

FROM: SPECIAL REPORT ON THE IMPACT OF THE CHANGE IN THE DEFINITION  
OF DEVELOPMENTAL DISABILITIES (MANDATED IN P.L. 95-602, SEC. 502(b)(2))  
U.S. Department of Health and Human Services  
May, 1981

The Current and Previous Definitions of Developmental Disabilities

The current definition of developmental disabilities, as contained in Public Law 95-602, the "Developmental Disabilities Assistance and Bill of Rights Act", Section 102(7), is:

"(7) 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 the 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: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic 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 life-long or extended duration and are individually planned and coordinated.\*"

The definition of developmental disability contained in Public Law 95-602, sometimes referred to as the new definition of developmental disability, is based solely on an individual's functional limitations and need for services, rather than the diagnosis or nature of his or her disabling condition.

*The* previous definition of developmental disability contained in Section 102(a) (7) of Public Law 94-103, the one used by the Developmental Disabilities Program until November 1978, generally applied to persons with one of the four handicapping conditions listed;

The term "developmental disability" means a disability of a person which—

"(A) (i) is attributable to mental retardation, cerebral palsy, epilepsy, or autism;

"(ii) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons; or

"(iii) is attributable to dyslexia resulting from a disability described in clause (i) or (ii) of this subparagraph;

"(B) originates before such person attains age eighteen;

"(C) has continued or can be expected to continue indefinitely; and

"(D) constitutes a substantial handicap to such person's ability to function normally in society."

In addition, the conference report on the 1978 Amendments carried a provision the the functional definition was intended to cover everyone covered under the P.L. 94-103 categorical definition. The conferees stressed that individuals currently receiving services should continue to receive those services irrespective of the revised definition. Data are not available to assess the impact of this "hold harmless" provision on the Developmental Disabilities Program.

This report contains the analysis of the impact of the change in the definition of developmental disabilities, in terms of both the numbers of individuals served and the Federal expenditures before and after enactment of Public Law 95-602 and the assessment of services provided to individuals with developmental disabilities. The baseline for the data to be analyzed is fiscal year 1978, the last year that the categorical definition from Public Law 94-103 was in effect. The succeeding fiscal years, fiscal years 1979 and 1980, saw the introduction of a functional definition of developmental disabilities into the service network for individuals with developmental disabilities.

The basic assumption of the report is that the fiscal year 1978 funds were expended based on the categorical definition of developmental disabilities and that the fiscal year 1979 and fiscal year 1980 funds were expended based on the functional definition of developmental disabilities.

The mandate for this special study grew out of concern that the use of a functional definition of developmental disabilities could result in a diminution of services to individuals with the conditions specifically mentioned in Public Law 94-103. Part II of this report discusses the specific impact of the change in the definition.

#### Reasons for the Change in the Definition of Developmental Disabilities

The philosophy underlying the Developmental Disabilities Program is unique in its broad ecumenical approach to advocacy and planning for a target population with various disabilities and needs. Since the inception of the Developmental Disabilities Services and Facilities Construction Act of 1970, the Developmental Disabilities Program has attempted to bring together a variety of agencies traditionally serving disabled persons to develop a coordinated and comprehensive service delivery system for its target population.

Because of the unique broad-based approach to the program, it is not surprising that ambiguity has existed about the program's target population. The question of which groups of disabled persons fall under the term "developmentally disabled" and which groups do not qualify has been raised by various agencies, programs, and consumers.

A discussion of the historical evolution of the definition of developmental disabilities, beginning with the originating legislation (P. L. 88-164} and tracing it through the current law, is contained in Appendix A. The bases for the changes reflected in P. L. 95-602 are, as determined by the National Task Force on the Definition of Developmental Disabilities who conducted the independent study mandated in P.L. 94-103 :

- The need to focus scarce resources on that segment of the disabled population most in need of services;
- Developmentally disabled persons will require 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 target population of developmentally disabled individuals is substantially and chronically disabled;
- Service agencies' traditional approaches are not oriented toward meeting the unique needs of this population so that the following combination is required:

Comprehensive planning;

Improved leverage on existing monies;

Increased access to existing services;

Interdisciplinary services in a variety of service delivery modes;

Advocacy to ensure the above; and

Coordination of services at the delivery point to ensure that needs are met.

- Concern that individuals with conditions or disabilities other than the four listed in P. L. 94-103 might share the limitations and service needs of the four named conditions and because of the definition be denied services.

The purpose of the functional definition was to emphasize the complexity/pervasiveness, and substantialty of the disabling conditions to be addressed by the Developmental Disabilities Program by focusing on the individual's functional limitations and the resulting need for comprehensive services. Thus, the definition of developmental disabilities changed from one which was categorically based to one which is functionally based.

## Historical Evolution of the Definition of Developmental Disabilities

The basic legislative action to which the 1978 Act is traced is the "Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963" (Public Law 88-164). Public Law 88-164 and its amendments are discussed below.

1. Public Law 88-164: The law provided Federal funds to: (1) build research centers for preventing and combating mental retardation; (2) construct public or non-profit clinical facilities (university Affiliated Facilities) which would provide inpatient/outpatient services, demonstrate how specialized services could be provided, and provide clinical training for physicians and others working with the mentally retarded; and (3) encourage States to build community facilities for the mentally retarded.

This was the first Federal categorical program for individuals with mental retardation, the only disability group specified in the legislation.

2. Public Law 90-170: The 1967 Amendments split the mental retardation and mental health components of the program and maintained the focus on persons with mental retardation.

3. Public Law 91-517: The 1970 amendments completely revamped the program in at least three ways. First, the target beneficiary group was broadened from persons with mental retardation to persons with "developmental disabilities." This was not merely a change or addition in label, presumably, since the term itself was new, but also a change in approach – an emphasis on similar service needs rather than clinical categories. The target population included, in addition to mental retardation, disabilities of cerebral palsy, epilepsy, and other neurological conditions closely related to mental retardation\* The term "developmental disability" was adopted to describe this new target group.

Second, it became a Federal/State partnership program involving extensive roles in decision-making at both the State and Federal levels.

And third, the purposes of the program became much more diversified. Rather than focusing exclusively on program assistance, the purposes were stated to include objectives like comprehensive State planning, models for innovative programming, demonstration and training grants – In short, capacity-building rather than the support of direct services, per se.

Mental retardation is, by definition, a disabling condition which begins early in life. It is a developmental disorder, interfering with normal development. There are, of course, a variety of other handicapping conditions experienced by children which interfere to some extent, either directly with their development or indirectly with their schooling and social experience as children. Not all of these handicapping conditions persist as substantial handicaps into adult life, however.

It had become apparent that the conditions which contribute to the disability of an adult and which are of early onset are quite different from those conditions experienced by adults who become disabled after they are adults. This fact was confirmed by the Social Security Administration in examining the disabilities of adults who are entitled to Social Security benefits because of the chronicity of their disability since childhood. The conditions identified by the Social Security Administration which contribute most to adult disabilities originating in childhood are mental retardation, cerebral palsy, epilepsy, autism, and various childhood psychoses.

When the term "developmental disabilities\*\* was first introduced into Federal law, the mentally retarded were perceived as a major portion of a larger population whose substantial, continuing handicaps originating early in life necessitated a coordinated and ongoing programmatic approach without limitation by age, discipline, or service system. The individuals, whether as children or adults, would need special attention from health agencies, education agencies, agencies concerned with employment, dependency, housing, and social services. Thus, persons in this target group had a uniquely urgent need for interagency planning, coordination, and continuity. They also had a need for certain types of direct services which were very frequently unavailable in the communities in which they lived or even in the segregated residential institutions to which they were often sent.

4. Public Law 94-103: These Amendments expanded the target population to include autism as a fourth categorical condition and then added two other conditions:

The term "developmental disability\*\* means a disability of a person which—

"(A)(1) is attributable to mental retardation, cerebral palsy, epilepsy, or autism;

"(ii) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons; or

"(iii) is attributable to dyslexia resulting from a disability described in clause (i) or (ii) of this subparagraph;

"(B) originates before such person attains age eighteen;

"(C) has continued or can be expected to continue indefinitely; and

"(D) constitutes a substantial handicap to such person's ability to function normally in society."

A few observations are offered about the second cluster. The condition had to be related to mental retardation and not to any of the other named conditions. The nature of the relationship to mental retardation need only encompass one of three possible links: similar impairment of general intellectual functioning, similar impairment of adaptive behavior, or need for similar treatment and services. One change from the 1970 Development Disabilities Act was that the other condition need not be neurological.

The third cluster of conditions which met the etiology restriction of the definition was dyslexia, but only when dyslexia resulted from mental retardation, cerebral palsy, epilepsy, autism, or conditions in the second cluster. Thus, the dyslexia category added little beyond emphasis to the overall scope of coverage.

This definition of developmental disabilities was intended to be inclusive of all individuals disabled by one or more of the four categories of disabilities who met certain criteria, e.g., who were disabled early in life and who were expected to remain disabled throughout their lives, and who were substantially handicapped. Unfortunately, perhaps because only four conditions were explicitly mentioned (along with dyslexia if it accompanied one of the other four conditions), the definition was frequently misinterpreted in ways which were simultaneously too inclusive and too exclusive. On the one hand, the definition had been interpreted to include all individuals who fell into the four categories mentioned in the definition (mental retardation, cerebral palsy, epilepsy, and autism) regardless of degree of disability. On the other hand, the definition had been interpreted as excluding all not fitting into these four conditions or categories. The specifics of this misinterpretation will be discussed later in this section.

In an effort to obtain an objective basis for reconciling the claims and counterclaims of different disciplinary and consumer interests concerning the definition of developmental disabilities, these Amendments called for a report to be made to Congress on the definition of developmental disability. Section 301(b) of the Act stipulated that:

"The Secretary shall contract for the conduct of an independent objective study to determine (A) if the basis of the definition of the developmental disabilities (as amended by Title I of this Act) with respect to which assistance is authorized under such title is appropriate and, to the extent that it is not, to determine an appropriate basis for determining which disabilities should be included and which disabilities should be excluded from the definition, and (B) the nature and adequacy of the services provided under other Federal programs for persons with disabilities not included in such definition."

To this end, the Developmental Disabilities Office of the Department of Health, Education, and Welfare awarded a contract in September 1976 to Abt Associates, Inc. of Cambridge, Massachusetts. To carry out the extremely complex job of arriving at the "appropriate basis" for a definition of developmental disabilities, a National Task Force on the Definition of Developmental Disabilities was selected to ensure as broad a representation of perspectives, experiences, knowledge, and geographic locations as possible. The Task Force had the responsibility and authority to make the final recommendations submitted to the Congress and to the Secretary of Health, Education, and Welfare.

The Task Force proposed a noncategorical definition which placed emphasis upon the criteria of chronicity, early onset, multiple impairment, and need for ongoing services involving a multiplicity of service providers.

In order to emphasize the complexity, pervasiveness, and "substantiality" of the disabling conditions to be addressed by the Developmental Disabilities Program, the Task Force proposed that persons who were to be considered as part of the primary target group of the program would be impaired in at least three major life activities among seven enumerated. The result of the Task Force's efforts is the definition of developmental disabilities contained in Public Law 95-602 and quoted later in this section.

Programmatic changes, other than the definition, which were enacted with Public Law 94-103 included two new programs to benefit developmentally disabled persons: a system to protect and advocate for the rights of persons with developmental disabilities and a special project authority for at least twenty-five percent (25%) of each year's appropriation for projects of national significance.

5. Public Law 95-602: The Title V Amendments included:

- A redefinition of the developmentally disabled population to focus on the substantially handicapped based on a definition which emphasized substantiality and chronicity established by functional limitations;
- A shift of emphasis from comprehensive planning to priority service areas;
- A clarification in the role and an increase in consumer membership of the State Planning Councils;
- A clearer statutory delineation of the mission of university affiliated facilities; and
- Increased authorization levels for State protection and advocacy systems.

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(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(B) is manifested before the person attains the 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: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic 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 life-long or extended duration and are individually planned and coordinated."

The definition of developmental disability contained in Public Law 95-602, sometimes referred to as the new definition of developmental disability, is based solely on an individual's functional limitations, rather than the diagnosis or nature of his or her disabling condition. The definition of developmental disability contained in Public Law 94-103, the one used by the Developmental Disabilities Program until November 1978, generally applied to persons with one of the four handicapping conditions listed: mental retardation, cerebral palsy, epilepsy or autism.

The concept of substantiality of the handicap which results from a developmental disability can be conveyed in a number of ways. The previous definition referred to "a disability of a person which...constitutes a substantial handicap to such person's ability to function normally in society." The recommendations from the National Task Force and the Public Law 95-602 definition further explicated this concept by specifying some of the main aspects of functioning in society. The Public Law 95-602 definition conveys the concept of substantiality by indicating that an individual must be limited in more than one area of life functioning; and that the limitation in each of these areas must be extensive. Both the previous definition and the new definition make it clear that the impact of the developmental disability on the person is pervasive in that it has direct ramifications for the person's ability to function in society, not just a substantial limitation in one aspect of life.