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*Management  
Systems, Inc.*

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Suite 301 • Clark Building • 5565 Sterrett Place • Columbia, Maryland 21044 • (301) 997-4060 • (301) 596-5655

SECOND

**DRAFT**

OPERATIONAL DEFINITION OF DEVELOPMENTAL DISABILITIES

MARCH 1980

Prepared for

"A Study of The Potential Impact of The Definition  
Recommended by The National Task Force on the  
Definition of Developmental Disabilities"

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MANAGEMENT CONSULTANTS

## I. INTRODUCTION: THE OPERATIONAL DEFINITION

The full scope of the project being conducted by Morgan Management Systems, Inc. includes:

- An exploration of the size and composition of the population covered within the new definition
- A field study of selected states that were in the process of introducing the new definition, specifically as the introduction affects the operations of the DD program
- The development of an operational definition of developmental disabilities

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 a part of the current 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\*\*.

\* 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.

### What is an "Operational Definition"?

An operational definition is one that can be easily used for specific purposes. To be effective and usable 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 developmental disabilities that is contained in P.L. 95-602 is:

"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."

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The focus of the definition of Developmental Disabilities is on individuals with severe, chronic disabilities beginning in childhood which have a pervasive impact on the ability to function normally in society. 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 two of which are presented in this paper:

1. For Planning: The definition can be used to identify a target group that can be described with its needs 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.
2. 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.
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.

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 and provides additional definitions of key words and 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 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 an "AND". For some criteria alternative questions are provided (indicated by an "OR"). 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: Is there reason to believe that the person has a severe, chronic disability?

MEASURES: This phrase functions as an initial screening item. It is necessary that there be, in someone's judgment, a reasonable expectation that the person has a severe, chronic disability. The person who has this judgment may include the disabled individual, a family member, or a professional.

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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 a physical impairment should, in general be determined by a physician. Specialists may be required to determine the presence of certain types of impairments, particularly neurological damage.

Presence of a mental 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 impairment itself begin prior to age twenty-two?

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

MEASURES: The impairment must have occurred 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 that manifests itself prior to age 22 in mild form (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 automatically 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

WHO MADE  
THIS DECISION?  
WHY?

familiar with the initial manifestation of the impairment, and with the presence of a resultant substantial functional limitation.

3  
The term "developmental disability" means a severe, chronic disability of a person which:

CRITERION C: is likely to continue indefinitely:

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

OR

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

OR

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

AND

7~

Is the disability likely to endure even if educational interventions, environmental modifications or similar efforts 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 a 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, nurses, therapists, counsellors, and psychologists.

It is most difficult to predict the potential duration of a mental illness. However, experienced mental health professionals such as psychiatrists or clinical psychologists should be able to predict duration, although this may be expressed in much less specific terms than for mental retardation or physical impairments.

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:

Under Age 5: Is the child performing below the expected level at his or her age in one or more of the following areas:

Self-care

Receptive and Expressive Language

Learning

Mobility

AND Is the amount of the delay at least 25% below age norms?

OR

Is assistance needed that is at least 25% more than expectation for age?

Ages 5 to 22: Is the person performing below the level expected at his or her age in two 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 amount of the delay at least 25% below age norms?

OR

Is assistance needed that is at least 25% more than expectation for age?

\* \* \* \* \*

Ages 22 to 64: 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 25% below expected for the person's age?

OR

Is assistance needed that is at least 25% more than expectation for the person's age?

\* \* \* \* \*

Over Age 65: Is the person performing below the level expected for his or her age in two or more of the following areas:

Self-care

Mobility

Self-direction

Capacity for Independent Living

AND

Is the person's level of performance at least 25% below expected for the person's age?

OR

Is assistance needed that is at least 25% more than expectation 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 substantial 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 below). Different types of professionals may be able to make the desired tests.

The measurement of substantial functional limitations for the elderly is an area which has received recent attention. 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, only four of the seven life activities have general relevance.

While norms of functioning for the elderly have not been set for all age groups, enough knowledge exists to make tentative assessments in all of the major Life Activity Areas.

WHO  
says so?



*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) could answer these questions.

## Summary

The operational definition that is presented here cannot be regarded as the "last word" on the subject. Rather, the operational definition will, we expect, evolve with its increased use and application. As long as the focus is kept clear, additional refinements to the precise meanings of individual words or phrases should not result in major changes. As the definition is used, additional thorny issues not addressed in this paper will undoubtedly be raised. We hope that enough of a basic framework is provided for users to apply the definition appropriately and responsively.

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

- The selection and interpretation of measurement tools for answering the questions is 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 follows: (See Table A.)

TABLE A. ASSESSMENT OF DEVELOPMENTAL DISABILITIES CRITERIA

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

X = Professionals who have the capacity  
and techniques to assess criterion

### 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 the new definition of developmental disabilities.

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 is attributable to a mental or physical impairment  
CRITERION A: 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 causal 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" (Saad Nagi, "Disability Concepts and Prevalence"). An impairment implies that there has been some damage or residual loss of physical or mental functioning.

DEFINITIONS  
OF KEY WORDS:

IS  
ATTRIBUTABLE is caused by  
TO

MENTAL of, or pertaining to, the brain

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

IMPAIRMENT loss or other abnormality; damage

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

EXPLICATION  
OF MEANING: This element has two parts that need explanation:

"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, i.e., if condition is degenerative it need not have reached its peak before age 22 but needs to have begun intervening.

"before the person attains age twenty-two" has a straightforward meaning which, taken in conjunction with the first phrase, means that the disability has to show itself and begin to have its limiting impacts on a person's functioning prior to age 22, 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

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.

*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.

DEFINITIONS  
OF KEY WORDS:

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

CONTINUE endure, remain

INDEFINITELY without known end; with an expectation of lasting forever

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 nonmedical remediation techniques and may be modified as these technologies improve.

Expectation of long duration will increase as condition has already endured, making it easier to predict continued duration for older people. Predictions of chronicity will be difficult and potentially most damaging (most through self-fulfilling prophecies) for infants and young children. 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.

"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.

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



EXPLANATIONS OF AREAS OR 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.	Eating:	drinking, mealtime manners, use of utensils, mastication and swallowing.	<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>
		Hygiene:	toileting, washing and bathing, toothbrushing.	
		Grooming:	dressing, undressing, hair and nail care, care of clothing, overall appearance.	
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.	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><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>
		Receptive:	understanding through listening, auditory comprehending, lip reading, comprehending other forms of communication (e.g. sign language, reading)	
Learning	General cognitive competence and ability to acquire new behaviors, perceptions and information, and to apply experiences in new situations.	Cognition:	ability to understand information recognition.	<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>
		Retention:	memory, knowledge.	
		Reasoning:	ability to generalize, to conceptualize, to see relationships among pieces of information, to use abstract concepts.	
		Pre-Academic and Academic Skills:	reading, writing, quantitative activities, shape and color recognition, etc.	

TABLE B

EXPLANATIONS OF AREAS ~~OF~~ OR 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.	Movement:	crawling, walking, climbing, use of mobility and aids such as crutches, wheelchair, cane or walker.	<p><u>Unable</u> to perform mobility skills <u>or</u> 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>
		Gross Motor Control:	balance, posture, sitting, standing, rolling.	
		Fine Motor Control:	manual dexterity, precision movements, ability to control or direct mechanical devices.	
		Coordination:	eye-hand, perceptual-motor, body-motor.	
Self-Direction	Management and taking control over one's social and personal life. Ability to make decisions affecting and protecting one's own interests.	Self-Concept:	self-esteem, self-confidence.	<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/her own rights</li> </ul>
		Socialization:	affect, emotion, social awareness, emotional stability, leisure time activities, community involvement.	
		Initiative:	responsibility, decision making.	
		Orientation:	awareness of environment, responsiveness to environment.	

TABLE B

EXPLANATIONS OF AREAS OF MAJOR 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.	Housekeeping:	cleaning, maintenance, making beds, cooking, laundry, care of clothing.	<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>
		Family Support:	maintaining relationships, being a spouse, parenting.	
		Money Management:	budgeting, purchasing, keeping track of expenditures, using money.	
		Health and Safety:	selecting appropriate clothing, balanced nutrition, health and safety.	
		Leisure Time Activities:	recreation, cultural activities, religious activities, social activities, clubs.	
		Using the Community Resources:	using transportation, telephone, post office, stores, and other community resources.	
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.	Pre-Vocational & Vocational Skills:	ability to perform tasks required for a job, ability to learn new skills as needed.	<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>
		Work Adjustment:	promptness, work habits, adjustment to work environment.	
		Job Finding:	ability to locate appropriate work, interviewing skills, presentation of self.	
		Income:	earning capacity.	

TABLE B

direct function of age. As indicated above, the concept of substantial limitation has implicit in it the concept of performance against age appropriate behavior.

- a. The Life Activity Areas. The way in which this factor affects measurement of substantially varies with the life activity area being examined.

Four areas can be considered basic: self-care, receptive and expressive language, mobility, and learning. Skills and competence in these four areas are acquired earlier in life and their acquisition, or lack of acquisition, is likely to have a direct impact on the other three more complex areas: self-direction, capacity for independent living, and economic self-sufficiency. The following chart illustrates how limitations in each of the life activity areas is likely to result in limitations in other life activity areas. As can be seen, limits in the four basic areas are more likely to result in limits in the three more complex areas than vice versa (see Table C).

- (1) The Four Basic Life Activity Areas. For the four basic areas--self-care, receptive and expressive language, mobility, and learning--the primary issue is identifying appropriate expectations for a person's age. For these areas there are generally accepted levels of performance that exist even for very

TABLE C. RELATIONSHIPS AMONG LIFE ACTIVITY LIMITATIONS

IF THEN		DD LIFE ACTIVITY LIMITATIONS						
		Self-Care	Expressive and Receptive Language	Learning	Mobility	Self-Direction	Independent Living	Economic Self-Sufficiency
Basic areas	Self-care						X	X
	Expressive and Receptive Language			X			X	X
	Learning	X	X		X	X	X	X
	Mobility	X					X	X
Complex Areas	Self-direction						X	X
	Independent Living							X
	Economic Self-Sufficiency						X	

X = Presence of life activity limitation of row indicates likelihood of limitation in life activity of column.

young children with some indicators of slow development in these areas existing for children one year old or even less.

- (2) Three Complex Life Activity Areas. For two of the more complex life activity areas--self-direction and capacity for independent living--little expectation of performance in these areas exists for children prior to school. At school age children begin learning to exercise judgments and to carry out basic independent living tasks such as helping set the table. Nonetheless, unlike with the basic areas, the expected stages of development are less well understood and identified and have less meaning for young school age children, and even less for pre-school age children.

The final complex area--economic self-sufficiency--has even less apparent relevance for children or indeed anyone who is still in school. For younger people it will therefore be necessary to identify surrogate measures or indicators of future economic self-sufficiency. For older people (over age 65) it may be necessary to examine past economic self-sufficiency.

- b. Major Age Groups. The second way to examine the relationship of age and substantiality is by looking at the issues

raised for each major age group: infants, school age children, working age adults, and older adults.

- (1) Infants, and Pre-schoolers. For children under 2 years old it is difficult to measure a "substantial" limitation because normal variations in development are so relative to the total amount of normal development. Even up to age 5 substantial limitation would be of concern. Children under age 5 are unlikely to have any development expected in the three more complex areas: Self-direction, capacity for independent living, and economic self-sufficiency. As indicated above, a substantial limitation in any of the four basic life activity areas--self-care, receptive/expressive language, mobility, or learning--would likely have a pervasive impact on the more complex areas. As a result, we recommend that any child 0-4 years old with a substantial limitation in any one of the four basic areas should be considered at risk of being DD or actually DD, if the other definition criteria are met.
- (2) School Age Children. For children 5 to 18 (or age 22 if in school) there cannot be any reasonable expectation of actual economic self-sufficiency and only limited but growing expectations for both self-direction and capacity for independent living. As with younger children it is therefore reasonable

to apply a modified standard for the number of substantial limitations that is likely to result in a developmental disability. Therefore, we recommend that for children 5 to 18 a substantial limitation in two of six major life activity areas (excluding economic self-sufficiency) means that the child has a developmental disability, if the other definition criteria are met.

- (3) Working Age Adults. For adults ages 18 to 64 (or beginning at age 22 for people remaining in school) it is reasonable to expect competence in all seven major life activity areas. Therefore, we recommend that for this age group the standard be interpreted as stated in the law: for adults ages 18(or 22) to 64 a substantial limitation in three out of seven life activity areas means that the person is developmentally disabled, if the other definition criteria are met.
- (4) 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. Where this is not possible, lack of current economic self sufficiency may need to be assumed, in effect reducing the relevant life activity areas to six and reducing the number of additional limitations required for substantiality from three to two. 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 judgment 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 of 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 both the substantial and the extended nature of a developmental disability. It also further reinforces the pervasiveness and complexity of developmental disabilities.

DEFINITION  
OF KEY WORDS:

COMBINATION More than one concurrent activity

SEQUENCE More than one activity following one another over time

<u>SPECIAL</u>	Aimed specifically at persons with developmental or other disabilities
<u>INTERDIS- CIPLINARY</u>	Drawing on the expertise of multiple professions (e.g., medicine, psychology, nursing, social work, physical therapy)
<u>GENERIC</u>	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
<u>CARE</u>	Supportive activities aimed primarily at maintenance
<u>TREATMENT</u>	Activities aimed at improvement, alleviation and possible cure of symptoms or damage to a body system
<u>OTHER SERVICES</u>	Other individually oriented activities aimed at meeting a person's needs, not readily met by that person for himself
<u>LIFELONG OR EXTENDED DURATION</u>	Lasting for a prolonged period of time (generally more than one year) and potentially throughout a person's life
<u>INDIVIDUALLY PLANNED</u>	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 that ensures that whatever is being provided to each client fits into a coherent package that does not have conflicting or unnecessarily duplicated parts or gaps at any one time or over time

IV. KEY SCREENING QUESTIONS

DEFINITION

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

Is there reason to believe that the person  
has a severe, chronic disability?

Check:

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

#### IV. KEY SCREENING QUESTIONS

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

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

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

Check two:

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

AND

Is the person's 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 regain 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 judgment that the person is likely to remain impaired for the foreseeable future?

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

AND

Check:

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

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



D. results in substantial functional limitations in there 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:

Under age 5

Check:

Is the child performing below the expected at his or her age in one or more of the following:

Self-care  
Receptive and Expressive Language  
Learning  
Mobility

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

AND

Check at  
least one:

Is the amount of the delay at least 25% below age norms?

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

OR

Is assistance needed that is at least 25% more than expectation for age?

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

Age 5 to 22

Check:

Is the person performing below the level expected at his or her age in two 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

Check at  
least one:

Is the amount of the delay at least 25% below age norms?

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

OR

Is assistance needed that is at least 25% more than expectation for age?

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

Ages 22 to 64

Check:

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

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

AND

Check at  
least one:

Is the person's level of performance at least 25% below expected for the person's age?

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

OR

Is assistance needed that is at least 25% more than expectation for the person's age?

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

Over Age 65

Check:

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

Self-care  
Mobility  
Self-direction  
Capacity for Independent Living

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

AND

Check at  
least one:

Is the person's level of performance at least 25% below expected for the person's age?

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

OR

Is assistance needed that is at least 25% more than expectation for the person's age?

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

4 7 2  
—  
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:

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

Check four:

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

AND

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

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

AND

Does the person 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 need to be individually planned and coordinated concurrently and over time?

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