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Administration on  
Developmental Disabilities  
Washington DC 20201

MEMORANDUM TO: Directors, State Administering Agencies  
Executive Directors, State Planning  
Councils  
Directors, State Protection and Advocacy  
Agencies

FROM : Jean K. Elder, Ph.D.  
Commissioner  
Administration on Developmental Disabilities

SUBJECT : Transmittal of Operational Definition of  
Developmental Disabilities

Attached for your review and application are copies of "Summary Report on the Implications of Modifying the Definition of a Developmental Disability" and "Operational Definition of Developmental Disabilities." These documents, developed under contract by Gollay and Associates, are intended to assist you in establishing criteria to determine which persons are eligible for services under the functional definition of developmental disabilities.

The Administration on Developmental Disabilities has established as a major program goal that by fiscal year 1984 all persons served under the Developmental Disabilities Program will meet the terms of the functional definition. It is anticipated that by that time sub-grants serving persons covered by the "grandfather clause" of the developmental disabilities legislation will have expired and that no sub-grants will be directed toward the needs of the population covered by the functional definition.

During the next year, we will seek verification that persons receiving services funded with the Federal developmental disabilities funds meet the functional definition of developmental disabilities. Consequently, it is important for you to inform us of any difficulties you encounter in applying the operationalized version of the functional definition. It is still considered a working draft to be revised as needed to overcome implementation problems. In addition, if you have developed any methods you deem to be effective in making determinations regarding whether persons meet the term of the functional definition, please share those techniques with us. I recognize that many States have had difficulty applying the functional definition to the client population, and are very interested in identifying and sharing best practices.

Page 2 - Directors, State Administering Agencies  
Executive Directors, State Planning Councils  
Directors, State Protection and Advocacy Agencies

At this time when priority must be placed on serving persons with the greatest needs for assistance, it is of particular importance that the functional definition be applied in determining the population to be assisted under the Federal Developmental Disabilities Program. I hope the attached documents are of assistance in making these important determinations.

Attachments

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## SUMMARY REPORT ON THE IMPLICATIONS OF MODIFYING THE DEFINITION OF A DEVELOPMENTAL DISABILITY

Principal Author: Elinor Gollay, Ph.D.

Summarizes the Results of Purchase Order ESA-80-7684  
and of Contract #HEW-105-78-5003  
June, 1981

*a non profit organization dedicated to the improvement of human services*

## TABLE OF CONTENTS

I.	Introduction.....	1
II.	Summary of Key Findings Regarding the Size and Characteristics of the Developmental Disabilities Population.....	3
III.	Operational Definition Summary.....	18
IV.	Summary of Some New Conditions that Might Lead to a Developmental Disability.....	22
V.	Field Study Summary .....	27
VI.	Conclusions and Recommendations.....	30

## ACKNOWLEDGEMENTS

The following report summarizes work initiated under Contract #HEW-105-78-5003 that Morgan Management Systems, Inc. had with the Rehabilitation Services Administration and that was completed (with the exception of the field studies) under purchase order #SA-80-7684 that Gollay and Associates, Inc. had with the Administration on Developmental Disabilities. In addition, some of the work concerning the identification of major conditions that might lead to a developmental disability was partially supported by a contract that Bron Cleveland Associates, Inc. had with the Illinois Governor's Planning Committee on Developmental Disabilities for which Gollay and Associates, Inc. was a subcontractor.

Some of the key individuals involved in the Morgan Management Systems project were Solomon Jacobson, Ph.D. and Valerie Nelkin. Carolyn Levin, Linda Roybal and Lucy Collier of Gollay and Associates, Inc. staff contributed heavily to the products. Stanley Handmaker, M.D. and Mark Merkins, M.D. provided medical consultation, primarily concerned with identifying and describing the major conditions that might lead to a developmental disability. Initial conceptual work on operationalizing the definition of a developmental disability for use with the SIE data, and on describing the SIE data was performed by Eugene Sobel, Ph.D. and Mildred Francis, Sc.D. and was completed by Chris Hoffmann. Valuable assistance throughout was provided by the Administration on Developmental Disabilities, particularly Kris Rogge, Marjorie Kirkland, John Pride, and Ann Queen.

## I. INTRODUCTION

The 1978 "Developmental Disabilities Assistance and Bill of Rights Act" (P.L. 95-602) revised the previous definition of a developmental disability from one that specified four major categories or conditions that generally lead to a developmental disability\* to a functional definition. This new definition stresses that a developmental disability is a severe, chronic disability beginning in childhood which has a pervasive impact on a person's ability to function in society and which results in the need for a variety of services over time.

The definition as 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."

\* It should be noted that the common practice was to assume that all individuals with mental retardation, cerebral palsy, epilepsy or autism were developmentally disabled, but the definition contained in P.L. 94-103 used early onset and severity as criteria to be applied to each condition.

The purpose of the current purchase order, and of the major contract that preceded it, was to explore the implications of changing the definition of developmental disability. In this summary report the following are presented briefly:

- Key findings from an analysis of the Survey of Income and Education and other data with respect to the size and characteristics of the developmentally disabled population in the United States;
- Key aspects of attempting to operationalize the definition of a developmental disability;
- Major conditions that have been identified as potentially leading to a developmental disability under the "new" definition that generally were not covered under the previous definition;
- Summary findings from the field study conducted by Morgan Management Systems, Inc.; and
- Conclusions and recommendations.

The other products completed under this purchase order are:

1. Estimates of the Size and Characteristics of the Non-Institutionalized Developmentally Disabled Population in the United States Based Primarily on an Analysis of the 1976 Survey of Income and Education.
2. Operational Definition of Developmental Disabilities.
3. Identification of Some Conditions that Might Lead to a Developmental Disability.

Further information on these products can be obtained from the Administration on Developmental Disabilities.

## II. SUMMARY OF KEY FINDINGS REGARDING THE SIZE AND CHARACTERISTICS OF THE DEVELOPMENTAL DISABILITIES POPULATION

### A. Non-Institutionalized Population

The following findings are derived from an analysis of the Survey of Income and Education, conducted in 1976 by the U.S. Bureau of the Census on the non-institutionalized population over age three. Each of the criteria in the definition of a developmental disability was operationalized for use with the data actually gathered. Since the SIE was not conducted with the definition of developmental disabilities in mind, the operationalization of the criteria was not always easy or precise. However, as can be seen from the summarized findings, the methodology used generally produced results that are consistent with other estimates and provided considerable additional insights into the characteristics of the developmentally disabled population.

It should be noted that although we determined that the SIE was the best source for deriving estimates, the data have a number of limitations. The strengths and weaknesses are described below in some detail.\*

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\* Detailed results and more details about the SIE itself can be found in the following volume completed under this purchase order:

Estimates of the Size and Characteristics of the Non-Institutionalized Developmentally Disabled Population in the United States Based Primarily on an Analysis of the 1976 Survey of Income and Education.



## 1. General Advantages and Strengths of the SIE

Despite the fact that it contains many weaknesses, the SIE remains the best source of data to estimate the size of the disabled population, particularly at a state level. The reasons for this are:

- The SIE is the only national survey effort that has been based on state samples so that direct state specific estimates can be derived. For other surveys, including the HIS and SSD,\* the only way to obtain estimates for states is to construct national rates and apply them to the state based upon certain basic demographic characteristics. Although the procedures for synthetic estimates are being improved, to date they have not been highly accurate.
- The SIE is relatively recent. (1976)
- The data gathered by the SIE do contain information on the functional limitations resulting from a condition.
- The general national results of the SIE in terms of the proportion of the population that appears to be disabled are quite similar to the results obtained from other surveys (including the HIS and SSD). This tends to validate the broad estimates that can be derived from the data. The accuracy of the data appears to decline as we make finer and finer breakdowns.
- It is possible to obtain sub-state information. The SIE gathered information on a large enough sample in each state to obtain breakdowns of the population for certain central city areas, metropolitan areas outside the central city, and non-metropolitan areas.
- Public use tapes were available, enabling us to manipulate the data in new ways.

## 2. General Limitations of the SIE

There are a number of specific ways in which the SIE data are limited. These limitations need to be kept in mind when attempting to use and interpret the estimates presented in this and similar reports. These limits include:

- The information is only gathered on the non-institutionalized\*\* population. This is a limitation of the HIS and SSD as well.

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\* Health Interview Survey conducted by the National Center for Health Statistics and the Social Security Surveys of Disabled Persons.

\*\* As indicated below, "institutionalized" included people in any congregate living arrangement including group homes in the community as well as traditional "institutions."

- The information is only gathered on the 3 years and older population. No information is gathered on infants.
- In order to be counted as a person with a limiting health condition, the person has to be limited in a major life activity for his or her age group. These are:
  - play for people ages 3 to 4
  - school or play for people ages 5 to 17
  - work or school for people ages 18 to 25
  - work for people ages 26 to 64
  - work around the house for people ages 65 and over

The method appears to function reasonably well for more severe disabilities, but perhaps not for "minor" disabilities. If a person is not identified as limited in a major life activity, then no additional information concerning limitations in mobility, self-care or household task work was obtained.

- The specific limiting health conditions that are listed in the SIE are a somewhat unusual list that does not appear to have much logic to it. The largest single category is "other health condition" about which no data was recorded on the tapes. The list does not necessarily coincide with a list that would be most useful for planning services or describing the population.
- The specific limiting health conditions in each category were not defined anywhere. For most of the conditions this was not important. However, for some this creates considerable difficulty. In particular, no definition was given for "chronic nervous disorder" so it is not possible to determine whether this was interpreted by respondents as a physical or a mental condition.
- Blindness is not separated from serious visual impairments. However, deafness is separated from hard of hearing.
- For a number of the specific limiting health conditions, no severity was provided at all. This is particularly true for speech impairment, which generally was a secondary impairment.
- Low prevalence disabilities, such as total deafness, are likely to be undercounted. The national estimates and estimates for all ages, sexes, ethnic groups is likely to be more accurate than those for specific parts of the population for a state overall and particularly for parts of states. With some low prevalence problems, no one with particular age and/or ethnic characteristics who was sampled had the problem. As a result, when extrapolations are derived the SIE indicates that there are no people with the particular problem, for the part of the population of concern.

- The mentally retarded population appears to be undercounted. A relatively conservative estimate of 1% is generally used to estimate the prevalence of retardation. When account is taken of those mentally retarded individuals not included in the SIE sample (people living in institutions, nursing homes and group homes) then the estimate is more reasonable. It can be assumed that most counted in the SIE are moderately or severely retarded.
- The individual functional limitations were also not defined for respondents. Therefore, it is quite possible that there is a wide range of actual ability/need represented within each response. In particular, the concepts of "occasionally" and "frequently" needs assistance are quite problematic. Parents of young children were not instructed to adjust for variations in need introduced as a result of age and it appears that they underestimated the extent to which children had unusual difficulty in taking care of themselves.
- For some of the functional limitations, no degree of difficulty was obtained. This was particularly true for degree of difficulty relative to performing work around the house.
- In general, because of the way in which a person is considered to be disabled in the SIE, it appears that the less handicapped population is somewhat undercounted. This however, is not a problem when counting developmentally disabled people.
- All the information was either self reported or reported by proxy (i.e., by a family member for the other family members). Self reported information is generally considered to be reasonably accurate, but there is a tendency to underreport those problems that might be stigmatizing (such as mental retardation or emotional disturbance).
- Although some information was obtained on the age at which the conditions first appeared, it is extremely difficult to interpret and use it. As a result, this criterion was very difficult to measure, particularly for the population over age 25

#### 4. Summary

Despite the many general limitations and limitations specific to estimating the size of the developmentally disabled population, the SIE remains the best source of estimating the population, particularly for an individual state. It is important, however, that the data be used with caution. In summary it should be noted that:

- The SIE data must be supplemented with information about the institutionalized population for each state (including people in state operated institutions, nursing homes, and group homes).
- The SIE data must be understood to be estimates. The numbers presented are best regarded as reasonable midpoints in a range within which the true number lies. They are all rounded (to the nearest 1000) to convey the sense of estimates. The actual numbers, therefore, could well be higher or lower than those presented.
- The SIE indicates that approximately 1% of the total non-institutionalized population is developmentally disabled. This is a small proportion but represents many people. This overall estimate is consistent with the idea that the developmentally disabled population is that most severely handicapped group of people.
- The SIE provides potentially useful information on the relationship between developmental disabilities and other characteristics including age, ethnicity, and specific limiting health conditions. It also shows many interesting distributions of each of the major life activity limitations and the differences between the mentally retarded and non-mentally retarded developmentally disabled populations in terms of these activity limitations.

## 5. Summary Findings from the SIE

- There were a total of approximately 2.5 million non-institutionalized developmentally disabled individuals over age three in the United States in 1976 who comprised about 1.2% of the total non-institutionalized population over age three.\*

DD Population	2,487,000	1.18%
Non DD Disabled Population	<u>26,565,000</u>	<u>12.57%</u>
Total Disabled Population	29,052,000	13.75%
Non Disabled Population	<u>182,232,000</u>	<u>86.25%</u>
Total Non-Institutionalized Population over age 3	211,284,000	100.00%

- The developmentally disabled population comprises about 8.5% of the over 29,000,000 disabled people in the United States.
- Of the total DD population, about 35% is mentally retarded, 10% is seriously emotionally disturbed, 17% is sensory impaired, and the remaining 38% is physically impaired.\*\*

DD MR population	870,000	35.0%
DD seriously emotionally disturbed population	259,000	10.42%
DD sensory impaired	427,000	17.17%
DD physically impaired	<u>931,000</u>	<u>37.43%</u>
Total DD Population	2,487,000	100.0%

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\* The following numbers are based on the counts provided in the "sex" tables for which the numbers were most complete.

\*\* Any DD persons who were retarded were counted as "mentally retarded" even if they had other conditions as well; they were counted as "seriously emotionally disturbed, if they were not retarded but were seriously emotionally disturbed, even if they had other (physical) conditions as well; they were counted as "sensory impaired" if they were not mentally disabled, but reported to be hearing impaired, deaf or visually impaired/blind regardless of what other physical impairment they had; and they were reported as "physically impaired" if they had not previously been counted as mentally disabled or sensory impaired.

- The developmentally disabled population has a somewhat higher proportion of males (about 51.5%) than does the population overall (about 48.5%), which is a result of the fact that males are over-represented in both the mentally retarded and DD seriously emotionally disturbed populations.
- Over half the DD population is under age 18, compared with the total population of which only about 30% is under age 18.
- A higher proportion of Blacks and Native Americans are reported to be developmentally disabled than of other ethnic/racial groups. More Blacks are reported to be mentally retarded or DD physically impaired and more Native Americans are reported to be mentally retarded or DD sensory impaired.
- About 25% of the DD individuals come from families that are below the poverty level, compared to only about 19% for the non-DD disabled population and 11% for the non-disabled population. This was true quite consistently for sub-groups within the DD population
- For individuals over age 15, a much higher proportion of the DD population reported having no schooling than either for the non-disabled or the non-DD disabled: almost 15% compared to less than one percent for the non-disabled population and slightly over one percent for the non-DD disabled population. However, it should be noted that one indicator of early manifestation of a disability was "no school." Thus, the discrepancy between the DD and non-DD disabled population may be an artifact of this criterion, rather than a true difference. However, the difference between the disabled and non-disabled population (about eight times the rate) is real. The differences follow through with a much smaller proportion of the DD population having attended, finished or gone beyond college than either for the non-DD disabled or the non-disabled populations. The group of DD individuals most likely to have had no schooling was the mentally retarded group, with almost one third reporting no education at all compared with about 5% for each of the other groups.
- More than three quarters of the total DD population over age 18 has had no previous work experience, compared with less than one quarter of the remainder of the population. This too might be an artifact of the criterion used to estimate early manifestation.
- The annual income in 1975 of the DD population is about one quarter the average of the non-disabled population and about one third of the income of non-DD disabled persons. While non-disabled persons receive only about 1% of their total income from public sources,\* and non-DD disabled persons receive about 14%, DD individuals

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\* Includes Social Security

receive about 67% from public assistance. Conversely, DD individuals receive less than 20% of their income from earnings compared to 65% for other disabled persons and 92% for non-disabled persons. Social security benefits are received by the largest number of DD individuals compared to other public sources.

- DD individuals are somewhat more likely than non-DD disabled person to have more than one limiting health condition; about 30% of the D population compared to about 25% of the non-DD disabled population. At least in part because of the way the DD subgroups were defined (i.e. anyone who was mentally retarded was counted as DD retarded even if they also had another condition, etc.), the group least likely to have other conditions is the physically impaired group.
- All individuals reported to be mentally retarded are counted as being developmentally disabled;\* about 47% of the seriously emotionally disturbed are counted as being developmentally disabled; about 25% of deaf people are counted as developmentally disabled; and about 17% of people who are visually impaired are counted as developmentally disabled. Nine percent of the people who are hard of hearing are counted as developmentally disabled and about 58% of the speech impaired are counted as developmentally disabled, primarily because it appears that these conditions are generally only reported for individuals who also have another more disabling condition or they would not have been counted as disabled at all.\*\* Less than 5% of each of the remaining conditions are counted as developmentally disabled.
- Over half the DD population has four or more life activity limitations and over 10% has six or more. In contrast, the non-DD disabled population has less than 5% that have three or more life activity limitations as defined for purposes of this analysis. The mentally retarded DD population had the most limitations, the seriously emotionally disturbed the next most.

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\* This is an artifact of the criteria we used, and should not be interpreted to imply that all retarded persons are, in fact, developmentally disabled. Rather, because the SIE seems to have undercounted mentally retarded persons we have assumed that virtually all counted are at least moderately retarded.

\*\* It should be recalled that individuals are only counted by the SIE if they report having a health condition that limits their ability to carry out their major life role. Once this has been ascertained, they were asked to indicate which of the conditions listed they have. Thus, with relatively mild conditions like most speech impairments, they would not have been the primary condition limiting a person's ability to function but might well have been an important concomitant impairment.

- About 25% of the DD population was reported to be limited in self-care and in mobility; about half the DD population was reported to be limited in self direction; 65% were limited in capacity for independent living; over 75% in receptive and expressive language; over 80% in learning; and over 90% in economic self-sufficiency.
- The proportion of a state's population that is reported to be developmentally disabled varies from a low of .6% in Alaska to a high of 2.04% in West Virginia. The states that have .90% or less of their total population reported to be developmentally disabled were:
  - Alaska
  - Colorado
  - Nevada
  - North Dakota
  - Oregon
  - Utah
  - Wyoming

The states that reported having 1.5% or more of their total population to be developmentally disabled were:

- Alabama
- Arkansas
- Georgia
- Louisiana
- Mississippi
- Tennessee
- West Virginia

In interpreting these variations it is important to take into account a number of factors including:

- The SIE only counts non-institutionalized individuals and the rate of institutionalization varies considerably from state to state, not only in public institutions but in nursing homes and other group living arrangements as well.
- The criteria used for developmental disability included some variables such as lack of schooling and low employment that are partially functions of the environment, not only of the individual.
- The definition of developmental disabilities contained in P.L. 95-602 was designed to be somewhat responsive to environmental differences so that in fact the same type and extent of impairment might have differential impacts on a person depending upon various environmental factors including the availability of special educational and other services.



- The rate of disability for the non-DD disabled population also varies from state to state from a low of 7.76% in Alaska to a high of 21.01% in West Virginia so that the DD population is reflective of variations in the overall disabled population in the state.
- In general, a somewhat higher proportion of the urban population is disabled (either developmentally or not), than is the non-disabled population, perhaps reflecting the tendency for disabled population, perhaps reflecting the tendency for disabled persons to move to urban areas to access services.

#### B. Institutionalized Population

The Survey of Income and Education only included the "non-institutionalized" population. It is well known, however, that many developmentally disabled persons are in fact institutionalized. To arrive at a reasonable estimate of the number of developmentally disabled persons not counted in the SIE, we can draw upon a number of sources. As with arriving at estimates of the non-institutionalized population, however, there is no one source that explicitly attempted to count the number of developmentally disabled persons who were institutionalized at a particular point in time. There are, then, a number of limitations on the existing data on the institutionalized population. Some of these include:

- Virtually all existing surveys were not comprehensive in the types of institutions that were surveyed. This is the case with those surveys that focus only on one type, such as public residential facilities for mentally retarded people, and even on the one major survey conducted by the Bureau of the Census that was intended to be comprehensive. For the 1976 Survey of Institutionalized Persons, the surveyors unintentionally omitted from the sample many psychiatric institutions.

- The descriptors used for the institutionalized population do not necessarily match those for the developmentally disabled population. However, we can go on the assumption that for certain populations they are likely to meet the criteria for the developmentally disabled population precisely because they are institutionalized.
- The institutionalized population, according to the SIE, also included people living in group facilities such as group homes. This definition of "institutionalized" differs from that which is typically used in the field, and requires that we draw upon sources of information about group living facilities in the community as well as upon information about what would more typically be defined as an institution.

We have drawn upon several sources to arrive at reasonable estimates of the number of developmentally disabled population who were institutionalized at the time that the Survey of Income and Education was conducted. In this way we can combine the two estimates to arrive at a reasonable estimate for the "total" developmentally disabled population. Since 1976 we would expect that there has been a shift in the distribution of the developmentally disabled population, with fewer people being "institutionalized" than in 1976. However, if we recognize the fact that the SIE considered group homes and similar congregate facilities to be "institutions", then in reality much of the population shift has been within the "institutionalized" population. There has even been some shift into the institutionalized population as more people move out of their family homes and into group homes. Some move out as people move from group homes to independent living settings but these in and out movements are assumed to cancel each other out for our purposes.

The sources we are using to arrive at an estimate of the "institutionalized" developmentally disabled population are:

- Public Residential Services for the Mentally Retarded, National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1976.

- The National Nursing Home Survey: 1977 Summary for the United States, U.S. Public Health Service, National Center for Health Statistics.
- The 1976 Survey of Institutionalized Persons, conducted by the U.S. Bureau of the Census.
- "National Survey of Community Residential Facilities: A Profile of Facilities and Residents in 1977," Robert Bruininks, et al American Journal on Mental Deficiency, March, 1980.

According to these sources, the following number of institutionalized people were likely to be developmentally disabled (see Table on next page):

- Public Residential Facilities for the Mentally Retarded: Approximately 153,600 mentally retarded persons who were in public residential facilities for the retarded in 1976. Of these virtually all were at least moderately retarded, and the assumption can be made that virtually the entire group was sufficiently retarded or otherwise disabled to be considered developmentally disabled.
- National Nursing Home Survey: Approximately 769,800 individuals with a primary diagnosis of mental retardation were in nursing homes in 1977. Approximately 48,400 individuals in nursing homes were placed there because of mental retardation, 42,400 had a primary diagnosis of mental retardation at their last examination, and a total of 79,800 were considered to have mental retardation as a chronic condition or impairment. These numbers are somewhat difficult to interpret but it would seem that we could say that somewhere between 40,000 and 80,000 individuals in nursing homes in 1976 were mentally retarded. We would probably be safe in considering this entire group to be developmentally disabled. There undoubtedly were other individuals who were developmentally disabled in nursing homes in 1976 but it is difficult to determine from the existing data. Unfortunately, the published information does not provide a table of disability by, for example, age or other criteria that might help us determine which ones are likely to be developmentally disabled. If we were to use a rough estimate based upon the non-institutionalized disabled population, about one tenth of the disabled population in the nursing homes would be developmentally disabled, or a total of about 130,000 individuals of whom over half or 80,000 are retarded.

A total of about 76,000 nursing home residents are under age 54, and this group has a greater likelihood of being severely disabled and perhaps developmentally disabled, but we do not know how many are, for example, mentally retarded. The total of 130,000 is probably a high estimate but at least provides a reasonable upper limit.

SUMMARY OF DATA ON THE INSTITUTIONALIZED  
AND NON-INSTITUTIONALIZED DEVELOPMENTALLY DISABLED POPULATION

Source	Year Conducted	Population Covered	Number of Facilities	Estimated Number Developmentally Disabled
1. Survey of Income and Education (SIE)	1976	"non-institutionalized" ages 3+	N.A.	2,487,000
2. Public Residential Services for the Mentally Retarded	1976	residents of public residential facilities for the MR	239	53,584
3. The National Nursing Home Survey	1977	residents of nursing homes of all types	18,900	40 - 80,000
4. Survey of Institutionalized Persons: A Study of Persons Receiving Long Term Care	1976	residents of institutions	sample of 915 out of about 26,000	254,000
5. National Survey of Community Residential Facilities	1977	residents of "community" facilities	4,400	76,000
TOTAL DEVELOPMENTALLY DISABLED (1+4+5)				2,812,000

- Survey of Institutionalized Persons (SIP). The SIP attempted to study all institutionalized persons including two populations just described, plus some others. According to the SIP there were a total of about 193,000 persons institutionalized with mental retardation of whom about 130,000 were in non-federal governmental facilities and about 40,000 of whom were in proprietary facilities. If the assumption is made that all these individuals were developmentally disabled then a minimum of 193,000 developmentally disabled persons were institutionalized.

The SIP provides us with some additional information about the age distribution of the institutionalized population and the number of limitations that the population has. In particular, the tables indicate that there are a total of about 151,500 individuals under age 18 who are institutionalized, of whom about 67,400 had no limitations, and about 84,000 of whom had at least one functional limitation. We can assume then, that those who had no limitations were unlikely to be developmentally disabled, but that the remaining group had a high likelihood of being developmentally disabled. That is, we are assuming that if children are disabled and institutionalized they run a high risk of being or becoming developmentally disabled.

Of the population between 18 and 64 years old, there were about 49,800 individuals with three or more limitations, and another 83,700 with two functional limitations for a total of 133,500 with two or more limitations. Since the limitations do not correspond directly to those contained in the definition of a developmental disability, it is possible that a person with two of the limitations listed in the SIP would actually have more than two life activity limitations. If we were to make the assumption that all would be sufficiently disabled to be considered developmentally disabled, but that only half meet the age of manifestation criterion, then this would be another approximately 66,500 individuals added to the 84,100 under age 18. This would give us a total of about 150,600 persons under age 64 with a high likelihood of being developmentally disabled.

The remaining population is over age 65, and it is probably reasonable to assume that a relatively small proportion are developmentally disabled. Most are likely to have become disabled late in life. Of the total 1,027,850 persons over age 65 who were institutionalized we suggest that about 10% were developmentally disabled, or about 102,300 persons. In addition to the population under age 65, this would be an estimated total of about 254,000 persons, of which 193,000 were mentally retarded and the remaining were physically handicapped. The SIP undercounted mentally ill persons because many mental hospitals were not included in the sample surveyed.

- Community Facilities for Developmentally Disabled Persons: In 1977, one year after the SIE and the Survey of Institutionalized Persons, a survey was performed of community facilities for developmentally disabled persons. The survey was a part of a national project funded through the Developmental Disabilities Program that was conducted by the University of Minnesota. The results of this survey indicated that there were a total of about 76,000 persons living in over 4,400 facilities. The definition of a developmental disability that was used for this survey was the "old" one contained in P.L. 94-103. However, we can assume that although some individuals would not meet the criteria in the "new" definition contained in P.L. 95-602, there undoubtedly were also some individuals not counted because they did not fit the old definition. We assume that the overcount and undercount more or less cancel each other out. This means that about 76,000 developmentally disabled persons who were in community residences were not counted either by the SIE or the SIP or other sources.

If we take the combined total of the number of persons institutionalized and those who were in community programs we arrive at about 325,000 persons not counted by the SIE. Adding this to the number derived from the SIE yields the total of 2,812,000 developmentally disabled persons. Of this total about 11.5% are "institutionalized" in the broad sense defined by the SIE (i.e., living in some group situation) and about 8.9% are institutionalized in the narrower sense as defined by the Survey of Institutionalized Persons.

### III. OPERATIONAL DEFINITION

In attempting to operationalize the definition of developmental disabilities, we decided that the best approach was to restructure each of the criteria for a developmental disability contained in the definition as a screening question. Each criterion was broken down into a set of simple questions that can be asked to determine if an individual or group of individuals is developmentally disabled.

No effort is made, deliberately, to present rigid criteria or to indicate that to be developmentally disabled a person must obtain a certain score on a certain test or group of tests. Rather, the definition is operationalized in such a way that a considerable amount of professional judgment needs to be exercised. In this way the current state of the art with respect to testing in the field is acknowledged: there is no one set of tests that could appropriately be applied to people of all ages with all types of limitations. We feel that any ambiguity created by the proposed approach is outweighed by the considerable advantages of flexibility and responsiveness.

The following pages contain the screening questions.

#### IV. KEY SCREENING QUESTIONS CHECKLIST

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

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

CHECK:

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

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

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

CHECK TWO:

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

AND

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

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

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

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

CHECK TWO:

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

AND

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

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

- C. *is likely to continue indefinitely;*

Is the body system that is impaired one which is known not to 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 or group of persons' ability to function?

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



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

CHECK:

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

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

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

AND

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

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

OR

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

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

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

CHECK FOUR:

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

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

AND

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

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

- AND

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

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

AND

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

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

#### IV. SUMMARY OF SOME NEW CONDITIONS THAT MIGHT LEAD TO A DEVELOPMENTAL DISABILITY

The concept of a developmental disability, both as it was originally defined and as it is currently defined in P.L. 95-602, is that individuals with different conditions share certain characteristics that imply shared service needs. This concept is generally referred to as "non-categorical" but actually is more appropriately seen as "trans-categorical" since the commonalities cut across or transcend specific categories. They do not, however, necessarily exist in isolation of very real characteristics that are rooted in specific conditions. That is, the attributes that an individual must display in order to be considered to have a developmental disability are "non-categorical" in that they are independent of any one category or condition. However, any individual who is developmentally disabled has other characteristics that are not described by those listed in the definition of a developmental disability, and has a particular combination of the characteristics that are listed. These often derive directly from the nature of that person's underlying condition.

To arrive at a full picture of a developmentally disabled person a lot of information is needed. Included is information about the specific ways in which the criteria contained in the definition are met (e.g., the actual age of manifestation, the specific life activity limitations); basic demographic characteristics (e.g., age, sex, ethnic group, family income level); and specific condition that has lead to the developmental disability. This chapter summarizes information contained in the volume of the final report that provides

information about some of the major conditions that are likely to lead to a developmental disability (excluding the four conditions that were listed in the previous definition: mental retardation, cerebral palsy, epilepsy, and autism). Only "new" conditions are described in any detail since a considerable amount of material has already been developed and disseminated with respect to the four "old" conditions.

The specific purposes of identifying some new conditions that might lead to a developmental disability as defined in P.L. 95-602 are to:

- (1) provide basis for service programs to determine who is developmentally disabled.
- (2) help people identify the major health conditions that are likely to result in a developmental disability.
- (3) help identify those conditions that are most likely to contribute a substantial population to the total developmental disabilities population. This is a function both of the likelihood of the condition resulting in a developmental disability and the overall incidence and prevalence of the condition.
- (4) provide information that might be useful in planning the delivery of services to the newly defined developmentally disabled population by describing its major characteristics, with a particular emphasis on the kinds of difficulties that the population is likely to have functioning in society.
- (5) identify possible consumer groups, constituencies, service providers, and other new sources of need and information regarding the developmentally disabled population.

The list and descriptions will NOT accomplish the following:

- (1) They will NOT indicate that all people with a specific condition have a developmental disability, but rather focuses on their ability to function.
- (2) They will NOT indicate that if a specific condition is not listed that it cannot lead to a developmental disability. Although most conditions will not result in a developmental disability, there are many that might but are of very low incidence; result in very early death; and/or rarely have substantial residual disabling effects.

- (3) They will NOT attempt to be all inclusive, since there are literally hundreds of specific conditions that might result in a developmental disability.
- (4) They are NOT intended to be used to describe the developmentally disabled population. That population is described by the extent to which it meets the criteria in the definition. Specific conditions are listed as a way of helping people identify some of the contributors to the new population, and as a way of adding descriptive information, not as a way of substituting for the non-categorical definition.

We have included two summary tables here that contain information on each of thirty two "new" and the four "old" conditions. The first table indicates the likelihood that each condition will result in the seven life activity limitations contained in the definition. The second table indicates the overall likelihood that a person with each condition will meet the criteria for a developmental disability.

**RELATIONSHIP BETWEEN SPECIFIC CONDITIONS AND MAJOR LIFE ACTIVITY LIMITATIONS  
WHEN CONDITION DOES NOT RESULT IN MENTAL RETARDATION**

Key: H = High  
M = Medium  
Blank means low  
or never

**LIKELY DAILY LIFE ACTIVITY LIMITATIONS**

"NEW" CONDITIONS	Self-care	Expressive/ Receptive Language	Learning	Mobility	Self- Direction	Independent Living	Economic Self- Sufficiency
1. Arthrogryposis	M			H		M	M
2. Severe Asthma							M
3. Early Onset Severe Bilateral Blindness	M	M	M	M		M	M
4. Bronchopulmonary Dysplasia*	H			H		H	H
5. Cerebrovascular Accident: Stroke*	M	M	M	M		M	M
6. Severe Craniofacial Disfigurement*		M				M	M
7. Curvature of the Spine	M			M		M	
8. Cystic Fibrosis				M		M	M
9. Early Onset Severe-Bilateral Deafness	M	H	H			M	M
10. Deaf-Blind*	H	H	H	H	H	H	H
11. Dwarfism	M			M			
12. Heart Disease				M		M	M
13. Hemophilia	M			H			M
14. Huntington's Disease*	H	M	H	H		H	H
15. Immunodeficiency Disorders**							
16. Juvenile Diabetes Mellitus		M	M			M	M
17. Juvenile Rheumatoid Arthritis	M			M		M	M
18. Limb Deficiency-Disfigurement of Extremity	H			H		M	M
19. Multiple Sclerosis	MH			MH		MH	MH
20. Hereditary Progressive Muscular Dystrophies*	MH			H		H	MH
21. Osteogenesis Imperfecta	M					M	M
22. Post Polio Paralysis	H			H		H	M
23. Childhood and Adolescent Psychosis		M	M	H	H	H	
24. Specific Learning Disability		M	H	M			M
25. Sickle Cell Anemia	M		M	M	M	M	M
26. Spina Bifida*	M			H	M	H	M
27. Spinal Cord Injury	M			H		H	M
28. Spinal Muscular Atrophy	M			M		M	M
29. Systemic Lupus Erythematosus*	M			H	M	H	M
30. Thalassemia Major	M						
31. Tourette Syndrome							M
32. Tuberculous Sclerosis*	M			M		M	M
<b>"OLD" CONDITIONS</b>							
1. Mental Retardation(moderate,severe,profound)	M	M	H	L	MH	M	MH
2. Cerebral Palsy	M	M	H	M	H	M	M
3. Epilepsy			M			M	M
4. Autism	H	H	H		H	H	H

\* Accompanied by mental retardation in some or virtually all instances.

\*\* Impacts depend on specific infections contracted.

# IN A DEVELOPMENTAL DISABILITY\*

## CRITERIA

KEY: A = Always  
H = High  
M = Medium  
L = Low  
N = Never

### "NEW" CONDITIONS

	PHYSICAL IMPAIRMENT	MENTAL IMPAIRMENT	MANIFESTS PRIOR TO AGE 22	INDEFINITE DURATION	3 OR MORE LIMITATIONS	MULTIPLE SERVICE NEEDS	LIKELIHOOD OF INCLUSION UNDER P.L. 94-103	LIKELIHOOD OF INCLUSION UNDER P.L. 95-602
1. Arthrogryposis	A	L	A	A	M	M	L	M
2. Severe Asthma	H	L	H	M	L	L	N	L
3. Early Onset Severe Bilateral Blindness	A	L	M	A	M	M	L	L
4. Bronchopulmonary Dysplasia	A	H	A	A	M	H	H	A
5. Cerebrovascular Accident: Stroke	M	M	H	M	M	M	M	M
6. Severe Craniofacial Disfigurement	A	M	M	H	M	H	M	M
7. Curvature of the Spine	M	L	A	H	L	L	L	L
8. Cystic Fibrosis	A	L	H	A	M	M	L	M
9. Early Onset Severe-Bilateral Deafness	A	M	A	H	M	L	L	M
10. Deaf-Blind	A	M	H	A	A	A	H	H
11. Dwarfism	A	L	A	A	M	M	L	M
12. Heart Disease	H	L	A	H	L	L	L	L
13. Hemophilia	A	L	A	H	M	M	L	M
14. Huntington's Disease	H	A	A	A	A	A	H	H
15. Immunodeficiency Disorders	M	M	A	H	M	M	L	M
16. Juvenile Diabetes Mellitus	H	L	A	A	M	M	L	M
17. Juvenile Rheumatoid Arthritis	H	N	A	H	M	M	L	M
18. Limb Deficiency-Disfigurement of Extremity	H	N	M	H	M	M	L	M
19. Multiple Sclerosis	H	M	L	H	MH	MH	L	L
20. Hereditary Progressive Muscular Dystrophies	A	M	A	A	H	H	L	H
21. Osteogenesis Imperfecta	A	N	H	A	M	M	L	M
22. Post Polio Paralysis	H	N	M	H	M	M	L	M
23. Childhood/Adolescent Psychosis/Schizophrenia	N	A	A	H	H	H	L	H
24. Severe Specific Learning Disability	L	A	A	H	M	M	L	M
25. Sickle Cell Anemia	H	M	H	H	M	M	L	M
26. Spina Bifida	H	M	A	A	H	M	M	H
27. Spinal Cord Injury	A	N	M	A	M	M	L	M
28. Spinal Muscular Atrophy	A	L	A	A	M	M	L	M
29. Systemic Lupus Erythematosus	H	M	H	H	M	M	L	M
30. Thalassemia Major	A	L	A	A	M	M	L	M
31. Tourette Syndrome	M	M	H	H	L	M	L	L
32. Tuberous Sclerosis	H	H	A	A	H	H	H	H

### "OLD" CONDITIONS

1. Mental Retardation(moderate,severe,profound)	M	A	A	A	H	H	A	H
2. Cerebral Palsy	H	M	A	H	M	M	A	MH
3. Epilepsy	M	M	M	M	L	L	H	L
4. Autism	L	A	A	H	H	H	A	H

\* This is not a list of the conditions leading to a developmental disability. It omits many conditions that might result in a DD, and includes some that are unlikely to result in a DD. This list is illustrative only. Includes some resulting in MR.

## V. FIELD STUDY SUMMARY

A field study of six states was conducted by Morgan Management Systems, Inc. in 1979 to explore how states were dealing with the modified definition of developmental disability.\* The field study of the introduction of the change in the DD definition within the state DD program and its environment had the following objectives.

- To identify the specific system components where the potential/actual impacts of the definitional change could be found.
- To determine the nature of the potential/actual impacts (the type, extent, and direction of the impacts).
- To evaluate the significance, advantages or disadvantages of the change from the perspectives of various actors in the DD system.
- To assess problems experienced in the states during the transitional period.
- To explore the effects of alternative methods of dealing with specific problems generated by the change in definition.

The major system components identified by the project staff in carrying out the first objective were:

- The target population.
- The DD Planning Council.
- Other State Agencies in the DD Service Network.
- Advocacy groups.
- Service Providers.

Project staff made site visits to two states--Massachusetts and Michigan. Reports were also prepared by project staff on four states--Illinois, Maryland, New Mexico and Wisconsin--based on data gathered from a variety of sources.

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\*This summary from this point on is taken from "Field Study Report" Vol. I, April; 1981, Prepared for "A Study of the Potential Impact of the Definition Recommended by the National Task Force on the Definition of Developmental Disabilities," Morgan Management Systems, contract #HEW-105-78-5003.



The initial concerns over the introduction of the new definition of a Developmental Disabilities may be summarized as follows:

- The target population would increase.
- The [DD Planning] Council would be disrupted.
- There would be many new advocacy groups in the DD system.
- There would be changes in interagency relationships.
- The states would have difficulties in determining eligibility.
- There would be a shortage of funds.
- There would be a lack of guidance in operationalizing the new definition.

The findings of the six state field study conducted six months to a year after the passage of P.L. 95-602 indicated that some of the initial concerns may have been exaggerated. Project staff found that many state agencies were already using some type of functional definition and that most claimed to be concentrating on the most severely disabled. Several states were systematically introducing the new definition. In general, providers felt more comfortable with the new definition, while planners were faced with difficulties in projecting service and financial needs for the newly defined developmentally disabled. However, few respondents in the states reported that these difficulties were insurmountable.

Project staff found that many established advocacy groups seemed to accept the new definition, although with qualifications based on concern for their constituencies. While a new coalition may form around the severely disabled in the DD system, it is too early to tell whether the established advocacy groups will remain within the system or if they will, once again, seek their own Federal program and its attendant visibility.

The findings were not yet in on the size of the DD population in the states and the subsequent availability of funds. It does seem safe to predict that changes in DD Planning Council composition will be handled fairly smoothly in the states and that there will be minimal and gradual changes in set patterns of interagency relationships. The increased involvement of Vocational Rehabilitation and Mental Health programs will cause concern among some established groups, but it will also provide new expertise to the DD networks. The difficulties in determining eligibility may be resolved when the new definition is fully operationalized.

The operational definition is the single most requested form of technical assistance in the states studied, followed by community education materials. While the introduction of the new definition was not as disruptive as some feared, it has created stresses in the DD system which can and should be reduced by Federal interventions, such as technical assistance.

## VI. CONCLUSIONS AND RECOMMENDATIONS

The basic conclusions to be drawn from the current project are:

- The overall size of the developmentally disabled population as defined in P.L. 95-602 does not greatly increase over the population that was previously covered by P.L. 94-103.
- However, the characteristics of this population would shift significantly in the following ways:
  - A wider diversity of types of conditions could lead to a developmental disability, implying a wider diversity of service needs. This is particularly the case with the non-retarded populations: mentally ill persons and "mentally alert" sensory and other physically impaired populations are now likely to be included in greater numbers.
  - The total group is more severely disabled. The previous definition was frequently (mis)interpreted to include virtually anyone with one of the four listed conditions. The new definition is more clearly focused on the most severely limited populations.
  - The characteristics of the DD population as revealed by the SIE data identify a group that is more severely disabled than most other disabled persons. It also is a group that is generally more limited in its ability to support itself than either the overall disabled population or the non disabled population.
  - A major concern of state and local programs has been the availability of an operational definition that can help them in determining if an individual is or is not developmentally disabled. Because of the complexity of the nature of a developmental disability, the limitations in the existing state-of-the-art in the field of testing and measurements, and the nature of the DD program the project decided not to create a rigid operational definition that can be applied uniformly to all individuals regardless of their age or condition. Rather, a list of screening questions was developed that can assist programs in making decisions. They rely heavily on the judgments of individual professionals. As a result, there remains in the field some ambiguity and discomfort with respect to the application of the definition to specific individuals. Given that the DD Program is not an entitlement program, nor even primarily a direct service program, it is not unreasonable to have some ambiguity regarding the population. Nonetheless, many people remain concerned.

- The definition appropriately focuses on characteristics that are not dependent upon specific conditions or categories of conditions. There is much to be learned about the nature of individuals with developmental disabilities by grouping those individuals according to their major mental and/or physical impairment (i.e., mental retardation, mental illness, sensory impairment, other physical impairment) as well as by understanding something about the specific condition that has resulted in the developmental disability. Using a "non-categorical" definition need not imply that categorical information should be overlooked.

## RECOMMENDATIONS

- The definition of a developmental disability as contained in P.L. 95-602 has created some difficulties both in terms of interpretation and implementation but despite these difficulties it has gained reasonable acceptance at the state and program level. It does not appear that the difficulties that have arisen warrant any further changes in the definition. Rather, it would appear that the program has suffered from the many changes many to date and that what is needed more than additional changes is some stability and time to work through the implications of the current definition.
- The materials developed by the current project should be useful to the states for planning and other purposes. There remain, however, several needs for additional materials that could be used by state and local programs as they implement the definition and integrate its implementation into their overall program directions.
- Some of the specific materials that might be useful to states would include guidelines that specifically address planning needs and issues; more in-depth information about the severely emotionally disturbed population and how its needs are similar to or differ from those of other DD individuals; guidelines on how best to determine where DD individuals currently are being served in a state and with what adequacy; guidelines on determining incidence (as opposed to prevalence) of developmental disabilities; and additional materials on services needs for the group as a whole, with particular attention to differentiating those instances where all DD persons should be served as a group, where they should be served as part of a larger group, or where they should be divided into smaller sub-populations.