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A Study of the Definition of
Developmental Disabilities
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BACKGROUND PAPER

The Demographics of Developmental Disabilities

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THE DEMOGRAPHICS OF DEVELOPMENTAL DISABILITIES

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The purpose of this paper is to present information about the number of people in the United States population who might be considered as developmentally disabled and to provide a basis for discussion within the Task Force. This paper has two parts: summaries of the best available information on prevalence of developmental disabilities; and brief discussions of some of the reasons why this information is not very reliable.

One main focus of this paper is on the relationship between definitional and demographic issues: without clear definitions there can be no clear counts. Also discussed are the difference between the incidence and prevalence of a disability, overlaps and duplicative counts, problems of restricted or small samples, and difficulties of projecting overall rates from incomplete or age-specific information. The relatively poor quality of the information available on the numbers of persons with developmental disabilities creates problems when attempting to understand the scope of the impact of the Developmental Disabilities Program.

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

A short bibliography of selected studies of disability rates can be found at the end of the paper.

1.0 ESTIMATES OF THE PREVALENCE OF DEVELOPMENTAL DISABILITIES AS CURRENTLY DEFINED

It is not certain how many people in the United states have developmental disabilities as currently defined by the Disabled Assistance and Bill of Rights Act (P.L. 94-103) (referred to henceforth as the 1975 DD Act). Gross estimates can vary by several hundred percent through

differences in definitions, reporting procedures, samples and considerations of severity levels as will be shown later in this paper.

Using different equations, particularly involving severity levels and functional disabilities, one can produce estimates of the overall rate of disabilities that vary from 1/2% - 1% (one million to two million people who have severe handicaps) to 25% or more (fifty million people including those with relatively mild speech, reading, emotional, or learning problems) of the U.S. population. The total target population for the 1975 DP Act is somewhere between these two extremes.

The definition, in the 1975 DP Act is as follows:

"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 conditions 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

(P) constitutes a substantial handicap to such person's ability to function normally in society."1

It is estimated that roughly three to six percent of the U.S. population or between approximately 6 and 12.6 million people have one or more developmental disabilities as currently defined.

As can be seen, the current definition includes a list of four specific disabilities (mental retardation, epilepsy, cerebral palsy, and autism) as well as some other descriptors of the disability (that it be substantial and have had its onset prior to the age of 18). Since currently there are few estimates of the total developmentally disabled population taken as a unified group, each of the four categories of disability is discussed separately. Each of these disabilities is described and recent estimates of prevalence and severity are presented. Available information on the prevalence rates for subgroups of the

United States population defined by sex and age is also presented. No judgment about the inclusion or exclusion of specific other disabilities is implied by limiting the discussion to these four categories.

One can see in each of the following sections how differences in definitions and measurement can lead to large variations in the estimates of the total developmental disabilities target populations. This variation can be thought of as a measure of how poorly we understand the prevalence rate for that disability. As a result, many of the prevalence estimates given in this paper derive from reasonable guesses which combine the results of several prevalence studies. The 6% prevalence rate can be seen as more of a reasonable though arbitrary percentage used for service planning and budgeting than a methodologically sound determination of the true prevalence rate.

In reading the literature on developmental disabilities one often sees both incidence and prevalence estimates. One should understand the difference between these two terms to avoid confusion between studies. Dorland's Illustrated Medical Dictionary defines these two terms as follows:

- prevalence - the number of cases of a disease in existence at a certain time in a designated area (Page 1217).
- incidence - an expression of the rate at which a certain event occurs, as the number of new cases of a specific disease occurring during a certain period (Page 730).

From these definitions one can see that prevalence is usually expressed as a whole number describing a state or condition whereas incidence is expressed as the rate at which an event occurs (a function) during a certain period. This difference is reflected in the Latin derivation of the word incidence (in + cadere: to occur, to happen).

This difference between a static description of a condition (prevalence) and an active description of occurrence of a condition (incidence) is further discussed by Bogue (1969: 119).

"A compositional analysis is a static comparative study of composition at a given point in time. A different set of methods is required on the measurement of populations dynamics or the occurrence of population events over time. Whereas compositional analysis asks the question, "How prevalent is this trait?" Dynamics analysis asks, "what is the incidence (rate of first occurrence) of this event?"

This paper will use prevalence figures rather than incidence rates to answer the question, "How many people in the United States population are considered developmentally disabled?" The rate of new occurrences of a disability is an interesting question which is beyond the scope of the paper. These prevalence whole numbers will be translated into percentage figures to produce prevalence rates. This is often done in demographic studies to control for possible differences in population bases. It should be noted that these rates are estimates of a static condition, the number of individuals at present in a particular area who have a developmental disability.

These prevalence rates should not be confused with incidence rates. If one knows the population base one can easily translate the prevalence rate for a developmental disability back, into an estimate of the total number of individuals who have the disability. This cannot be done with incidence, or more conditional, dynamic measures. The descriptions of each disability as currently defined are taken from a 1976 pamphlet published by the Developmental Disabilities Office, What are Developmental Disabilities? (HEW Publication No. (OHD) 76-29002). Prevalence figures are taken from a variety of sources as noted in the text.

1.1 Mental Retardation

1.1.1 Description of Mental Retardation

"Persons who are mentally retarded are limited in their ability to learn and are generally socially immature. Some are further handicapped by emotional and physical disabilities. There are significant sub-average intellectual functioning and defects in adaptive behavior. Mental retardation is a condition, not a disease, manifested during the developmental period."

1.1.2 Causes of Mental Retardation

"About 80 percent of retardation has socio-environmental causes, not biomedical causes. Among the latter causes of mental retardation are; genetic and chemical abnormalities, poor maternal nutrition and malnutrition in infancy, damage to the central nervous system, toxic agents (such as lead), viruses, or brain injury early in life. Premature infants are especially vulnerable, as are children born to women over 35."

1.1.3 Classification and Effects of Mental Retardation

Retardation has been divided into four levels: mild, moderate, severe and profound. Mildly retarded persons differ from non-retarded people in

rate and degree of intellectual functioning and are usually not identified as retarded until they enter school. As adults they are often absorbed into the competitive labor market. Moderately retarded persons are usually identified before they reach school age. They, too, may become productive members of the community through appropriate education. Severely and profoundly retarded persons can learn to care for their basic needs and can adapt to normal patterns of life, (See Table I).

Mentally retarded persons are found among every race, religion and nationality, as well as every educational, social, and economic background. However, there is a greater likelihood of socioeconomically caused mental retardation in lower socioeconomic classes.

1.1.4 Prevalence of Mental Retardation

The most often quoted prevalence for the United States is 3% or about 6.3 million individuals out of a population of 210 million (National Association for Retarded Citizens). This estimate is predicated mainly on the distribution of IQ scores in the U.S. population and has changed dramatically over the years as the definition of mental retardation has changed. The 1973 Manual on Terminology and Classification in Mental Retardation (Grossman et al., 1973) defines mental retardation as follows: "Mental Retardation refers to significantly subaverage general intellectual functioning existing concurrently with defects in adaptive behavior, and manifested during the developmental period." One can see from this definition that to classify an individual properly one needs both a test of intellectual functioning and a measure of adaptive behavior. The handbook lists ten different types of IQ tests such as the Stanford-Binet, Cattell, and Wechsler Scales and lists five types of adaptive behavior scales including the American Association of Mental Deficiency Adaptive Behavior Scale and the Vineland Social Maturity Scale. Different tests and scales are more appropriate for certain age levels and for certain types of mental retardation.

The 1973 edition of the Manual lists the breakpoint for sub-average intellectual functioning as two standard deviations below the average score. Using the most common IQ tests which have a mean score of 100 points and a standard deviation of 15 or 16 points, this places the point at a score of 68 or 70. The criterion of two standard deviations represents a change from previous ideas about mental retardation in that it reflects a more positive attitude toward the social capabilities of persons with low intelligence. Presuming a normal distribution of intelligence in the U.S. population one can

Table I
INFORMATION ON LEVELS OF RETARDATION

DEGREES OF MENTAL RETARDATION	PRE-SCHOOL AGE (0-5) Maturation and Development	SCHOOL AGE (6-20) Training and Education	ADULT (21 and over) Social and Vocational Adequacy
MILD (IQ 60-75)	Can develop social and communication skills; minimal retardation in sensorimotor areas often not distinguished from normal until later age.	Can learn academic skills up to approximately sixth grade level by late teens. Can be guided toward social conformity.	Can usually achieve social and vocational skills adequate to minimum self-support but may need guidance when under unusual social or economic stress.
MODERATE (IQ 40-60)	Can talk or learn to communicate; poor social awareness; fair motor development; profits from training in self-help; can be managed with moderate supervision.	Can profit from training in social and occupational skills; unlikely to progress beyond 2nd grade level in academic subjects; may learn to travel alone in familiar places.	May achieve self-maintenance in unskilled or semi-skilled work under sheltered conditions; needs supervision and guidance when under mild social or economic stress.
SEVERE (IQ 20-40)	Poor motor development; speech is minimal; generally unable to profit from training in self-help; little or no communication skills.	Can talk or learn to communicate; can be trained in elemental health habits; profits from systematic habit training.	May contribute partially to self-maintenance under complete supervision; can develop self-protection skills to a minimal useful level in controlled environment.
PROFOUND (IQ under 20)	Gross retardation; minimal capacity for functioning in sensorimotor areas; needs nursing care.	Some motor development present; may respond to minimal or limited training in self-help.	Some motor and speech development; may achieve very limited self-care; needs nursing care.

estimate that 2.275% of the population have a score of less than 70 on an IQ test with a standard deviation of 15 points. This translates into 4.78 million individuals.

The 1959 edition of the Manual gives one standard deviation IQ score of about 85 as the cutoff point for subaverage intellectual functioning. If this definition is applied to a normal curve distribution table the result is an estimate of nearly 16% of the population or about 33.3 million individuals with subaverage intellectual functioning. Taking only these two numbers it can be stated that the number of mentally retarded individuals declined by nearly 30 million in the period between 1959 and 1973- Of course, this decline is based solely on a statistical adjustment of the data, deriving directly from a change in the definition used.

Nicholas Hobbs in the Futures of Children notes these changes in the definition and cites a 1974 study by Haywood which reviews sampling surveys of the empirical prevalence of IQs below 70 and arrives at a figure of 6,791,800 in a population of 208,000,000 (roughly 3.3 percent). The difference between this figure and a figure of 2.275 percent which is predicated on a normal distribution of IQ scores lies in the fact that IQ scores are not normally distributed in the U.S. population. The empirically determined distribution of IQ scores can be viewed as a roughly normal bell-shaped curve with a pronounced secondary bump at the lower end resulting from genetic and environmental causes which were described above in section 1.1.2

Hobbs describes the tests of general intellectual functioning and measures of adaptive behavior and notes that a person must score low on both dimensions to be properly classified as being mentally retarded although diagnosticians often use only the mental test score. The figure reported by Haywood must be discounted to exclude those individuals who exhibit generally adaptive behavior. Hobbs finds the current tests of adaptive behavior unsatisfactory. He also criticizes the use of IQ tests stating that it places too great an emphasis on academic achievement rather than broad social adjustment; it discriminates against certain social-cultural minorities, it emphasizes the negative rather than the positive aspects of a person's ability to function; it pigeon-holes individuals into narrow fixed IQ groups (mild, moderate, severe, and profoundly retarded) with fixed expectations; it often denies retarded

children access to regular classrooms; it suggests that the individual rather than the environment is the problem; and it does not lead to the specification of educational goals and time limits for achieving these goals.

Given the problems of defining and measuring mental retardation the 3% prevalence figure can only be a gross estimate. Haywood estimates that an additional 25-44 million individuals fall into the 70-74 IQ range; this represents an additional 12 percent of the population who avoid being placed below the 70 point cutoff by correctly answering one or two additional items on an IQ test. Thus, the criterion for "profoundly retarded" is of great importance to the DD Program.

1.2 Epilepsy

1.2.1 Description of Epilepsy

"The term epilepsy (or 'the epilepsies') applies to a number of disorders of the nervous system, centered in the brain. While the term comes from the Greek word meaning 'to be seized,'¹ epilepsy is a symptom of a disorder of the central nervous system. It is characterized by sudden seizures—muscle convulsions and a partial or total loss of consciousness—due to abnormal electrical discharges of brain cells."

1.2.2 Causes of Epilepsy

"There is no precise answer as to why brain cells discharge abnormally. Epilepsy can result from defects in the brain; brain injury before, during or after birth; head wounds; chemical imbalance; poor nutrition; childhood fevers; some infectious diseases; brain tumors; and some poisons."

1.2.3 Effects of Epilepsy

"Seizures of one kind or another are the primary characteristic of all forms of epilepsy. The three major types are: Grand mal seizures last a minute or more and can occur one or more times daily, weekly, monthly, or annually. The victim loses consciousness and has convulsions. Afterward he is confused or drowsy and might sleep for several hours. Petit mal, most common in children, lasts from 5 to 20 seconds and can occur many times an hour. It can be accompanied by staring or twitching of the eyelids and momentary lapse of consciousness. The patient is seldom aware he has had a seizure. Psychomotor seizures can occur at

any age. They have the most complex pattern of behavior, including activities such as chewing and lip-smacking, staring and confusion, abdominal pains and headaches, changes in color perception, spots before eyes, ringing ears, dizziness, fear, anger, and, following the seizure, sleep. The seizure might last from a minute to several hours. After the attack, the person is unable to remember what happened.

It is important to know that epilepsy usually does not affect a person's intelligence."

1.2.4 Prevalence of Epilepsy

The DDO pamphlet states that there are about 4 million individuals in the United States with some form of epilepsy (and states that this is the incidence of the disease; this may be an inappropriate use of the word incidence.) The 4 million figure arises from an estimate of 2 percent for the prevalence rate by the Professional Advisory Board (PAB) of the Epilepsy Foundation of America.

The Foundation produced Basic Statistics on the Epilepsies in 1975. This book lists nine studies done in the United States and 17 studies performed outside of the U. S. which give estimates of the prevalence rate for epilepsy. Three of the U. S. estimates are taken from Kurtzke et al., (1971) and the remaining six from an overview of the literature.

The prevalence rate for the U. S. studies ranges from a low of 2 per thousand to a high of 18.6 per thousand. Of the 17 studies done elsewhere the range is 1.5 per thousand to 22.7 per thousand. Basic Statistics states, "In an effort to draw order from the diverse research findings on prevalence, the Professional Advisory Board (PAB) of the Epilepsy Foundation of America weighed all the evidence and concluded that 2% of the present population of the United States, or a minimum of 4 million persons, suffer from some form of epilepsy. This estimate includes the commonly recognized forms of epilepsy plus the numerous other, often unidentified epileptiform manifestations."

There are a number of problems with this estimate. First, only one of the nine studies has a national sample and that one produced one of the lowest estimates; it is not clear that one can general-

ize from the other eight studies. Secondly, these nine studies undoubtedly used different definitions of epilepsy; it is therefore difficult to arrive at one estimate. Thirdly, most of the studies used small samples which lead to large sampling errors. Finally the official estimate of 2 percent is higher than any of the calculated U. S. estimates and is posited on some unknown rate of underreporting and the inclusion of mild manifestations of epilepsy. The estimate is put forward as a lower bound of the true prevalence rate ("at least 2% of the present population," "a minimum of 4 million persons"). A central tendency of the estimate is not given.

The PAB has not attempted to draw conclusions on age and sex prevalence although the book states that the most recent work favors male prevalence by 1.2:1 (Kurtzke et al., 1971).

Given a total U. S. population of 210 million, the 2 percent prevalence rate translates to 4.2 million individuals with epilepsy. If one takes the 1.2:1 sex ratio as being accurate there are approximately 2.3 million males and 1.9 million females with some form of epilepsy.

1.3 Cerebral Palsy

1.3.1 Description of Cerebral Palsy

" 'Cerebral' refers to brain, 'palsy' to lack of control over muscles. It is not a single disorder but a group of dysfunctions having a variety of symptoms. All are brain-centered and all affect muscular control as well as sensory functions. There are three main types: The spastic person moves stiffly and with difficulty. The athetoid has involuntary and uncontrolled movements. The ataxic has a disturbed sense of balance and depth perception."

1.3.2 Causes of Cerebral Palsy

"Poor maternal nutrition and health before and during pregnancy can affect the brain development of the baby. Any damage to brain tissue can cause cerebral palsy, whether the result of defective development, disease or an injury occurring any time in life. A chief cause

is insufficient amount of oxygen reaching the fetal or newborn brain. Other causes might be premature birth, Rh or A-B-0 blood type incompatibility between parents, or infection of the mother with German measles or other virus diseases in early pregnancy, and viruses attacking the newborn's central nervous system."

1.3.3 Effects of Cerebral Palsy

"There is difficulty in muscular control and coordination. Sometimes cerebral palsy shows itself only by slight awkwardness of gait or hand movement. More often there are other complications, such as seizures; the inability to see, hear, speak or learn as other people do; or psychological and behavioral problems. Cerebral palsy is not always associated with mental retardation,, Any combination of physical and mental states is possible,,"

1.3.4 Prevalence of Cerebral Palsy

The DDO pamphlet states that there are 750 thousand individuals in the United States with cerebral palsy. This translates into a rate of about .36 percent. Cerebral palsy is perhaps the most easily diagnosed developmental disability and yet there is still some disagreement about its true prevalence rate. E. Stephen and G. Hawks in Mental Deficiencies: The Changing Outlook (Ann M. Clarke and A. D. B. Clarke, editors, 1974) report a prevalence rate between .34 percent and .48 percent from a 1938 New Jersey survey of children of school age, and a range of .1 percent to .2 percent from studies performed in Denmark and Eastern Scotland.

Cruickshank (1975) gives other incidence rates from a survey of the research. A 1949 survey of cerebral palsy in Schenectady County, New York, supplies an incidence rate of 5.9 births per thousand and a prevalence rate of .152 percent. A Connecticut study completed in 1950 gives an incidence rate of ,23 percent for individuals under twenty-one years of age. Fairly arbitrary adjustments were made to the two studies to account for misdiagnosis and underreporting. This produces a "true" prevalence rate in the Connecticut study of between .265 and .31 percent.

Stephen and Hawks quote Rutter, Graham, and Yule (1970) as attributing differences in reported rates to differences of definition and methodology; in clinical and administrative studies, to inadequacies in case-finding methods; and to chance variation. Cruickshank notes that until the 1940s cerebral palsy was ignored as a psychological or a social problem and also mentions the problems of misdiagnosis and underreporting.

Cruickshank notes that it is difficult given wide variation in estimates of prevalence to produce reasonable estimates of the relationship of sex and age to the condition. The state of Connecticut study reports a rate of .148 for individuals under five years of age, a rate of .275 percent between five and nine years, a rate of .291 percent between ten and fourteen years, and .199 percent between fifteen and nineteen years. A 1951 New Jersey study identified 662 boys and 493 girls for a male preference of 58:42. If one adds ataxia, tremor, mixed cases, and rare cases to the above, one arrives at a male percentage of 57 percent. A report on sex distribution of 575 cerebral palsied children from England and Wales by Dunsdon gives a male preference by 51 percent to 49 percent.

1.4 Autism

1.4.1 Description of Autism

"Autism refers to severe disorders of communication and behavior which begin in early childhood. The word is from the Greek autos, which means 'self,' reflecting the stage children go through when they are withdrawn into themselves and do not show interest in others. Autistic children include those afflicted with infantile autism (Kanner's syndrom), childhood psychosis, childhood schizophrenia or other conditions characterized by severe defects in language (such as profound aphasia), behavior, and by the inability to relate to others."

1.4.2 Causes of Autism

"The causes of primary childhood autism are not known. Autism is found throughout the world, in every social class, with a uniform clinical picture. Many autistic children have abnormal or borderline brain wave patterns, and a small proportion develop seizures. Evidence suggests that autism is like some of the inborn disorders of metabolism."

1.4.3 Effects of Autism

"There is a lack of contact with reality. The universal symptom is the child's inability to relate to other persons in a normal way. This becomes more apparent as the child grows older. 'Autistic aloneness' is characterized by staring at space, non-response to sounds, and a total lack of interest in other persons. Other common characteristics include failure to use speech effectively, rocking or other repetitive behavior, tantrums, difficulties in toilet training, problems in feeding, and absence of social awareness. Autistic children can show normal skill in some isolated areas of functioning, such as mathematics and music performance."

1.4.4 Prevalence of Autism

The DDO pamphlet states that there are about 100 thousand individuals in the United States with this disability. This works out to a prevalence rate of almost .05 percent. This is by far the smallest developmental disability in size. A second source gives the number as 80 thousand or a prevalence rate of almost .04 percent. Most of the research on autism deals with the causes, behavioral manifestations, and treatment of autism in clinical settings, usually involving at most a few hundred children. Since the numbers involved are very small compared to the numbers for the other developmental disabilities either prevalence rate is probably more exact in absolute terms and possibly more exact in relative terms than the rates for mental retardation and epilepsy. This paper will use the .05 percent rate and the 100 thousand figure.

Autism is described almost totally as a childhood disability. Most researchers use the term as connoting childhood autism although many children with autism reach adulthood with the same symptoms. These adults are likely to be labelled mentally retarded or mentally ill. This procedure by definition insures that the prevalence rate for autism is highest among children. There is also an historical problem here. Most of the work on autism has occurred in the last twenty-five years so that the oldest cohort of individuals who were correctly labelled as autistic in childhood is now only 30 or 40 years old.

1.5 Overlaps among Disabilities

If the best estimates of the range of prevalence estimates for each of the four disabilities are added together a total of 5.41 percent of the population would be considered developmentally disabled. However, assuming that each prevalence estimate is accurate this summed figure is an overestimate of the total prevalence because of the fact that certain individuals have more than one developmental disability. Overlaps in the occurrence of developmental disabilities mean that a person with two (or more) developmental disabilities (e.g., mental retardation and cerebral palsy) is counted twice (or more times).

The Epilepsy Foundation of America estimates that roughly 5.9 percent of individuals with epilepsy also have some form of mental retardation. The 1951 New Jersey study of cerebral palsy is quoted (Clark and Clark, Mental Deficiency) as estimating that 29.2 percent of those individuals who have cerebral palsy also have epileptic seizures. This figure is approximately in the middle of the overlap estimates from four other studies. Finally, the Institute for the Study of Mental Retardation in 1974 estimated that approximately 75 percent of all children with cerebral palsy are to some degree retarded in their intellectual development.

Using the "best estimates" comprising the 5.41% and the estimates of overlaps we can estimate the total percentage and number of individuals with two developmental disabilities:

(.27%)	(.105%)	(.118%)	(.158%)	
(.36% X 75%)	(.36% X 29.2%)	+ (2% X 5.9%)	(2 X .079%)	.335%
Best estimate of percentage of total population with cerebral palsy X percentage of persons with cerebral palsy who are also mentally retarded	Best estimate of percentage of total population with cerebral palsy X percentage of persons who also have epilepsy	Best estimate of percentage of total population with epilepsy X percentage of persons with epilepsy who are also mentally retarded	Twice the overlap of three disabilities.*	Best estimate of overlap among cerebral palsy, epilepsy and mental retardation
				= 704 thousand

That is twice the product of the following rates: .36% X 75% X 29.2% X 5.9% = .079%

In addition, a small percentage will have more than two developmental disabilities. This would leave us, then, with an estimate of about five percent of the total population or approximately 10.5 million individuals.

1.6 A Summary Table of Prevalence Rates

A summary of the various prevalence rates for each of the four developmental disabilities discussed in the preceding four sections is presented in Table II. Also included in this summary are estimates for developmental disabilities as a whole, developed by adding the prevalence rates for the four specific disabilities mandated in the 1975 DP Act.

TABLE II
 U.S. PREVALENCE RATES OF DEVELOPMENTAL DISABILITIES
 (Based on U.S. Population of 210 Million)

Category of Developmental Disability	Range of Estimates	Most Common or "best" Estimate	Specific Estimates and Sources
Mental Retardation	2.275% to 3.3% 4.78 million to 6.93 million	3% or 6.3 million	3%(Prevalence most quoted by NARC) 6.3 million 2.275% (Grossman, 1973) 4.78 million 3.3% (Hayword, 1974) 6.93 million
Epilepsy	.2% to 2% 420 thousand to 4.2 million	2% or 4.2 million	2% (Professional Advisory Board of the Epilepsy Foundation of America) 4.2 million .2% to 1.86 (Epilepsy Foundation of America, 1975) 420 thousands to 3.9 million
Cerebral Palsy	.265% to .48% 556 thousand to 1.008 million	.36% 750 thousand	.36% (DDO Pamphlet) 756 thousand .34% to .48% (Clark, 1974) 714 thousand to 1.008 million .265% to .31% (Cruick- shank, 1976) 556 thousand to 651 thousand
Autism	.04% to .05% 84 thousand to 105 thousand	.05% 100 thousand	(DDO Pamphlet)
Total Developmental Disabilities based on estimates cited above ignoring overlaps	2.78% to 5.83% 5.838 million to 12.243	5.41% or 11.65 million	
Total DD based on estimates cited above and discounting overlaps.		5.025% or 10.55 million	

2.0 SOME REASONS FOR INACCURACY IN COUNTS

There are many reasons why the figures cited above are often only estimates or are given in the form of ranges. Because of the importance of arriving at clear estimates of how many people would be included under any particular definition of developmental disabilities which might be generated, some of these reasons are discussed briefly in this section.

2.1 The Diagnosis of a Developmental Disability

One problem in determining how many people are developmentally disabled derives from difficulty in diagnosing the existence of specific disability in an individual. Many disabilities are difficult to diagnose, especially in young children. For example, persons are at times misdiagnosed as having a particular developmental disability. Thus, differences among studies in prevalence estimates may reflect differences among researchers in their ability to identify a developmental disability at the clinical level. For example, a recent study performed at McGill University Medical School demonstrates that the problem of misdiagnosis can be severe. One third of the deaf children in the sample were misdiagnosed usually as mentally retarded, autistic, brain damaged, or schizophrenic. Deafness often leads to delayed speech or language development which is one of the possible symptoms of mental retardation although there is no real reduction in general intellectual functioning. One can only guess how many people in the past have been included in a categorical developmental disability group incorrectly. Conversely, it has been noted above that many individuals with a developmental disability such as epilepsy often fail to be diagnosed correctly. One wonders if the false positive diagnoses cancel out the false negatives.

A related problem is the difficulty of transforming clause (ii) of the definition into an operational statement. Other disabilities not currently included in the definition can produce a need for services similar to those required by persons who are mentally retarded. Congenital deafness is not now considered to be a developmental disability and yet a deaf person may need a variety of special services which are provided to eligible people under the developmental disabilities program. It is not clear how closely a disability must mimic mental retardation in terms of service or treatment needs to qualify under this clause. Thus, estimates of the non-categorical disabilities are less reliable and more idiosyncratic in terms of definitions across studies.

2.2 Differences in Definitions

Studies may use different definitions even for the seemingly more reliably diagnosed categorical disabilities. This can lead to great variation in prevalence studies. As an example the Epilepsy Foundation of America summarized prevalence studies of epilepsy and other convulsive disorders. Certain researchers included febrile convulsions.* If one did not understand this addition to the more basic definition of epilepsy one would find it difficult to explain why these researchers obtained higher prevalence rates. To complicate the problem further, definitions can change not only across studies but also across time. All estimates of prevalence rates for mental retardation before 1959, as has been noted, are dated because of the change from one to two standard deviations in defining a ceiling point for mental retardation. These definition changes may be confounded with real differences in prevalence between two areas or two time points.

2.3 Differences in Age Breakdowns

Although the 1975 DDO Act specifically mentions that the disability must originate before a person attains age eighteen, many studies do not break down prevalence rates by age or divide a total group by age of onset. For example, Lennox (1960) (cited in Basic Statistics of the Epilepsies) estimates that only slightly more than three-fourths of people with epilepsy have their first seizure before the age of twenty.** Thus, a study may produce a prevalence estimate that is roughly three-fourths as large as a second estimate merely because it excluded individuals who experience seizures only in adulthood. This is further complicated by the fact that the service and treatment needs of a person with epilepsy are often unrelated to the age at onset. These and other definitional problems make it difficult to tailor published prevalence rates to the current definition of developmental disabilities.

2-4 Severity Levels

Another set of problems in counting the number of developmentally disabled persons is related to the severity of a disability. Most diagnosticians can agree on the category of a disability particularly for those people who have a severe handicap (uncontrolled epileptic seizures, profound mental retardation, total spasticity). However, for those individuals

*Convulsions resulting from a very high fever.

**Note that even here the age cutoff differs from the one used in the law.

with less than severe forms of the disability one finds differences of opinion. It was reported in section 1.4 that approximately 3 percent of the U.S. population has some form of mental retardation. Of these people only about one tenth have a severe or profound form. Lindberg, in a 1976 survey of developmental disabilities in West Virginia, chose to concentrate on the moderately, severely, or profoundly retarded individual and found a prevalence rate of .81 percent. The definition states that a disability must constitute "a substantial handicap to such person's ability to function normally in society." It is difficult to judge where to draw the line (e.g., should "moderately" retarded persons be included?). Criteria for substantial handicaps may include the inability to live outside of an institutional setting, difficulty in being trained for or holding a job, or a failure to reach a specified education grade level. Many of these criteria can clearly vary as much with attitudes, policies and training techniques as with characteristics inherent in the individual.

As a second example, many people with epilepsy may not be able to function normally in society without medication to inhibit seizures. However, with control over their seizures they are able to function extremely well. Should inclusion be based upon the treated or untreated condition? It would be difficult to justify including these people in the developmental disabilities population before treatment but excluding them because the treatment is successful. It would also potentially introduce a dangerous incentive to overcount people as "untreatable" or "untreated" just to add numbers to a particular program.

The issue of severity or "substantiality" becomes even more complicated when one understands that it is difficult to develop a definition of severity level which is not disability specific. In the case of mental retardation a criterion of general intellectual functioning and adaptive behavior given subaverage intellectual functioning is generally used. For most individuals with epilepsy and many persons with cerebral palsy the general intellectual functioning criterion is irrelevant; these people may very well have above average IQ scores. In addition, those individuals with epilepsy whose seizures are controlled may also have no substantial handicap to functioning normally in society as required in the developmental disabilities definition.

Multiple handicapped individuals present further problems in arriving at prevalence rates based on a standard of disability severity. It shall be in Section 2.5 that there is a tendency for a person with one disability to have one or more other disabilities. Thus, a person may have a relatively mild form of epilepsy and mental retardation, a second person may have one mild form and one severe form, and so on. One can imagine agreement on placing a multiple handicapped person in the target population. But suppose one comes across an individual whose IQ score is in the borderline range and who is also totally deaf or blind from birth. The mild disability is included in the definition while the severe one is not. It may be only the interaction between the two disabilities which suggests that one can include the particular individual in the developmental disabilities target population.

In reading the demographic studies of disabilities one must understand the researchers' definitions of the severity of a disability. In this way one may be able to reconcile seemingly widely varying prevalence estimates among studies. Also, one may be able to adjust particular rate estimates in accordance with the current and future definitions of developmental disabilities.

2.5 Overlaps and Multiple Handicaps

A person with one disability such as cerebral palsy is more likely than a person who does not have the disability to have a second disability such as mental retardation. The estimate of the total target population is therefore not the sum of the estimates for the separate disabilities. In discounting the degree of overlap among disabilities one can obtain a more precise number for the target population. Also one can measure the number of individuals with multiple handicaps who often have service needs that are different from the needs of persons with only one disability. In addition to the overlaps among the developmental disabilities it is important to understand the degree of overlap between developmental disabilities such as mental retardation or epilepsy and those disabilities which are not covered by the 1975 DP Act such as blindness or deafness. This second type of overlap will not affect the estimate of the overall target population; however, it does indicate more acute service needs for certain subpopulations.

As discussed in Section 1.5, the overlap can be relatively small as in the case of autism and epilepsy or large as in the case of mental retardation and cerebral palsy. In producing an overall rate for developmental disabilities this overlap must be discounted from the sum of two or more disability rates. If this were not done one would be overestimating the number of people with

developmental disabilities. However, in stating the overall rate one should explicitly estimate the number of multiple handicapped individuals. In doing this one can plan for the service and treatment needs of the multiply handicapped; this would not be possible if one merely looked at separate rates.

2.6 Duplicate Counts

The problem of duplicate counts can arise from reasons other than the presence of multiple handicaps and can result in overestimates of prevalence rates in some studies. This can occur when a prevalence rate for an area is obtained by adding together counts from various sources. A person may appear on two or more lists because of, for example, participation in more than one program and may therefore be counted more than once if the lists are singly added. For example, a child may appear both on the records of a state service agency for the mentally retarded and also on public school records. If the researcher is not careful his estimate of the prevalence rate may be substantially higher than the actual rate. This method of gathering counts from many sources is decidedly inferior to a general survey.

2.7 Program Based Samples

On the other hand, errors can be introduced by relying only on one existing source of estimates. Thus, one finds in the literature prevalence studies on disabilities using nonrepresentative samples. For example, estimates of mentally ill people might be based solely on counts of patients in mental institutions or estimates of school age handicapped children might be based on public school counts. It is clear that samples such as these can lead to incorrect estimates of the total number of persons with a disability or the distribution of severe disability within a disability category. Some disabled people may not be included in a program and those who are included may be more or less severely disabled than the overall group. Thus, at best these studies can estimate the prevalence rates for people in hospitals, institutions, public schools or other programs. At the other extreme, in some instances an overestimation might be made by a program which feels that its funding level is dependent on identifying as many "handicapped" people as possible. Either way studies of prevalence rates using restricted samples cannot be easily generalized to the larger population.

2.8 Small Samples

A second sampling problem arises in studies using small samples. The size of sampling error is inversely proportional to the size of the square root of the sample size. If a sample is small the sampling error may even be larger than the estimated prevalence rate. In reading studies on prevalence rates one should always keep in mind this problem of sampling size.

2.9 Projections from Time Specific Data

Over the years developmental disabilities have received increasing attention from both researchers and the general public. The United States is spending more money for treatment and information dissemination than ever before. These facts should be kept in mind in attempting to generate prevalence rates for the entire U.S. population from prevalence rates for children. It is not the case that the developmental disabilities prevalence rate for adults is a simple function of the prevalence rate for children.

Doctors are much more able to identify disability problems both before and after birth than in the past. Also, advances in medicine make it more likely that infants with previously fatal disabilities survive into adulthood. In this way an extrapolation of the prevalence rate may be inappropriate. Fetal screening tests, coupled with liberalized abortion laws may lead to a smaller prevalence rate for certain profound disabilities whereas advances in life support technologies may lead to a higher prevalence rate for other severe disabilities. It is not certain how these two factors will balance out over the next few decades.

A time-invariant attitude towards prevalence rates does not take into account historical shifts both in the diagnosis of a specific disability or its actual rate in the population. For example, researchers have only recently arrived at an estimate for the prevalence rate of autism. In the past most of these children were given the label of mentally ill or mentally retarded.

The 3 percent mental retardation rate was developed in the late 1960's and has stayed reasonably constant since then. The method of determining the number of school children either served or not served at the state level is still being computed using a rate reported twenty years ago. One can think of reasons why these two rates may be increasing or decreasing over time. If the rates are changing and the cause is age specific then extrapolation and projection techniques will be incorrect.

2.10 Summary

To sum up, when reading the literature on prevalence rates one should ask the following questions:

- What is the researcher's definition of the disability?
- Do severity levels determine whether or not a person has a developmental disability?
- Is the researcher using incidence rates or prevalence rates?
- Does the researcher take into account the problem of multiple handicapped individuals?
- Is there a possibility that certain individuals are counted more than once?
- What is the nature of the researcher's sample? Can the results be generalized to a larger population?
- What is the sample size?
- What is the date of the research and does the researcher estimate an overall prevalence rate from subjects of a restricted age?

These concerns are in addition to the questions of how the researcher performs his survey and compiles his results.