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OPERATIONAL DEFINITION OF DEVELOPMENTAL DISABILITIES

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This paper presents an operational definition of developmental disabilities for use by planners and service providers. This paper builds directly on a previous paper disseminated by Morgan Management Systems, Inc. as part of the previous project.\*\* The concepts set forth here are also related to those being used to derive estimates of the size and characteristics of the population with developmental disabilities.\*\*\*

Major contributions were made to the paper by Solomon Jacobson, Ph.D and Valerie Nelkin who were both working on the Morgan Management Systems contract.

\* Other people whose comments were much appreciated and are incorporated are: Elizabeth Boggs, Ph.D., New Jersey; Matthew P. Janicki, Ph.D., New York; Leopold Lippman, California.

\*\* Elinor Gollay, "The Modified Definition of Developmental Disabilities: An Initial Exploration." Morgan Management Systems, Inc., March, 1979.

\*\*\* Will be made available in forthcoming products from this project.

TABLE OF CONTENTS

I. Introduction.....1

II. Key Screening Questions and Explanations.....4

III. Explication of the Definition of Developmental Disabilities and Related  
Issues.....18

IV. Key Screening Questions Checklist.....40

## I. INTRODUCTION

The focus of the definition of Developmental Disabilities is on individuals with severe, chronic disabilities beginning in childhood which have a pervasive impact on their ability to function in society and which lead to the need for a variety of services over time. This focus was kept in mind during the process of operationalizing each component of the definition.

A number of important limitations exist in attempting to operationalize the definition:

Different applications may require different approaches to operationalization. We have identified three major uses for the operational definition, the first of which is presented in this paper.

1. For Service Delivery: The definition can be used to identify a specific individual to determine eligibility for programs, need for certain services and to develop individual plans. This is the use with which recipients of DD funds tend to be most concerned. Protection and Advocacy Systems offering individual advocacy services are also concerned with this application.
2. For Planning: The definition can be used to identify a target group that can be described with its need identified and be located within the existing service system for planning and development purposes. This is the primary use that the State DD Planning Councils can make of the definition.
3. Data Analysis/Population Estimates: Information from existing population surveys can be used to estimate the size of and describe the developmentally disabled population. Because existing surveys do not contain information that directly matches the criteria for a developmental disability, it is necessary to operationalize the definition using existing survey information to estimate the prevalence of people meeting the DD definition criteria.

This third application is not discussed in this paper but is contained in other products developed for the current project.\*

\* An operational definition for use with the 1976 Survey of Income and Education data is presented in a separate document prepared under contract #HEW-105-78-5003 and purchase order #SA-80-7684.

## What is an "Operational Definition"?

An operational definition is one that can be easily used for specific purposes. To be effective and useable it should meet certain criteria:

- an operational definition should refer to a specific measurable condition which may range from completely present in some people to completely absent in others;
- it should be user-oriented;
- It should contain a statement of conditions under which an intervention, such as treatment, should take place;
- the conditions or interventions covered by the definition should have a definitive starting and stopping time of occurrence;
- it should be clear and concise.

The definition of a "developmental disability" that is contained in P.L. 95-602 presents a legal definition that is intended for use primarily with the federal program that is authorized by that legislation. As a legislative definition it is not as detailed as is a totally operational definition. Rather, the operational definition that is presented here builds on and further explicates the meaning of the terms contained in the legislation.

The definition of developmental disabilities that is contained in P.L. 95-602 is as follows:

*"The term 'developmental disability' means a severe, chronic disability of a person which:*

- A. is attributable to a mental or physical impairment or combination of mental and physical impairments;*
- B. is manifested before the person attains age twenty-two;*
- C. is likely to continue indefinitely;*
- D. results in substantial functional limitations in three or more of the following areas of major life activity:*
  - (1) self-care*
  - (2) receptive and expressive language*
  - (3) learning*
  - (4) mobility*
  - (5) self-direction*
  - (6) capacity for independent living, and*
  - (7) economic self-sufficiency; and*
- E. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated."*

The next sections of this paper are:

II. Key screening questions and explanations. This section provides screening questions to be used in determining if an individual (or group of individuals) is developmentally disabled. The section also reviews approaches to answering the questions. These questions are expected to be of most direct assistance to direct service providers, but should be relevant to planners as well if the questions are regarded as dimensions for describing a target population.

III. Additional explication of the definition of developmental disabilities. This section builds on previous project work. It provides additional definitions of key words and defines some remaining issues in implementing the definition.

IV. Key screening questions for determining if an individual (or group of individuals) is developmentally disabled. This section repeats the screening questions from Section II without any explanations and with the addition of check-off boxes. This section is provided for possible direct use as a screening tool for determining whether or not a person has a developmental disability.

## II. KEY SCREENING QUESTIONS AND EXPLANATIONS

This section is intended for use by program staff and others who wish to determine whether or not an individual (or group of individuals) is developmentally disabled. The questions and measures are offered as guides.

Each element of the definition is a criterion that must be met if a person is to be considered developmentally disabled. For a person to be developmentally disabled all the criteria contained in the definition must be met. However, some flexibility of interpretation is required when applying the substantial functional limitations (Criterion D) to children and older adults (see the following section for a further explanation of the effect of age and other factors on interpreting the definition criteria).

Each of the five criteria is presented in the order in which they appear in the definition. They are introduced by the first phrase of the definition. For each criterion one or more questions are provided that, when answered affirmatively ("yes"), indicate that the criterion is met. When more than one question needs to be answered this is indicated by "AND". For each question, suggested measures for arriving at answers are presented. An approach is indicated, including the type of professional who would be involved in determining if a criterion is met and the types of assessment tools that might be appropriate.

DEFINITION

INTRODUCTION: *The term "developmental disability" means a severe, chronic disability of a person which;*

QUESTION: Does the person or group of persons have major and long lasting pervasive limitation in ability to function in society?

MEASURES: This phrase functions as an initial screening item. All the remaining criteria in the definition provide further explication of the characteristics of the basic "severe, chronic disability" that comprises a developmental disability.

The measures for severe are explicated in the later criteria that require three out of seven functional limitations and that require the need for multiple services.

The measures for chronic are explicated in the later criteria that require "indefinite duration" of the disability itself and of the need for services.

A "disability" is taken here to mean a pervasive limitation in a person's ability to carry out a major life function. As is required in the first criterion, this limitation, in the case of a developmental disability, must result from a physical and/or mental impairment rather than from such other factors as the environment, cultural deprivation or other experiences.



*The term "developmental disability" means a severe, chronic disability of a person which:*

CRITERION A: *is attributable to mental or physical impairment or combination of mental and physical impairments;*

QUESTIONS: Does the person have a measurable physical and/or mental impairment as determined by a qualified professional?

AND Is the person's disability, i.e., his or her limited ability to function, a result of the impairments?

MEASURES: Both questions can be answered through the same process.

Presence of an impairment should, in general, be determined either by a physician (preferably a psychiatrist or a neurologist) or by a clinical psychologist.

The precise procedures to be used are appropriately determined by the qualified professional in response to the manifestations of the apparent impairment.

*The term "developmental disability" means a severe, chronic disability of a person which:*

CRITERION B: *is manifested before the person attains age twenty-two;*

QUESTIONS: Did the disability itself begin prior to age twenty-two?

AND Did the disability result in severe functional limitations (or disability) prior to age twenty-two?

MEASURES: The disability must have become apparent prior to age twenty-two. In addition, it has to have resulted in a severe disability (as defined in Criterion D) prior to this age. Thus, an impairment or combination of impairments that gives rise to a disability that is only slight, mild or moderate prior to age twenty-two (e.g., progressive visual or auditory loss) would not be considered to meet the criteria of the definition.

For individuals under age twenty-two, these questions are answered at the time a determination is made regarding the presence of a physical and/or mental impairment.

For individuals over age twenty-two, these questions can be answered by reviewing a person's history. Reliable information should be sought and may be present in a person's medical or school history. The individual and/or a parent/guardian may also be familiar with the initial manifestation of the impairment and with the presence of a resultant substantial functional limitation.

It need not have manifest itself in its most severe form but must be severe enough to interfere with the acquisition of basic skills.

This creates problems, however, with the inclusion of individuals with certain conditions that, with early intervention upon their initial and relatively mild manifestation may be prevented from becoming more severe later in life such as juvenile diabetes. Also excluded might be most people with conditions such as multiple sclerosis that are not likely to have severe manifestations prior to age 22. This is consistent with the notion that not all conditions that result in disabilities will necessarily result in a developmental disability.

The essence of a developmental disability is that it has a major impact on a person's ability to function during the crucial developmental years when skill acquisition and preparation for adult functioning is taking place. In general, a condition that has not yet become a severe disability, but that has the potential of becoming one in adulthood would not be included as a developmental disability, although ones that are severe prior to age twenty-two and become progressively

more severe later would be. This in no way implies that such conditions should not receive full attention and early intervention services, but only that they do not appropriately fall within the purview of the developmental disabilities program.\*

\* A companion document from this project includes a brief description of some major conditions that have been mentioned as likely to lead to developmental disability and a more complete list of other conditions less likely to result in a developmental disability because they are unlikely to meet a criterion such as manifestation prior to age twenty-two.

*The term "developmental disability" means a severe, chronic disability of a person which*

CRITERION C: *is likely to continue indefinitely;*

QUESTIONS: Is/are the body system(s) that is/are impaired one which is known not to regain capacity once damaged even with medical or surgical intervention?

OR

Is the condition causing the mental and/or physical impairment(s) one which is known to be chronic with little expectation of remediation or cure?

OR

Is it professional judgment that the person is likely to remain impaired for the foreseeable future?

AND

Is/are the major limitation (s) likely to be reduced but not eliminated by interventions, environmental modifications or similar efforts which are made to increase the person's ability to function?

MEASURES: There is considerable medical knowledge based upon the current state of the art in treating and projecting the course of specific disorders leading to impairments. However no standard measures exist to predict the duration of resultant functional limitation or disability. In general, a medical evaluation will be required to determine the chronicity of a condition or an impairment. The trajectory or life course of a disability can usually be projected by such professionals as physicians (physiatrists, neurologists, psychiatrists), nurses, therapists, counselors, and psychologists.

*The term "developmental disability" means a severe, chronic disability of a person which:*

CRITERION D: *results in substantial functional limitations in three or more of the following areas of major life activity:*

- (i) self-care; (ii) receptive and expressive language;*
- (iii) learning; (iv) mobility; (v) self-direction;*
- (vi) capacity for independent living; and (vii) economic self-sufficiency;*

QUESTIONS: Is the person performing below the level expected for his or her age in three or more of the following areas:

Self-care

Receptive and Expressive Language

Learning

Mobility

Self-Direction

Capacity for Independent Living

Economic Self-Sufficiency

AND Is the person's level of performance at least three standard deviations below norm for the person's age on standardized tests?

OR

Is required assistance at least twice that expected for the person's age?

MEASURES: Many tests exist that measure limitations in life activities. These tests include measures of physical as well as mental ability to perform specific tasks. However, measuring a sub-

stantial limitation in each of the life activity areas will be complicated by a number of factors, including:

- No one test can be used for all seven areas
- In some instances more than one test may be needed to measure one life activity area (e.g., independent living)
- No one test can be used for all age groups or all types of impairments
- Good age norms do not necessarily exist for many of the available tests
- Different professionals may be needed to test an individual across or within the different areas

These and other constraints are discussed in various handbooks and compilations of behavioral assessment tools (see References at the end of this section). Different types of professionals may be able to make the desired tests.

The measurement of substantial functional limitations for various age groups is particularly problematic. For the elderly population, both the impairment and resulting disability must have been manifested before age 22 for an adult to be considered developmentally disabled. However, in terms of current functioning, not all seven areas of life activity have equal relevance for persons of all ages. Specifically, for many individuals over age 65 typical concepts of economic self-sufficiency would not be appropriate just as they would not for most individuals under age 22. Similarly, for very young children, particularly pre-school children under age 5, capacity for

independent living will be different than it will for older children and in turn will be different again for adults. In section III of this paper there is a discussion of how to interpret limitations in each of the major life activity areas for different age groups. Without arguing that the concepts have equal applicability for all ages, it is hoped that this discussion is useful in showing how to arrive at an age-appropriate interpretation of each major life activity limitation.



*The term "developmental disability" means a severe, chronic disability of a person which:*

CRITERION E: *Reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated:*

QUESTIONS: Does the person need a combination of more than one type of service, care or treatment?

AND Does the person need a combination of service, care and treatment sequenced over a prolonged (potentially lifelong) period of time?

AND Does the person need services, care or treatment provided by personnel trained in a variety of disciplines?

AND Do the services, care or treatment provided to the person need to be individually planned and coordinated concurrently and over time?

MEASURES: There are virtually no standardized tests or procedures for determining current or projected future service needs. However, there are many professionals with considerable expertise to help answer the questions. The person with overall responsibility for determining whether or not a person has a developmental disability, or another qualified professional with a broad perspective on a person's comprehensive needs (such as a social worker or a case management specialist) could answer these questions on the basis of an examination of, for example:

- previous use of services by that person;
- use of services by persons with similar conditions and limitations;
- the expressed needs of the primary consumer or his/her parent, guardian or advocate;
- measured deficits in functioning;
- the expressed ability of any one service provider to meet the person's needs;
- a person's individual habilitation plan, individual education plan, or other individual plan.

TABLE A  
 MOST LIKELY PROFESSIONAL GROUPS TO CONDUCT ASSESSMENT OF EACH CRITERION  
 FOR A DEVELOPMENTAL DISABILITY\*

| CRITERION                                   | Specialist Physician | Educator | Therapist<br>(e.g., Physical,<br>Occupational<br>Speech) | Psychologist | Social Worker,<br>Counselor,<br>Case Manager | Other<br>(e.g., Self<br>Parent) |
|---|----------------------|----------|--|--------------|--|---------------------------------|
| A. Impairment                               | X                    |          | X  | X            |  |                                 |
| B. Before Age 22                            | X                    | X        |  |              | X  | X                               |
| C. Chronic                                  | X                    |          | X  |              |  |                                 |
| D. Substantial<br>Functional<br>Limitations |                      |          |  |              |  |                                 |
| Self-care                                   | X                    |          | X  |              |  | X                               |
| Receptive<br>and<br>Expressive<br>Language  |                      | X        | X  | X            |  |                                 |
| Learning                                    | X                    | X        |  | X            |  |                                 |
| Mobility                                    | X                    |          | X  |              |  | X                               |
| Self-<br>direction                          |                      |          |  | X            | X  |                                 |
| Capacity<br>for<br>Independent<br>Living    |                      |          | X  |              | X  | X                               |
| Economic<br>Self-<br>Sufficiency            |                      |          |  | X            | X  | X                               |
| E. Services                                 | X                    | X        | X  | X            | X  | X                               |

X = Most likely professional to have the capacity and techniques to assess criterion.

\* May be based on an assessment conducted specifically to determine the presences of a developmental disability or may be based on records of previous assessments.

### III. EXPLICATION OF THE DEFINITION OF DEVELOPMENTAL DISABILITIES AND RELATED ISSUES

In this section the meaning of certain key terms contained within the definition of developmental disabilities is provided along with an exploration of some issues that affect its interpretation. This information is provided to increase the users understanding of implications of the definition.

Each criterion within the definition is explored in the order in which it appears in the definition.

DEFINITION

INTRODUCTION:\*     *The term 'developmental disability' means a severe, chronic disability of a person which:*

EXPLICATION

OF MEANING:\*\*     The definition emphasizes in its introductory phrase the chronic and severe nature of a developmental disability. This phrase does not modify or add to the content of the criteria but simply reinforces their meaning as indicated below.

DEFINITIONS

OF KEY WORDS:\*\*\*

SEVERE

*"substantial functional limitations in three or more . . . areas of major life activity . . ." (CRITERION D) reflecting " . . . the person's need for a combination . . . of special, interdisciplinary, or generic care, treatment, or other services . . . ." (CRITERION E)*

CHRONIC

*"likely to continue indefinitely" (CRITERION C) and reflecting " . . . the person's need for a . . . sequence of . . . care, treatment, or other services which are of lifelong or extended duration . . . ." (CRITERION E)*

\*     The words underlined are defined in the "Key Words" sections.

\*\*    The "Explication" sections are taken directly from an earlier product of the study: Elinor Gollay, "The Modified Definition of Developmental Disabilities: An Initial Exploration", Morgan Management Systems, Inc., March, 1979.

\*\*\*   In this section only, the definitions of key words consist of direct quotes from criteria for a developmental disability contained in other parts of the definition. This is done to illustrate that the introductory phrases reiterates other criteria rather than introducing new ones.

DISABILITY

"Substantial functional limitations in . . . areas of major  
life activity . . ." (CRITERION D) "attributable to a mental  
[and] or physical impairment." (CRITERION A)

The term "developmental disability" means a severe, chronic disability of a person which:

DEFINITION

CRITERION A: is attributable to a mental or physical impairment or combination of mental and physical impairments;

EXPLICATION

OF MEANING:

There are two parts of this element which need explication:

"is attributable to" means there is some casual relationship between the presence of an impairment and the disability .  
No specific etiologies for the impairment itself are implied.

"a mental or physical impairment or combination of mental and physical impairments" covers virtually any specific type of impairment, including neurological, sensory, biochemical, intellectual, cognitive, perceptual, affective and mobility impairments. "Impairment" is taken to mean "a physiological, anatomical or mental loss or other abnormality or both"\* An impairment implies that there has been some damage or residual loss of physical or mental functioning.

\* Saad Nagi in E.B. Whitten, ed., Pathology, Impairment, Functional Limitation and Disability--Implications for Practice, Research, Program and Policy Development and Service Delivery.

DEFINITION  
OF KEY WORKS:

IS  
ATTRIBUTABLE  
TO

is caused by

MENTAL

of, or pertaining to, the brain

PHYSICAL

of, or pertaining to, any part of the body: bones;  
muscles; organs; nerves; etc.

IMPAIRMENT

Physiological, anatomical or mental loss or other  
abnormality or both

ISSUES:

The cause of the impairment or specific condition  
leading to the impairment is not relevant. Age has  
no impact on presence or absence of impairment, but  
in very young children (infants) it may be difficult  
to determine presence of certain impairments.



The term "developmental disability" means a severe, chronic disability of a person which:

DEFINITION

CRITERION B: is manifested before the person attains age twenty-two;

EXPLICATION  
OF MEANING:

This element has two parts that need explication:

"is manifested" means that the disability (and its various functional limitations) actually appears and begins to have its impact on a person, not just that it has its roots in childhood. The disability need not be manifest in its most severe form but sufficiently severe to interfere with basic acquisition of skills; i.e., if condition is degenerative it need not have reached its peak before age twenty-two but needs to have begun intervening.

"before the person attains age twenty-two" has a straightforward meaning which, taken in conjunction with the first phase, means that the disability has to show itself and begin to have its limiting impacts on a person's functioning prior to age twenty-two or during the developmental period. That is, it interferes with a person's normal development.

DEFINITION  
OF KEY WORDS:

IS  
MANIFESTED

is apparent; is present in visible form (to be differentiated from originated which may or many not be manifested)

ATTAINS

reaches

AGE  
TWENTY-TWO

twenty-second birthday

ISSUES:

Age twenty-two is an arbitrary cut-off. Responsive and responsible services should be somewhat flexible in meeting the needs of people with similar problems whose disability manifests itself after age 22 although it may be that those individuals' costs are covered through other funding sources. Funds from the Developmental Disabilities Program should focus only on persons whose disability manifested prior to age twenty-two. However, a service for adults need not necessarily best be designed only for developmentally disabled persons but might best serve people's needs if it draws on other finding sources as well and serves a somewhat broader population.

The term "developmental disability" means a severe, chronic disability of a person which:

DEFINITION

CRITERION C: is likely to continue indefinitely.

EXPLICATION  
OF MEANING:

This criterion means that a developmental disability is one which has a reasonable likelihood of continuing for a protracted period of time, including a reasonable likelihood that it will continue throughout a person's life. The long term quality of a developmental disability is reiterated in the criterion on service need.

DEFINITION  
OF KEY WORDS:

IS LIKELY can be expected to, according to common knowledge and/or professional judgement

CONTINUE endure, remain

INDEFINITELY without known end; with an expectation of lasting forever (throughout a person's life)

ISSUES: Ability to project the course of a condition and the resultant impairment will be influenced primarily by current medical knowledge. The trajectory of a disease is related to currently available medical and non-medical remediation techniques and may be modified as these technologies improve. Expectation of long duration will increase as a condition has already endured, making it easier to predict continued duration for older people. Predictions of chronicity may be difficult for infants and

young children. However, for such individuals, being  
"at risk" of having a chronic disability will be adequate  
to meet this criterion.

The term "developmental disability" means a severe, chronic disability of a person which:

DEFINITION

CRITERION D:

results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care; (ii) receptive and expressive language; (iii) learning; (iv) mobility; (v) self-direction; (vi) capacity for independent living; and (vii) economic self-sufficiency:

EXPLICATION

OF MEANING:

Two parts of this criterion need explicating:

"results in substantial functional limitations" means that a developmental disability results in an individual's having major difficulties in performing certain tasks. The crucial concept here is "substantial." The term is used to describe the extent of a person's limitations in each of three major areas of life activity as well as to convey the overall extent of a person's functional limitations. (See Table A.)

"the following areas of major life activity" each area required its own explanation and definition. As has been indicated, there are no universally agreed upon ways of dividing major life activities into categories, nor is there agreement on the precise meaning or content of categories using the same title. Indeed, reviews of major behavioral assessment tools reveal that there is little uniformity among these tools. The importance of each major area for a person might vary considerably with specific activities contained within an area. ( See Table A.)

EXPLANATIONS OF AREAS JOR LIFE ACTIVITY

| ACTIVITY                          | DEFINITION  | EXAMPLES OF SPECIFIC ACTIVITIES OF SKILLS   | DESCRIPTION OF SUBSTANTIAL LIMITATIONS  |
|-----------------------------------|---|---|---|
| Self-Care                         | Daily activities which enable a person to meet basic life needs for food, hygiene and appearance.   | <p>Eating: drinking, mealtime manners, use of utensils, mastication and swallowing.</p> <p>Hygiene: toileting, washing and bathing, toothbrushing.</p> <p>Grooming: dressing, undressing, hair and nail care, care of clothing, overall appearance.</p>   | <p>Activities in <u>two or more</u> of the component skill areas must be performed at an age appropriate level:</p> <ul style="list-style-type: none"> <li>• by another person and/or</li> <li>• with a maximum of human assistance and/or</li> <li>• on a continuing or regular basis and/or</li> <li>• with a maximum and regular supervision and/or</li> <li>• with such difficulty as to take an unusually protracted amount of time</li> </ul>   |
| Receptive and Expressive Language | Communication involving both verbal and non-verbal behavior enabling the individual both to understand others and to express ideas/information to others. | <p>Expressive: use of oral or sign language or other intelligible gestures or sounds, use of mechanisms (such as letter boards or typewriters) for expression, and communication with others, voice control.</p> <p>Receptive: understanding through listening, auditory comprehending, lip reading, comprehending other forms of communication (e.g. sign language, reading)</p> | <p><u>Receptive:</u> unable to take in or process verbal and/or non-verbal information, <u>or</u> does so at an age appropriate level:</p> <ul style="list-style-type: none"> <li>• with a maximum of human assistance and/or</li> <li>• on a continuing or regular basis</li> </ul> <p><u>Expressive:</u> unable to express self (verbally or non-verbally) in a manner that can be understood by others <u>or</u> be able to express self at an age appropriate level only:</p> <ul style="list-style-type: none"> <li>• with a maximum of human assistance on a continuing or regular basis and/or</li> <li>• with such difficulty that an unusually protracted time is required and/or</li> <li>• if able to be understood only by a small group of people</li> </ul> |
| Learning                          | General cognitive competence and ability to acquire new behaviors, perceptions and information, and to apply experiences in new situations.               | <p>Cognition: ability to understand information recognition.</p> <p>Retention: memory, knowledge.</p> <p>Reasoning: ability to generalize, to conceptualize, to see relationships among pieces of information, to use abstract concepts.</p> <p>Pre-Academic and Academic Skills: reading, writing, quantitative activities, shape and color recognition, etc.</p>                | <p>Cognition, retention and reasoning are impaired such that the person is unable, or is extremely limited in ability, even with specialized intervention, to acquire new knowledge or transfer knowledge and skills to new situations. Specifically only able to perform, at substantially below age appropriate levels, pre-academic and academic tasks</p>   |

TABLE A

EXPLANATIONS OF AREAS ■ JOR LIFE ACTIVITY

| ACTIVITY       | DEFINITION  | EXAMPLES OF SPECIFIC ACTIVITIES OF SKILLS  | DESCRIPTION OF SUBSTANTIAL LIMITATIONS  |
|----------------|---|--|---|
| Mobility       | Motor development and ability to use fine and gross motor skills. Ability to move one's person from one place to another with or without mechanical aids. | <p><b>Movement:</b> crawling, walking, climbing, use of mobility and aids such as crutches, wheelchair, cane or walker.</p> <p><b>Gross Motor Control:</b> balance, posture, sitting, standing, rolling.</p> <p><b>Fine Motor Control:</b> manual dexterity, precision movements, ability to control or direct mechanical devices.</p> <p><b>Coordination:</b> eye-hand, perceptual-motor, body-motor.</p> | <p>Unable to perform mobility skills or two out of four activities can only be performed at an age appropriate level:</p> <ul style="list-style-type: none"> <li>• with maximum human assistance and/or</li> <li>• on a regular or continuing basis and/or</li> <li>• with such difficulty that an unusually protracted time is required and/or</li> <li>• if a barrier-free environment is required</li> </ul>               |
| Self-Direction | Management and taking control over one's social and personal life. Ability to make decisions affecting and protecting one's own interests.                | <p><b>Self-Concept:</b> self-esteem, self-confidence.</p> <p><b>Socialization:</b> affect, emotion, social awareness, emotional stability, leisure time activities, community involvement.</p> <p><b>Initiative:</b> responsibility, decision making.</p> <p><b>Orientation:</b> awareness of environment, responsiveness to environment.</p>  | <p>Unable, at an age appropriate level, to initiate and/or maintain personal relationships, to behave socially in an acceptable manner, or to exercise judgments or can only do so with:</p> <ul style="list-style-type: none"> <li>• maximum supervision on a regular basis and/or</li> <li>• maximum human assistance particularly in performing tasks basic to a person's ability to protect his/hor own rights</li> </ul> |

TABLE A

EXPLANATIONS OF ARFAS JOR LIFE ACTIVITY

| ACTIVITY                        | DEFINITION   | EXAMPLES OF SPECIFIC ACTIVITIES OF SKILLS  | DESCRIPTION OF SUBSTANTIAL LIMITATIONS   |
|---------------------------------|--|--|--|
| Capacity for Independent Living | Age appropriate ability to live without extraordinary assistance from other persons, especially to maintain normal societal roles.   | <p><b>Housekeeping:</b> cleaning, maintenance, making beds, cooking, laundry, care of clothing.</p> <p><b>Family Support:</b> maintaining relationships, being a spouse, parenting.</p> <p><b>Money Management:</b> budgeting, purchasing, keeping track of expenditures, using money.</p> <p><b>Health and Safety:</b> selecting appropriate clothing, balanced nutrition, health and safety.</p> <p><b>Leisure Time Activities:</b> recreation, cultural activities, religious activities, social activities, clubs.</p> <p><b>Using the Community Resources:</b> using transportation, telephone, post office, stores, and other community resources.</p> | <p>Activities in one or more of the 3 areas cannot be performed at an age appropriate level only:</p> <ul style="list-style-type: none"> <li>• performed by another person and/or</li> <li>• with maximum human assistance on a regular basis and/or</li> <li>• if continuing supervision is provided and/or</li> <li>• with such difficulty as to take an unusually protracted amount of time and/or</li> <li>• if barrier-free environment exists</li> </ul> |
| Economic Self-Sufficiency       | Maintaining adequate employment and financial support. Ability to earn a "living wage," net, after payment of extraordinary expenses occasioned by the disability. Absence of dependence on family or welfare for financial support. | <p><b>Pre-Vocational &amp; Vocational Skills:</b> ability to perform tasks required for a job, ability to learn new skills as needed.</p> <p><b>Work Adjustment:</b> promptness, work habits, adjustment to work environment.</p> <p><b>Job Finding:</b> ability to locate appropriate work, interviewing skills, presentation of self.</p> <p><b>Income:</b> earning capacity.</p>  | <p>Activities in one or more of the four areas cannot be performed adequately such that individual is fully dependent (or for children is likely to be dependent) upon external (public and private) sources of money as a result of limited ability to find and keep adequate employment</p>  |



TABLE B. RELATIONSHIPS AMONG LIFE ACTIVITY LIMITATIONS

| LIFE ACTIVITY LIMITATIONS         | LIFE ACTIVITY LIMITATIONS |                                   |          |          |                |                    |                           |
|-----------------------------------|---------------------------|-----------------------------------|----------|----------|----------------|--------------------|---------------------------|
|                                   | Self-care                 | Expressive and Receptive Language | Learning | Mobility | Self-direction | Independent Living | Economic Self-Sufficiency |
| Self-care                         | —                         |                                   |          |          |                | X                  | X                         |
| Expressive and Receptive Language |                           | —                                 | X        |          |                | X                  | X                         |
| Learning                          | X                         | X                                 | —        | X        | X              | X                  | X                         |
| Mobility                          | X                         |                                   |          | —        |                | X                  | X                         |
| Self-direction                    |                           |                                   |          |          | —              | X                  | X                         |
| Independent Living                |                           |                                   |          |          |                | —                  | X                         |
| Economic Self-Sufficiency         |                           |                                   |          |          |                | X                  | —                         |

X = Presence of life activity limitation

Example: If a person is limited in SELF-CARE, it is likely he/she will also be limited in INDEPENDENT LIVING and ECONOMIC SELF-SUFFICIENCY.

DEFINITIONS  
OF KEY WORDS:

SUBSTANTIAL: severe; major; with reference to functional limitation, it means considerably below expected level of functioning for age group \*

FUNCTIONAL LIMITATION limited ability or inability to perform specified tasks

AREAS OF MAJOR LIFE ACTIVITY aspects of functioning in "normal" society, groups of specific tasks that comprise the bulk of what people do and/or need to do to perform in society

ISSUES: There are three major factors that need to be taken into account in attempting to assess a life activity limitation: age, environment and partial limitations.

1.. Age: The most central and potentially problematic factor in attempting to determine if a person is substantially limited in a life activity area is that person's age. The standard for expected performance in each of the seven areas is a direct function of age. As indicated above, the concept of substantial limitation has implicit in it the concept of performance against age appropriate behavior for each major age group: children, working age adults and older adults.

a. Children. For infants and children under age five the life activity limitations have to be interpreted somewhat differently than for older persons. For very young infants the major manifestations of a developmental disability might be in only one area initially such as mobility or learning. However, for a young child, having a major deficit in one area such as learning, mobility, receptive language (e.g., deafness) is even

\* Three standard deviations below the norm is being recommended for the DD definition.

more likely than in an adult to have a pervasive impact on that child's ability to acquire basic skills and to function later in life. For a child under the age of one, there would also be relatively few self-care criteria. A child as young as one year old will have begun to acquire certain basic self care skills, such as self-feeding, but other areas of functioning such as capacity for independent living, self-direction and economic self-sufficiency will not take on much meaning until a child is older. For an infant, however, it is reasonable to expect that his or her ability to acquire these more advanced skills will be limited by early major limitations in an area such as learning or mobility. Similarly, for an older child we can begin to see limitations first in self-care, and then both in capacity for independent living and self direction. These three areas will need to be regarded in terms of age-appropriate levels. Thus, it might be reasonable to expect that most three year olds are toilet trained, but not that they can tie their own shoes. Similarly, even a young child can begin to evidence self-direction in terms of the ability to make simple choices for themselves. Independent living can be seen in terms of early ability to help set the table, put one's toys away or begin to get around the neighborhood. Age appropriate measures can, then, reasonably be expected to be made in these areas. Economic self sufficiency is clearly not an area in which we normally have expectations for persons under 18 and in many instances even under age 22. However, if a young child is substantially limited in two of the other areas listed in the definition, there is a reasonable expectation that those limitations will create problems for the individual in terms of obtaining and maintaining a job and in supporting him or herself. This last area, then, is most problematic for children but can be reasonably regarded as a likely area of difficulty for children with major difficulties in the other areas that are mentioned.

- b. Older Adults. For many adults over age 65 the concept of economic self-sufficiency begins to lose meaning upon retirement from the work force. It is, therefore, difficult to measure current economic self-sufficiency. To measure this dimension it then is necessary to develop concepts of past economic self-sufficiency just as for children it is necessary to have a concept of future or potential economic self-sufficiency. Therefore, we recommend that an effort be made to obtain information on past economic self-sufficiency. It should also be noted that the aging process, particularly after age 65, is likely to result in functional losses that compound any that a person had earlier in life and would increase the likelihood that a developmentally disabled person who was functioning with relatively few supports during adulthood would require services.
2. Environment: The second factor that influences judgement regarding the substantiality of a person's limitation is the environment in which that person is living. The impact of the environment is greatest on the three more complex life activities--self-direction, capacity for independent living and economic self-sufficiency. Particularly for these areas, the demands or constraints of the environment need to be taken into account when judging the extent to which a person is substantially limited. The environment creates different standards or norms for these life activities and also imposes differing constraints. For example, in a rural area ability to drive a car might be very important for a person's capacity for independent living whereas in an urban area using public transportation might be more important. Similarly, ability to earn a living is only partly a result of a person's inherent capacity and is also a function of the job opportunities available in the community.

It is necessary, therefore, to arrive at measures that either cut across different environments uniformly or that allow for flexibility in their application to different settings.

3. Partial Limitations. Each of the major life activity areas is really comprised of many different skill areas (see definitions above). Although the component skill areas are related to each other it is possible to be limited in some and not in others or at least to be limited in a non-uniform fashion. This raises the question: when is a person considered substantially limited in the overall activity area given that partial limitations within the area exist?

Does a substantial limitation in one area, such as dressing, equal a partial limitation in all components of self-care? Does being limited only in dressing constitute a self-care limitation? Similar questions can be raised for each of the life activity areas.

If, as a result of a major limitation in one aspect of a life activity area or an accumulation of less substantial limitations in all aspects of a life activity area, a person needs the types of assistance identified above, then it is appropriate to consider the person to be substantially limited in that life activity area.

Recommended guidelines for substantiality are provided in the definitions above.

The term "developmental disability" means a severe, chronic disability of a person which:

DEFINITION

CRITERION E: reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

EXPLICATION  
OF MEANING:

This criterion means that a person with a developmental disability is likely to need many services throughout life. It does not mean that all developmentally disabled persons will need the same types or amounts of services, nor does it mean that any particular developmentally disabled individual will need the same types or amounts of services throughout the lifespan. This criterion reinforces the pervasiveness and complexity of severe developmental disabilities.

DEFINITION  
OF KEY WORDS:

COMBINATION more than one concurrent activity

SEQUENCE more than one activity following one another over time

SPECIAL aimed specifically at persons with developmental or other disabilities

INTERDIS-  
CIPLINARY drawing on the expertise of multiple professions (e.g., medicine, psychology, nursing, social work, physical therapy), including through a team approach of a combination of professionals and paraprofessionals from different disciplines working together for the benefit of the developmentally disabled individual rather than

a collection of individuals from multiple professions who work independently without the benefit of shared expenses

GENERIC

aimed at a population defined by a common need, not at a categorically defined population; in particular, not specifically designed for, or limited to, serving disabled individuals

CARE

supportive activities aimed primarily at maintenance

TREATMENT

activities aimed at improvement, alleviation and possible cure of symptoms or damage to a body system

OTHER  
SERVICES

other individually oriented activities aimed at meeting a person's needs, not readily met by that person for himself

LIFELONG OR  
EXTENDED  
DURATION

without known end; with an expectation of lasting forever (throughout a person's life)

INDIVIDUALLY  
PLANNED

arranged for each client, with explicit needs, goals, objectives, time frames and procedures identified for that person

INDIVIDUALLY  
COORDINATED

managed by a person or process which ensures that activities provided each client fit into a package that does not have conflicting or needlessly duplicative aspects at any given time or over time

ISSUES:

The administration of coordinated care requires communication among agencies. The selection of universal measurement instruments and the coordination of record keeping may be difficult to achieve in some jurisdictions. The long term care nature of developmental disabilities presents another administrative problem. Nonetheless, case management and other coordinative mechanisms exist which serve to operationalize this criterion.

## Summary

A number of points from Sections II and III need to be highlighted:

- The selection and interpretation of measurement tools for answering the questions are left to the users of the operational definition. No Federal or even State guidelines exist that specify which scores on which tests should be used to say a person has met a particular criterion. The state of the art and complexity of the task make such guidelines unlikely and possibly undesirable. An agency might wish to set its own standards. In most instances, the professionals who are called upon to determine if a person meets a criterion will be expected to select and interpret tests appropriately. The main area of difficulty is measuring substantial functional limitations in the seven major life activity areas. At the end of Section II a bibliography of some compilations and analyses of currently available behavioral assessment tools and standard references is provided.
- A major difficulty in implementing the definition is determining how to interpret it across various age groups, particularly for very young children.
- A variety of professionals may be needed to assess whether an individual meets all of the criteria in the definition. Some of the most appropriate professionals to answer the questions associated with each criterion are included in Table A.
- As the operational definition is used and evolves, additional refinements to the precise meaning of certain words or phrases can be expected. There may also be issues raised which were not anticipated in this paper. As long as the focus on the basic



meaning of the definition is kept clear, these refinements or issues should not result in major changes. While this document cannot be regarded as the "last word" it does provide a basic framework which allows users to apply the definition appropriately and responsively.

IV. KEY SCREENING QUESTIONS CHECKLIST

*The term "developmental disability" means a severe, chronic disability*

*of a person which:*

Is there reason to believe that the person or group of persons has a severe, chronic disability?

CHECK:

YES \_\_\_\_\_ NO \_\_\_\_\_

A. *is attributable to mental or physical impairment or combination of mental and physical impairments;*

Does the person or group of persons have a measurable physical and/or mental impairment as determined by a qualified professional?

CHECK TWO:

YES \_\_\_\_\_ NO \_\_\_\_\_

AND

Is the person's or group of persons' disability, i.e., his or her limited ability to function, a result of the impairments?

YES \_\_\_\_\_ NO \_\_\_\_\_

B. *is manifested before the person attains age twenty-two;*

Did the impairment itself begin prior to age twenty-two?

CHECK TWO:

YES \_\_\_\_\_ NO \_\_\_\_\_

AND

Did the impairment result in severe functional limitations (or disability) prior to age twenty-two?

YES \_\_\_\_\_ NO \_\_\_\_\_

C. *is likely to continue indefinitely;*

Is the body system that is impaired one which is known not to retain capacity once damaged?

CHECK AT  
LEAST ONE:

YES \_\_\_\_\_ NO \_\_\_\_\_

OR

Is the condition causing the mental and/or physical impairment one which is known to be chronic with little expectations of remediation or cure?

YES \_\_\_\_\_ NO \_\_\_\_\_

OR

Is it professional judgement that the person is likely to remain impaired for the foreseeable future?

YES \_\_\_\_\_ NO \_\_\_\_\_

AND

Is the disability likely to endure even if educational interventions, environmental modifications or similar efforts are made to increase the person's or group of persons' ability to function?

CHECK:

YES \_\_\_\_\_ NO \_\_\_\_\_

D. results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care; (ii) receptive and expressive language; (iii) learning; (iv) mobility; (v) self-direction; (vi) capacity for independent living; and (vii) economic self-sufficiency;

CHECK:

Is the person or group of persons performing below the level expected for his or her age in three or more of the following areas:

Self-care  
Receptive and Expressive Language  
Learning  
Mobility  
Self-direction  
Capacity for Independent Living  
Economic Self-sufficiency

YES \_\_\_\_\_ NO \_\_\_\_\_

AND

Is the person's or group of persons' level of performance at least 3 standard deviations below expected for the person's age?

YES \_\_\_\_\_ NO \_\_\_\_\_

OR

Is assistance needed that is at least twice that expected for the person's age?

YES \_\_\_\_\_ NO \_\_\_\_\_

E. reflects the person's or group of persons' need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated.

CHECK FOUR:

Does the person or group of persons need a combination of more than one type of service, care or treatment?

YES \_\_\_\_\_ NO \_\_\_\_\_

AND

Does the person or group of persons need a combination of service, care and treatment sequenced over a prolonged (potentially lifelong) period of time?

YES \_\_\_\_\_ NO \_\_\_\_\_

AND

Does the person or group of persons need services, care or treatment provided by personnel trained in a variety of disciplines?

YES \_\_\_\_\_ NO \_\_\_\_\_

AND

Do the services, care, or treatment provided to the person or group of persons need to be individually planned and coordinated concurrently and over time?

YES \_\_\_\_\_ NO \_\_\_\_\_