advocacy services.*

There does not now exist a comparable program for the remainder of the handicapped population which can act as the focus at the state level for their interests in the way the Developmental Disabilities Program is intended to function. It is, however, difficult to assess the extent to which the non-developmentally disabled population of persons with disabilities require this type of program. It is precisely because of their unique characteristics that the developmentally disabled persons are seen as being more likely than other disabled individuals to require comprehensive services throughout life; are most likely to be excluded from existing service programs including those intended to serve handicapped persons; and are least likely to be able to advocate on their own behalf to ensure that their needs are met.

THE PURPOSES OF THE DEVELOPMENTAL DISABILITIES PROGRAM

Marjorie Kirkland*

I would like to clarify an issue that has come up a number of times today: that is, the relationship of this program to services. Yes, there is money in the program for services. The way that the Developmental Disabilities Office sees the program, however (which gets translated quite differently from one state to another), is that that amount of money is not intended to provide all the services for all the developmentally disabled people, no matter how big the budget ever gets, because that would really be contrary to the purpose of the whole Act. We do not want a separate channel of funds to the state to serve this population. That would continue the traditional segregation that they have suffered for generations. What we want to do is to get them into the service systems that the other people use, as limited as they may be.

Now, statistics have been batted around about how much money has been going into services versus how much is going into planning. The small amount for planning is due to the fact that as yet we have been unable to convince many states that the biggest payoff to the state is going to come from good planning and less from the small, isolated service projects that they are funding out of the handful of peanuts that we give them every year. If they would put those peanuts into planning they could pry loose lots more money, even with all the constraints that many "feds" express concerning the feasibility of accessing their agencies.

Even the demonstration monies, the discretionary funds that they have and that we have, we see as intended to make it easier to pry those things open, rather than to say to the Education Department or the Title XX Agency: "You won't have to do this because we will meet the needs without your few little pennies." These are funds to set up a service that Title XX should be but is not providing to our group and to say to the Title XX administrator: "Look, bud, you didn't think it could happen, but there it is. Now it's your business to take this over; we've demonstrated its reliability, its

*Statement made to the Steering Committee of the National Task Force on the Definition of Developmental Disabilities, July 8, 1977.

validity to you. Now, you do it. And we'll put our money into another service and start convincing somebody else."

So we are doing everything that we can with our limited resources to convince the states that the percentage should be turned around and that more money should go into planning and administration and less into the services than most of them are presently doing. Rewards come from granting these projects, and it is very difficult to take those M&Ms away from the Councils and provide anything that is equally motivating to them, but we're doing what we can and some states are doing very well.

So, I just want to emphasize that so far as we see it, it would be counterproductive to think in terms of limiting the services or the definition in terms of the money that is going to come through this Act down to the local service level. That would be a terrible disservice to our population!

5.0 ABSTRACTS OF KEY BACKGROUND PAPERS

A series of background papers were prepared by staff for use by the Task Force during the study. These papers were generally intended to provide members with an overview of the current state of the art with respect to a certain topic, or to provide members with a think piece on topics of concern to them. In general, an effort was made to provide a balanced perspective on the issues considered. The papers were also intended to be relatively highly focused and reasonably brief, and therefore were not comprehensive or in-depth reviews of a subject. They did, however, provide a considerable amount of information which the members of the Task Force reviewed and used in their deliberations.

Abstracts of some of the key papers are included here. These abstracts are intended to summarize the basic purpose of the paper, the topics covered, and the main conclusions. Full versions of these and other related background materials are available in the Volume II of the Final Report of the Special Study.

The topics covered are:

- 5.1 History and Background of the Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103);
- 5.2 Analysis of Federal Laws and Compilation of Definitions Pertaining to the Handicapped and the Disabled in Federal Statutes and Regulations;
- 5.3 An Overview of the Implementation of the Developmental Disabilities Program;
- 5.4 A Framework for the Basis for a Definition of Developmental Disabilities: Some Options;
- 5.5 The Demographics of Developmental Disabilities;
- 5.6 Brief Descriptions of Specific Impairments;
- 5.7 An Analysis of a Functional Approach to the Definition of Developmental Disabilities;
- 5.8 Age of Onset: Some Issues;
- 5.9 Alternative Approaches to a Definition of Developmental Disabilities: Potential Impacts on the State Developmental Disabilities Program;

- 5.10 Some Federal Implications of Changes in the Definition of Developmental Disabilities;
- 5.11 Implications of the Definition of Developmental Disabilities for Non-Federal Users Outside the DD Program.

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

Donald Freedman

The purpose of this paper was to discuss the legislative context of the Developmental Disabilities Program and the definition of developmental disabilities. Specifically, this paper examined:

- Different types of federal programs for disabled individuals and definitions of the persons served by these programs;
- The historical and legislative context from which the Developmental Disabilities Program developed;
- The purposes of the Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103);
- The current definition of developmental disabilities.

The conclusions drawn in the paper were:

1. The nature of the definitions of disability varies with the type of program involved. Definitions for programs which provide individual income supports tend to be the most narrow and rigid. Definitions tend progressively to be broader among programs of the following types: individual remedial programs, such as those under the Rehabilitation Act; individual insurance programs, such as Social Security Disability Insurance Benefits, Medicare, and workers' compensation; grant-in-aid programs; planning and advocacy programs; and federal standards requirements for facilities and programs.

2. The nature of definitions of disability varies also with whether the program is basically oriented to establishing an individual entitlement to some service or benefit, or to acting upon a particular problem. For example, the nature of the cause of the disability is likely to be a critical concern to a problem-oriented program such as the National Institute for Neurological Disorders and Stroke, but is completely irrelevant to a determination of eligibility for Supplemental Security Income. For SSI, only the individual's current capacity (or incapacity) to work matters.

3. Looking at the legislative history of disability legislation at the federal and state level, two general trends can be identified:

- Legislation tends now to focus less on named specific impairments or conditions, and more on very broad and nonexclusive categories of impairments such as "physical or mental."
- The focus of legislation has shifted from the impairment underlying the disability to the functional limitations or special service needs which the impairment creates for the individual.

4. Historically, the current DD Program is an outgrowth of both recent specific federal legislation and a century of state and federal legislative activity in the field of disabilities generally and in the areas of vocational rehabilitation, special education, medical and social services, and income maintenance. A review of this history shows that in essence, the DD Program is not intended as "another direct service program" for disabled persons; but rather as a management tool operating at both the federal and state levels to make existing programs for disabled persons, and people in general, more responsive to the general and special needs of one particular group of disabled persons who are the most in need of services from a number of diverse sources and who are the least capable of obtaining these services for themselves. As a management tool, the program is intended to fill gaps in services, remedy existing inefficiencies and waste, and establish better communication and relations between independent state and federal agencies. The main mechanisms used are comprehensive state planning and grants to expand existing programs, or establish new programs for model service or training programs. The most recent amendments to the Act in 1975 add new dimensions of individual statewide advocacy systems and standards for programs and facilities receiving assistance. The major goal of establishing a mechanism particularly at the state level for managing services and service systems for persons severely disabled early in life remains pivotal.

5.2 Analysis of Federal Laws and Compilation of Definitions
Pertaining to the Handicapped and the Disabled
in Federal Statutes and Regulations

Donald Freedman

This paper compiled and reviewed legal definitions of handicapped and disabled persons used by major federal programs in the areas of rehabilitation, social security (including Medicaid and Supplemental Security Income), education, transportation, housing, public contracts, and non-discrimination. The paper provided information to facilitate arriving at the appropriate basis for the definition of developmental disabilities in two ways: (1) by listing some programs with which the DD Program might work and with which it might therefore be appropriate to have compatible definitions; and on the other hand, (2) by listing the target populations for other major federal programs which serve disabled persons not covered under the definition of developmental disabilities.

The analysis of Federal definitions of disability is attached.

An Overview of the Implementation of
the Developmental Disabilities Program

Paula Hammer

The purpose of this paper was to inform the Task Force about the implementation of the DD Program at the state level.

In 1970 Congress recognized the wide range of human service needs of the developmentally disabled citizen and the complexity of agencies, both private and public, responsible for providing those services. The developmental disabilities (DD) legislation marks a new phase in the federal government's efforts to provide a better system of services to developmentally disabled persons. Shifting to the states' broad responsibility for planning and implementing a comprehensive program of services, the federal-state DD Program is characterized by broad federal goal statements and minimal specific federal program mandates. Thus, considerable discretion is left to the states to allocate federal formula funds, establish program objectives and priorities, and select implementation strategies.

The DD program is, in effect, a type of block grant allowing states considerable flexibility in the use of funds. The legislation and federal regulations set minimum levels of compliance. Beyond these levels of minimum compliance, the DD Act and regulations by their lack of specificity, encourage flexibility and creative initiation on the part of each state and DD Council to work out patterns of organization and activity which are effective in their unique situation.

- Federal cash allocations are available to participating states on a formula basis (Federal Formula Grant to States). To qualify states must establish a State Planning Council, provide Council staff, designate a state agency to administer the funds, and submit a state plan document to HEW.
- The DD Council is the heart of the developmental disabilities concept. The composition of the Council is defined by federal statute to include representation of each principal state agency, of local agencies and non-governmental organizations and groups concerned with services for persons with developmental disabilities, and of consumers.
- State DD Councils are not agencies of state government, but have an independent integrity that supercedes the services and generic agencies of state government. This allows State Councils to

exercise an overview of the quality of life of developmentally disabled citizens throughout the state. This overview is essential to the major Council functions and activities in planning and advocacy.

- Most DD Council staff are state civil service employees administratively housed in some state executive agency, and responsible to a superior in that agency's managerial hierarchy.
- The DD Act and regulations require that a state agency be designated to administer or supervise the administration of the State DD Plan and monies which flow to the state under the DD Act.
- The federal government offers the state an amount of money provided the state meets specified requirements. The state plan has four major sections: description of the "quality, extent and scope" of services provided; goals, objectives, and priorities; a plan for deinstitutionalization; the design for implementation.
- One strategy Councils have used to address the goal of increasing services to the DD population is the allocation of DD formula funds to pay for service projects.
- Some Councils have turned to the resource accessing approach. This model has its ideological roots in the concepts of normalization and individual entitlement to generic services. Council activities focus on analysis of existing funding resources and influencing other federal-state programs to serve the disabled.

A Framework for the Basis for a
Definition of Developmental Disabilities: Some Options

Elinor Gollay

In the mandate to the Task Force on the Definition of Developmental Disabilities Congress asked that there be a determination of the "appropriate basis" for the definition and whether the current definition meets the criteria established for appropriateness. In effect, the Task Force had to address itself more intensely to the issue of the criteria for the definition than to the details of the definition itself. This paper presented a possible framework within which to regard the possible "bases" for a definition. Each aspect of the basis for a definition was presented, along with some thoughts about the advantages and disadvantages built into each type of definition.

A framework was developed which suggested that the "appropriate basis" for the definition would have two components: approaches and qualifiers. Both components would need to be specified once selected as part of the definition:

a) Approaches

Six major possible "approaches" to the definition were identified: (1) etiological or based upon the cause or pathology of a disability; (2) impairment or based upon the physical, emotional, or mental manifestation or location of a disability; (3) functional or based upon the limitations in a disabled individual's ability to perform certain tasks; (4) individual service need or based upon the requirement an individual has for a particular service such as planning; and (6) a combination of two or more of the above approaches.

b) Qualifiers

The second general aspect of the definition of developmental disabilities which we identified was that of qualifiers. These are aspects of the disability, or other aspects of the potential target population not directly related to the disability, which further narrow the population of concern. We identified four major disability-related qualifiers and

and a number of possible non-disability related qualifiers which the Task Force could consider as it arrived at a definition. The four disability-related qualifiers were:

1. Age of onset. This qualifier addresses the concept that the target population ought to be defined by the age at which a disability either originates or is manifest.
2. Severity or substantiality. This qualifier addresses the concept of the extent or intensity of the particular disabilities. This would be the severity of the impairment, the functional limitation, and/or the service need.
3. Prognosis. This qualifier refers to the predicted outcome of a service for a person with a disability: that is, will the person "benefit" from a particular service; is the disability eventually "curable" or "improvable."
4. Chronicity. This qualifier refers to the duration or natural course of the disability: is it expected to last a long or short time? It is clearly related to but separable from the prognosis qualifier.

Included as some non-disability related qualifiers might be the age of the population and the income level of the individual or his/her family. The qualifiers, in general, can be seen to apply across the board to all the approaches. Thus, severity can apply to the impairment, the functional level, and to the need for services (though probably not to etiology). Similarly, the age of onset can apply to all approaches by determining when the disability had its origin or etiology, when the impairment became manifest, when the functional limitation became a problem, etc.

c) Advantages and Disadvantages

There are advantages and disadvantages with each of the possible approaches and qualifiers, and with their specifications. Some of these advantages and disadvantages seem inherent in any classification scheme. On the positive side, any definition regardless of approach or qualifier can be useful for certain purposes. It can facilitate the identification of the subset of individuals who are intended as the beneficiaries of the program in question. All the approaches and qualifiers are, in fact, descriptive of real and important aspects of the target population and, hence, could serve to facilitate the tasks facing the various potential users of the definition.

On the negative side, any definition is going to be arbitrary, particularly at its borders. Even using etiological definitions does not guarantee certainty in terms of inclusion or exclusion of particular individuals from the target populations because diagnosis is not a refined enough art. Problems arise with the specifications used both for qualifiers and for approaches: invariably the definition requires drawing a line and invariably there will be difficulty with that line at the edges -- why include someone who becomes disabled one day before turning eighteen but not one day after eighteen, etc. To varying degrees, measurement is a problem with all approaches.

All these approaches are "correct" in that they can be used to describe accurately the same person or group of persons--but the information conveyed through the terms will be different.

A brief discussion of the advantages and disadvantages of each approach follows.

1. Etiological approach. In this approach specific causes of conditions are identified.

Potential Advantages

- Relatively well established taxonomies of etiologies exist.
- The terminology is familiar to certain practitioners in the field, particularly physicians.
- Certain types of data are already collected according to etiology.
- In many instances the etiology can be readily determined.
- Knowledge of etiology can help predict the lifelong course of the disability and probable needs.

Potential Disadvantages

- Etiology is primarily a medical condition and is not generally relevant to non-medical practitioners.
- Etiologies are rarely directly related to the prescription of particular services other than certain preventive services, and hence are not very useful for planning.
- In many instances the precise reason for or cause of an impairment or disability cannot be determined.

- The close link between etiological categories and medicine frequently conjures up strong connotations of disability as primarily a medical problem when in reality the manifestations of a disability are largely non-medical in nature.
- The set of etiologies is potentially almost infinite.
- The same etiology can result in widely divergent impairments, functional limitations or service needs.
- Diagnosis is, in fact, not that highly developed, and in many instances the search for the etiology has led to misdiagnosis, mislabeling, and unreliable prognosis.

2. Impairment approach. In this approach the symptoms or physical, mental, or emotional manifestations or states are described.

Potential Advantages

- Impairments are more descriptive of problems presented to the individual and society than etiologies.
- Fairly well-established taxonomies of impairment have been developed and could be developed fairly readily.
- Impairments are familiar to many users: some of the more common ones are mental impairment or retardation, visual impairment and hearing impairment.
- Impairments are fairly well understood and understandable because they have a concrete manifestation.
- A lot of data is collected using major impairment categories.

Potential Disadvantages

- Impairments do not necessarily aid in predicting what interventions or services a person will need.
- Impairment categories differentiate individuals according to characteristics which do not necessarily help in determining need but which can have negative or stigmatizing connotations, such as "mentally impaired."
- Impairment is regarded by some people as a negative concept since it only addresses a limitation and not an ability.

3. Functional approach. In this approach the behavioral manifestation of the impairment is described. A functional limitation is a reduced ability, on the part of an individual, to perform a particular task or tasks.

Potential Advantages

- The trend in many federal programs and federal definitions is towards a functional definition of disability.
- Functional definitions are closely related to needs for service or intervention and hence are potentially very helpful for planners.
- Functional definitions are not based upon a medical model and hence are more favorably viewed by many service providers and planners.
- Functional definitions can be used to differentiate areas of ability as well as areas of inability in an individual rather than providing an across-the-board label.
- Functional definitions relate directly to a variety of readily understood behaviors rather than on more obscure medical or technical terminology or concepts.
- It is possible to develop fine instruments for measuring functional level in many aspects of behavior.

Potential Disadvantages

- There are no well accepted taxonomies of functional disabilities.
- It is extremely difficult to develop a meaningful taxonomy which is both exhaustive and mutually exclusive.
- The actual operationalization of a functional definition can be extremely difficult and require extremely tedious work if it is to be useful to a clinician.
- Only spotty data exist on functional categories and because of the lack of uniformity in these categories the data that exist are not compatible.
- It is difficult to establish absolute criteria for functional levels independent of the environment in which the individual lives.
- Despite the trend towards more functional approaches, few pure functional definitions are being used.

4. Service need approach. In this approach a person is defined in terms of a specific service or set of services which are needed or in terms of his/her ability to use existing services or fill existing roles.

Potential Advantages

- Using a service need or inability to perform a particular role in society as the basis for the definition would point directly to needed services and hence would facilitate planning.
- Because the service need is relative to the environment it is potentially less stigmatizing and negative about the individual, but places more responsibility on the society.
- Use of a service need definition is potentially the most equitable definition from the perspective of helping to ensure that anyone requiring a particular service or intervention receives it.
- As a person no longer required a service he/she could potentially be rid of his/her "disability" label or status.

Potential Disadvantages

- Because it is so relative, it would be extremely difficult to establish uniform standards.
- The state of the art in terms of assessing individual needs is unevenly developed: in some service areas there is a great deal of sophistication and in others the measurements are quite primitive.
- By defining a disability in terms of a required service it is quite possible that there would be an overestimation of the disabled population because of individuals requiring similar services not available to "non-disabled" populations.
- Concepts of needed services change over time and to tie a definition solely to a particular type of service could be too rigid as intervention strategies improve.

5. Class service need. In this approach a person is considered developmentally disabled if he/she falls within a group which as a whole needs a particular type of service.

Potential Advantages

- Reduced dependency on individual diagnosis, since the primary focus is on a group of individuals taken as a unit.
- Less chance that rigid criteria of eligibility would be applied in the planning and development of services, since the target population would be broadly defined.

Potential Disadvantages

- Group service needs are difficult for many people to conceptualize.
 - Because of the lack of precise criteria it would be difficult to estimate population size for planning purposes or to determine the precise characteristics of the included population.
 - A group service need concept may be too abstract to be helpful since to say, for example, that developmentally disabled persons are persons in need of deinstitutionalization services does not describe in fine enough detail what people in fact need.
6. Combination. A mix of the above approaches can be used, as is the case with the current definition.

Thomas Cerva

The purpose of this paper was to present information about the number of people in the United States population who might be considered developmentally disabled and to provide a basis for discussion within the Task Force.

One main focus of this paper is on the relationship between definitional and demographic issues: without clear definitions there can be no clear counts. This paper has two parts: summaries of the best available information on prevalence of developmental disabilities as currently defined, and brief discussions of some of the reasons why this information is not very reliable.

The relatively poor quality of the information available on the numbers of persons with developmental disabilities creates problems when attempting to understand the scope of the impact of the Developmental Disabilities Program. The difference between the incidence and prevalence of a disability, overlaps and duplicative counts, problems of restricted or small samples, and difficulties of projecting overall rates from incomplete or age-specific information are discussed as contributing to the poor quality of the data.

This paper does not claim to be either an in-depth analysis of demographic issues or a presentation of new information on incidence or prevalence. Rather, it is intended to provide reasonable ranges for the size of the developmentally disabled population as currently defined, based upon currently available information.

Because of the importance of arriving at clear estimates of how many people would be included under any particular definition of developmentally disabled which might be generated, some of the reasons that prevalence rates are often only given as estimates or given in the form of ranges are:

- There are many difficulties in diagnosing the existence of specific disability or condition in an individual.
- Studies may use different definitions even for the seemingly more reliably diagnosed conditions. Definitions can change not only across studies but across time. This can lead to great variation in prevalence studies.

- While some studies provide a breakdown of prevalence rates by age, very few attempt to divide a total group by age of onset (either origination or manifestation).
- Little agreement exists on the definition of a severe disability.
- Few studies even attempt to count the number of people with severe disabilities, however defined.
- Because of overlaps and multiple handicaps the estimate of the total target population is not the sum of the estimates for the separate disabilities.
- The problem of duplicate counts can also occur when a prevalence rate is obtained by adding together counts from various sources which use different approaches.
- Another sampling problem arises in studies using small samples. The size of sampling error is inversely proportional to the size of the square root of the sample size.
- A time-invariant attitude towards prevalence rates does not take into account historical shifts both in the diagnosis of a specific disability or its actual rate in the population. For example, researchers have only recently arrived at an estimate for the prevalence rate of autism. In the past most of these children were given the label of mentally ill or mentally retarded.

Suzanne Simenson

The purpose of this paper was to give Task Force members information about the four impairments considered developmental disabilities as currently defined as well as information about fifteen other specific impairments which were suggested for possible inclusion within the definition. First, the main aspects of those impairments in the current definition were highlighted: autism, cerebral palsy, epilepsy and mental retardation. This was followed by descriptions of other conditions: childhood psychosis, congenital malformation, cystic fibrosis, deafness (early onset), deaf-blind, Huntington's disease, learning disabilities, minimam brain dysfunction, muscular dystrophy, narcolepsy, osteogenesis imperfecta, severe visual impairment, spina bifida, Tourette's syndrome, and tumerous sclerosis.

Throughout the course of the study advocates for people with these various psychological, mental, physiological, and behavioral conditions brought the existence of these impairments to the attention of the Task Force.

For each condition key features were outlined which provided a basis for discussion of the many elements considered by the Task Force:

- A definition of the impairment;
- A description of the symptoms;
- An indication of service needs;
- Age of onset, both origination of manifestation;
- Prevalence rates.

This paper was not intended to be an exhaustive compendium of conditions, nor the result of a comprehensive, definitive search of the literature. Rather, it included any specific condition which had been mentioned for possible inclusion with developmental disabilities.

An Analysis of a Functional Approach to the
Definition of Developmental Disabilities

Ruth Freedman

There was a great deal of discussion at the Task Force meetings about the advantages and disadvantages of using functional limitations as the primary basis for the definition of developmental disabilities. Three main options were considered by the Task Force:

- Purely functional definitions with no condition categories specified;
- Functional definitions with condition categories specified as examples;
- Categorical definitions including functional limitations as descriptors of the disabilities.

Because of the attention focused on functional versus categorical definitions and the relative newness and complexity of a functional approach, this paper was put together to explore some of the issues inherent in operationalizing a functional approach. It was not intended either as an endorsement or an indictment of such an approach.

Key Problems

One of the major problems encountered in using the functional approach is determining precisely which areas of functioning are central to the concept of a developmental disability and which are not. Exemplifying this problem is the confusion manifest among the types of functional measures used in existing assessment instruments. Some instruments measure abilities (e.g., the ability to feed or dress oneself); some measure physical development (e.g., motor or sensory development); some measure skills (e.g., homemaking or pre-vocational skills); some measure behaviors (e.g., hyperactivity, aggression); while others measure personality traits (e.g., self-esteem, initiative, perseverance). Most existing functional taxonomies use an assortment of measures, rarely distinguishing among the various measures or pointing out the areas of overlap.

Another major problem in measuring functional limitations is the interrelationship between functional level and environment. A person with certain functional limitations might be considered "disabled" in one context,

yet "non-disabled" in another context, depending on the expectations imposed by the environment on the individual and the ability of the environment to accommodate to the individual's functional limitations.

Existing Functional Taxonomies

This paper examined a number of commonly and less commonly used functional assessment tools for the purpose of extracting taxonomies of functional areas. Most of the tools which have been developed focus on self-help skills, but a few (such as the Adaptive Behavior Scale) are more comprehensive and attempt to provide an overall picture of an individual's ability to function in society.

Most of the tools divide human behavior into a number of areas of functioning. Within each of these areas of functioning, such as self-help, there are more specific types of behavior which are listed. In turn, each type of behavior (such as eating) is broken down into levels of performance.

The review of existing taxonomies indicates that:

- There is little agreement among developers of functional assessment tools on how to divide human behavior into major categories or areas of functioning, and within an area of functioning there is little agreement about the types of behavior or components of behavior which comprise a major area.
- There is little agreement on the specific components of behavior which should be used as measures of functional ability or inability for a particular area or type of behavior.

There are, however, some common themes which can be identified across the many scales which have been examined:

- Independent functioning/self-help. This generally includes such things as eating, toileting, dressing and bathing. Some instruments like the ABS also include appearance, care of clothing and travel (mobility).
- Language development/communication. Expressive and receptive language skills can be found in this category as well as social interaction and the ability to use the telephone.
- Vocational activity/occupation. This group includes job complexity and work habits in some scales and dexterity (fine motor) and agility (gross motor) in others.
- Domestic activity. Cleaning, laundry and food preparation are examples of activities found in this category.

- Economic activity. Items that are found in this area of functioning include such things as money handling, budgeting and shopping skills.
- Self-direction/personal assessment. This area involves responsibility, initiative, attention and leisure time.
- Physical development. Sensory and motor development are part of this area which can be broken down to include vision, hearing, body balance, and limb function.
- Socialization. This area of functioning refers to cooperation, social maturity, and appropriate interaction with others, including awareness of and consideration for others.
- Negative, maladaptive behavior/problem behavior. Inappropriate behavior such as violent and destructive behavior, as well as withdrawing and antisocial behavior are part of this category.

Determining Severity of Functional Limitations

Many functional taxonomies attempt to determine not only the areas in which an individual has functional limitations but also the severity of those limitations. There have been three basic approaches used to measure severity based on either: (1) degree of limitations, (2) number of limitations, or (3) type of limitation. Most severity scales fall into this first category.

Relationship Between Functional Areas and Disability Categories

There are no clear-cut lines which relate specific kinds of functional needs to specific disability categories. The interrelationships between functional needs and disability categories are quite complex and difficult to unentangle.

Ruth Freedman

The purpose of this paper was to examine the issue of age of onset of developmental disabilities in terms of two concepts: origination (the point at which the specific condition actually began or was caused) and manifestation (the point at which this condition became evident or was detected). Two overall questions were addressed:

1. What cutoff point, if any, should be used in the definition of developmental disabilities?
2. If an age cutoff is used should it refer to origination or to manifestation?

The Task Force's two related decisions are displayed in the following table:

	prior to specific age	at any point in life
originates		
manifests		

This paper addresses these options by examining some of the underlying policy, program and political issues and by presenting, where possible, existing data on technical issues such as the incidence of disabilities by age and the prevalence of disabilities originating during childhood but not manifested until adulthood.

Based on the data of the various studies described in this report, the following concluding statements were made:

- It is generally held that the age of origination of all childhood impairments is birth or infancy. Therefore a change in cutoff from 18 to 21 or to below 18 would have little effect on the total size of the population included in the definition.
- It is unclear whether a change in the cutoff point from 18 to 21 would make the definition more "compatible" with other legislation since the cutoff points used in other legislation vary considerably.
- There are a variety of conditions which originate prenatally or at birth but are not manifested until later in life. No study, however, has attempted to estimate the size of this population. If this group is included in the DD definition, it will be difficult to estimate its impact on the size of the DD population.

- There are many disabilities with origination and manifestation after age 18. These adulthood disabilities are quite different from those originating in childhood--particularly with respect to adults becoming disabled due to injuries in accidents and to degenerative disorders related to aging.
- Most experts maintain that the service needs of persons disabled in childhood are frequently quite different from those of persons disabled in adulthood. Disabilities occurring in early childhood tend to interfere more with the individual's opportunities for education, employment, and social relations than disabilities occurring later in life. Habilitation is the primary emphasis of services for persons disabled in childhood; rehabilitation is the focus of services for persons disabled later in life.

5.9 Alternate Approaches to a Definition of Developmental
Disabilities: Potential Impacts on the State Developmental
Disabilities Program

Carolyn Cherington

The purpose of this paper was to discuss the potential impacts that new approaches to the definition would have on the Developmental Disabilities Program at the state level.

Five alternate approaches to defining developmental disabilities were posited--etiological, impairment, functional, individual service need, and class service need. This paper explored the possible impacts of each approach on selected aspects of the State Developmental Disabilities Program:

- Individual habilitation planning;
- Protection and advocacy systems;
- Comprehensive planning;
- Strategies for improving the quality and quantity of services;
- The designation of administering agencies;
- The appointment of State Planning Council members;
- The advocacy role of State Planning Councils.

While an etiological, impairment, and class service need approach each had positive implications for one or more of the aspects examined, a functional and individual service need approach appeared to have some positive implications for each aspect of the program. These approaches also raised concerns with respect to some program aspects.

Table I illustrates the positive and negative impacts that each approach to defining developmental disabilities would have on selected aspects of the State Developmental Disabilities Program.

The exploration concludes with the observation that any change in the definition of the population to be served should be accompanied by a careful appraisal of the administrative requirements and expected outcomes of the State formula grant program.

TABLE I

SUMMARY: POTENTIAL IMPACTS ON THE DEVELOPMENTAL DISABILITIES PROGRAM AT THE STATE LEVEL

KEY FEATURES OF PROGRAM								
Approach	PRIMARY BENEFITS INTENDED FOR TARGET POPULATION		SECONDARY BENEFITS THROUGH STATE SERVICE SYSTEM IMPROVEMENTS			PROGRAM FUNCTIONS AND ACTORS AT STATE LEVEL		
	IHP*	P&A**	Comprehensive Planning	Quantity Improvements	Quality Improvements	Adm. Agency Designation	State Planning Council Appointment.	State Planning Council Advocacy
Etiological	-	-	+	-	-	-	-	-
Impairment	-	-	+	-	+	+	+	-
Functional	+	+	+	+	+	+	+	+
Individual Service Need	+	+	+	+	+	+	+	+
Class Service Need	+	+	-	+	+	+	-	+

* Individual Habilitation Plan

**Protection and Advocacy

Some Federal Implications of Changes in
the Definition of Developmental Disabilities

Ruth Freedman

This paper integrated information obtained from various sources on the effect of a change in the definition of developmental disabilities upon other federal programs and the populations which they serve. The sources upon which this paper is based include discussions of the first and second Task Force meetings, papers prepared by staff for the Task Force, a questionnaire sent by staff to various federal agencies concerned with disabled persons and a meeting with federal agency representatives on the impact of a change in the definition of developmental disabilities.

Three possible impacts on federal programs were identified if there were a change in the definition of developmental disabilities:

- A direct impact on agencies which specifically use the term "developmental disabilities" in their legislation/regulations.
- An indirect impact on agencies in terms of gaining visibility, political clout, and access to services for those groups included in the definition.
- No direct impact on an agency's mandate or functioning.

What follows is a summary of the implications of these three possibilities.

Direct Impact on Agencies Specifically Using the Term "Developmental Disabilities"

At the federal level, the term "developmental disabilities" is used in several major pieces of legislation: the National Housing Act; regulations for Intermediate Care Facilities for the Mentally Retarded under the Social Security Act; and regulations for the Early and Periodic Screening, Diagnosis and Treatment Program of the Medicaid Program. Changes in the definition of developmental disabilities could lead to changes in the size and/or characteristics of the current developmentally disabled population. These changes in the population would, in turn, affect the number and characteristics of persons eligible under other legislative programs described above and, possibly, the nature of the services provided by these programs.

Whatever changes are made to the current definition of developmental disabilities, legislation and regulations using the term "developmental disabilities" will have to be reviewed in order to determine their compatibility with the newly defined population groups. If it is determined that the new definition is not compatible with the purposes or scope of these other legislative programs, then these programs will either have to adapt their functions to meet the needs of the new groups or the term "developmental disabilities" will have to be deleted from these statutes and regulations.

Indirect Impacts on Visibility and Access

Federal representatives felt strongly that the definition of developmental disabilities has an indirect impact on a broad range of agencies concerned with the handicapped--in terms of gaining visibility, political clout, and access to services for those groups included in the definition. It was felt that a broadening of the developmental disabilities definition might increase the visibility of this group and the attention afforded to them in various state plans.

No Impacts on Agencies/Programs

A change in the definition of developmental disabilities would yield no impact on a variety of federal programs concerned with the handicapped. These programs are generally entitlement-based, providing specific services or benefits to individuals meeting specific eligibility criteria. A change in the definition of developmental disabilities would not affect these programs because their eligibility criteria are not related to the developmental disabilities criteria.

5.11

Implications of the Definition of
Developmental Disabilities for Non-Federal Users
Outside the DD Program

Ruth Freedman

A change in the definition of developmental disabilities does have implications at the state and local levels as well. The purpose of this paper was to discuss the implications of changes in the definition for non-federal users outside the DD Program. In some states, the term "developmental disabilities" is currently used in guardianship, commitment, and voting laws. Changing the definition of developmental disabilities implies potential changes in these laws. The state legislation and regulations using the term developmental disabilities would need to be reviewed, similar to their federal counterparts, to determine the appropriateness and compatibility with the newly defined population of developmentally disabled persons.

In some states, the Mental Retardation Agency or Authority has changed its title to a "Developmental Disabilities" agency. These state developmental disabilities agencies will have to determine whether the new definition is compatible with their present roles. If it is determined that the definition is incompatible, then a decision will have to be made concerning whether the agency should adapt its roles to fit the new definition or should cease serving developmentally disabled persons.

Other users of the term "developmental disabilities," such as physicians, educators, advocacy groups, and standards-setting agencies would also have to evaluate the appropriateness of the new definition to their roles. Changes in the definition might imply changes in the goals, standards, and organization of these groups.

Another critical area to evaluate is the effect of new the definition on the persons defined and not defined as developmentally disabled. There are both positive and negative consequences of being so defined, classified, or labeled.

It is, therefore, crucial that the Task Force give consideration to what will happen to those individuals included and those implicitly excluded from coverage as a result of the criteria established for the definition of developmental disabilities.

DEFINITIONS OF TERMS USED IN THIS REPORT

Approaches to the Definition -- the incorporation of various criteria which may be used singly or in combination to determine the appropriate basis for the definition of developmental disabilities.

Etiological -- based upon the cause or pathology of a disability. In this approach, specific causes of conditions are identified, such as genetic anomalies, various accidents or diseases occurring prior to birth or after birth.

Impairment -- based upon the physical, emotional, or mental manifestation or location of a disability. In this approach, the symptoms or physical, mental or emotional manifestations or states are described. Some of the common impairments include visual, hearing, mental, physical, and motor impairments.

Functional -- based upon the limitations in a person's ability to perform certain tasks. In this approach, the behavioral manifestation of the impairment is described. Some of the specific domains of behavior commonly used as measures of functional ability or inability include: independent functioning/self help; language development/communication; vocational activity/occupation; domestic activity; economic activity; self-direction; physical development, socialization, and problem behaviors. The use of the term "functional limitation" in this study closely parallels the term "disability" as defined by Saad Nagi:

"disability can be defined as a form of inability or limitation in performing roles and tasks expected of an individual within a social environment. These tasks and roles are organized in spheres of life activities involved in self-care, education, family relations, other interpersonal relations, recreation, economic life, or employment and vocational concerns."

Prognosis -- the ability of the individual to benefit from interventions. This qualifier refers to the predicted outcome of a service for a person with a disability: that is, will the person "benefit" from a particular service; is the disability "curable" or "improvable."

Chronicity -- expected duration or life course of the disability: is it expected to last a long or short time?

Severity -- the substantiality or intensity of the particular disabilities, usually measured according to: 1) the extent or degree of the limitations, (ranging from most dependent to independent or most limited to least limited); 2) the number of limitations; or 3) the type of limitations or specific areas in which a person is limited.

Purposes of the DD Program -- some of the major goals and activities of the DD Program as specified in legislation and regulations and as perceived by Task Force members and staff at the Task Force meeting. These purposes were presented at the Seattle Task Force meeting in order to examine their implication for a definition of developmental disabilities.

Comprehensive Planning -- defining and describing the target population; defining target population service needs; identifying/describing a service delivery network for the population; identifying gaps in the delivery network; setting priorities for action and financial allocation.

Service Delivery -- provision of Individual Habilitation Plans (as specified in Section 112 of the DD Act) and protection and advocacy services (Section 113).

Systems Advocacy -- addressing interagency gaps in service; seeding/supplementing other agencies' efforts; reforming laws and administrative regulations; developing quality assurance standards.

Service Need -- based upon the requirement an individual has for a particular service or environmental modification. In this approach, a person is defined in terms of a specific service or set of services which are needed or in terms of his/her ability to use existing services or fill existing roles. This concept is sometimes referred to as "disabled" or "handicapped" because it has a strong social context. A person is defined in terms of a particular role in society, expectations for performance, or environmental factors rather than strictly in terms of inherent characteristics. Some of the service needs which might be mentioned include special protective and advocacy services, transportation, job training, etc. This approach may be based upon individual service need --- the requirement an individual has for a particular service or environmental modification --- or class service need --- the need of an entire group of individuals for broad policy or program thrusts, such as planning, protection and advocacy, or deinstitutionalization.

Qualifiers -- aspects of the disability, or other aspects of the potential target population not directly related to the disability, which further narrow the population of concern.

Age of Onset -- encompasses two separate concepts: 1) age of origination -- the point at which the specific condition actually began or was caused; and, 2) age of manifestation -- the point at which this condition became evident. In many cases a condition originates at birth but is not manifest until later in childhood or even in adulthood. Often, a condition may only be manifest when it has resulted in a limitation in functioning or in a disability. Because the term "age of onset" has been used in various ways in previous literature (sometimes synonymously with the term "origination" and sometimes with "manifestation"), in this study we prefer to use the actual terms "manifestation" and "origination," rather than the more nebulous term "age of onset."