

STUDY OF THE FEDERAL DEFINITION
OF DEVELOPMENTAL DISABILITY:

Final Report

Volume I: Summary of Findings

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PREFACE

This is the first of two volumes of the Final Report of BPA's study of the federal definition of developmental disabilities. This volume presents a summary of study findings and a discussion of the issues and potential scenarios relevant to potential implementation of the definition in California. The second volume, the Technical Report, provides detailed descriptions of study methodology and of the state agencies included in the case review, copies of instruments used in data collection, and detailed analysis of study data.

Special thanks go to all of the individuals who have contributed their time, expertise, and ideas to this study, including the staff of the Departments of Developmental Services, Health, Education, Rehabilitation, Social Services, Mental Health, Alcohol and Drug Abuse, and Employment Development; consultants Dr. Elinor Gollay and Valery Bradley, members of the State Council on Developmental Disabilities, and the many Review Group members and individuals who shed light on the complex issues involved in assessing the potential impact of adopting the federal definition of developmental disabilities in California.

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I. INTRODUCTION

The purpose of this report is to summarize the findings of BPA's study of the federal definition of developmental disabilities for the California State Council on Developmental Disabilities and the California Health and Welfare Agency. The purpose of the study was to estimate the total number of individuals in the State of California who meet the federal definition of developmentally disabled set forth in P.L. 95-602, to estimate the total number of those who are currently receiving services from various state agencies, to identify gaps in services currently available to those meeting the definition, and to analyze the potential impacts on the state service system of adopting the federal definition in California.

BACKGROUND

Services targeted to the developmentally disabled (DD) have their roots in federal legislation adopted in 1963 and 1967, providing services to the mentally retarded. The Developmental Disabilities Services and Facilities Construction Act of 1970 completely revamped this program by diversifying the purposes of the program, and by expanding the target population. The 1970 Act (PL 94-103) defined "developmental disabilities" to include mental retardation, cerebral palsy, epilepsy, as well as other neurological conditions. This act marked the beginning of a move toward an emphasis on similar service needs rather than clinical categories or impairments. Later legislation took this concept a step further by including autism as a "developmental disability," and by including individuals with intellectual functioning, behavior, or service needs similar to the mentally retarded, resulting from some other neurological condition.

Even with these changes, the definition continued to use a categorical basis for defining "developmental disabilities" and was found to permit varied interpretations, which made it difficult to establish program parameters and set program priorities. To some, the definition was interpreted

to include all individuals who fell into the four specified impairment categories, regardless of the degree of severity. To many, the definition was interpreted as excluding all those who did not fall into the four categories. By 1978, there was concern that scarce resources were not being focused on those most in need of services and that many with limitations and service needs similar to the DD population were not being served. This led to the new functional approach to defining the DD population set forth in PL 95-602. This new federal definition emphasized the complexity, pervasiveness, and substantiality of the disabling conditions to be addressed by the DD program by focusing on functional limitations rather than specific clinical categories. The new definition, as contained in PL 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 imitations 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 that are of lifelong or extended duration and are individually planned and coordinated.

At the federal level, the implementation of the new functional definition of DD was intended:

- to focus scarce resources on that segment of the disabled population most in need of services (i.e., the severely disabled);
- to emphasize that the developmentally disabled have in common a need for an individually planned combination and sequence of specially coordinated services, which are of lifelong or extended duration;

- to emphasize the need for special efforts to ensure that service agencies are responsible to the unique needs of the developmentally disabled, through: comprehensive planning, improved leverage on existing monies, increased access to existing services, interdisciplinary services in a variety of service delivery modes, advocacy to ensure the above, and coordination of services at the delivery point to ensure that needs are met; and
- to encourage access to services on the part of individuals with conditions or disabilities other than the four listed in PL 94-103, but who, nevertheless, share the functional limitations and service needs of this group.

California, like all other states receiving federal DD planning monies, has been required to adopt the new federal functional definition of developmental disability in its planning activities. The state, however, has far more discretion in deciding how to respond to the federal definition in shaping its own state-supported DD service system. This service system consists of service provided or administered by a wide variety of state agencies including the Departments of Rehabilitation, Social Services, Education, Employment Development, Mental Health, and Health Services. That portion of the services specifically targeted towards the developmentally disabled, administered by the Department of Developmental Services (DDS) within the California Health and Welfare Agency, currently offers:

- institutional care to approximately 8,000 individuals in eight state hospitals;
- case management services and purchase of other needed services to both the institutionalized population and developmentally disabled individuals residing in their local communities through 21 Regional Centers located throughout the state; and
- continuing care services to individuals making the transition from institutional settings to community living (in all but two

These concerns are cited in U.S. Department of Health and Human Services, Special Report on the Impact of the Change in the Definition of Developmental Disabilities, Washington, D.C., May 1981.

catchment areas, these services are provided by the Regional Centers themselves); and

- "habilitation" monies set aside for the provision of pre-vocational and vocational rehabilitation services to the developmentally disabled by the Department of Rehabilitation.

Currently, the definition of DD used for the state's own DD service system targets services to individuals with a substantial handicap who meet one of the five qualifying conditions stated in previous federal DD definitions (i.e., mental retardation, epilepsy, cerebral palsy, autism, and other neurological conditions resulting in similar service needs), and who became disabled prior to age 18.

PURPOSE OF THIS STUDY

The current study is intended to provide the California State Legislature, the Health and Welfare Agency, and the State Council on Developmental Disabilities with sufficient information: (1) to estimate the extent and service needs of the DD population identified by the federal functional definition, and (2) to make a decision about whether to adopt the federal definition to establish eligibility for its own state-supported DD service system. The study has been broken down into several components, which are designed: (1) to establish an agreed-on conceptual approach to follow in operationalizing the federal functional definition of developmental disability for California; (2) to estimate the prevalence of developmental disabilities among California State residents; (3) to estimate the present level of demand for and utilization of state-supported services by developmentally disabled individuals, and to estimate the costs and funding sources of these services; (4) to assess the extent to which the current inter-agency configuration of service delivery responsibilities for the disabled is meeting or failing to meet the needs of California's developmentally disabled residents; and (5) to analyze the implications of this information for policy decisions and alternative implementation strategies.

Study Issues

The issues to be tackled by this study are highly complex and highly controversial. While the current study is intended merely to provide background information to support subsequent policy decisions about who should be eligible for state-supported DD services and what the state-supported DD service system should look like, it has been impossible to completely avoid reference to these issues in developing data on the state's DD population and the impact of adopting the federal functional definition. It is our intent to present choices or point out the implications of alternative scenarios, wherever possible, rather than to advocate for one or another of the "alternative futures" for DD services in California.

Research issues addressed during the conceptualization and implementation of the study design included the following:

- (1) How should the federal definition be "operationalized"? That is, how should specific terms within the definition such as "substantial" or "onset" be further defined in order to determine whether these conditions are met by an individual or target group?
- (2) Is the operational definition of developmental disability primarily a tool for planning services for the DD population, or can it be expected to also serve as an eligibility determination tool for actual service delivery; and
- (3) What are the differences between prevalence estimates of the extent of developmental disabilities among California residents, and service-demand estimates based on actual utilization of state services, and how should these different *sets* of estimates influence California's service system response?

Each of these issues is discussed briefly below.

Operationalizing the Federal Definition

The federal definition of developmental disabilities has been subject to much criticism by those who perceive the age cut-off and the requirement

of three substantial functional limitations to be arbitrary. There has been much concern that the definition encompasses too broad a population to be useful as a planning or eligibility tool. The overriding assumption guiding this effort has been that the intent of the federal definition is to describe a target population which, because of the occurrence of functional limitations during developmental and formative years, has a distinctive need for case management and support services that differs from the need of those whose disabilities are less severe or have occurred later in life. It has been argued that for some types of disabilities, age of onset is relatively unimportant. For example, in the case of blindness, the relative disadvantages of blindness during childhood may be offset by the disadvantages of having to adjust to blindness later in life, and that, in fact, the attitudinal barriers that must be overcome and the need for services such as mobility training represent similarities that far outweigh the differences between those with early onset and onset in adulthood. However, others suggest that lowered expectations, limited opportunities for social development, barriers to community participation, burden on the family, that characterize those disabled early in life do, in fact, set the developmentally disabled apart from other disabled groups.

Other issues related to operationalizing the definition include:

- to what extent should the determination of specific criteria be specified through standards in the definition versus reliance on professional judgement?
- how stringent should the definition be? Should it seek to identify only those with the most substantial limitations or should it seek to identify the largest target group who may need an individualized "coordinated package of services?"

The first major component of the study sought to address these and other related issues. The operational definition used in this study is included as an appendix to Volume II of this study. A summary appears later in this chapter.

Use of the Operational Definition

The interpretive framework set forth in the Operational Definition of Developmental Disability (Berkeley Planning Associates, October 1982), discusses the various possible situations in which the operational definition can be applied: (1) to develop population estimates of the prevalence of developmental disabilities within the California state population as a whole, using published data and available data tapes on aggregate population characteristics; (2) to determine the proportion of state agency caseloads that meet the DD definition, through case file reviews; and (3) to determine whether an individual seeking services falls within the target DD population, through the collection of new data in an eligibility determination procedure. While the interpretative framework laid out in the Operational Definition offers a guideline for each of the applications, we have found that the actual implementation of the definition needs to be designed anew for each type of situation, based on the available data and the specific objectives. For example, in developing prevalence estimates, the descriptive data can represent rough approximations of the definitional criteria, 'because we are interested in population aggregates, rather than knowing whether a specific individual meets the definition. In contrast, in using the definition for making eligibility determinations, the need for detailed documentation expands, as does the need to design a number of different instruments, each of which is relevant to the data maintained by a particular agency, or the particular measures of functioning relevant to a particular type of impairment or age group. The implication of this phenomenon is that it appears that no single instrument can be developed to operationalize the DD definition for all the different subgroups within the DD population. In the present study, we developed a different case file review instrument for each of the different state agencies for which case file reviews were performed.

Prevalence Estimates Versus Service Utilization Estimates

In the original RFP, the state requested a research design that would utilize a cross-agency comparison of specific DD individuals receiving state services to develop an unduplicated estimate of the number of DD individuals in the state and the current level of service utilization within the state's DD population. However, the proposed case file review did not suffice to obtain these estimates because it proved infeasible to collect data from every agency and program that serves individuals who may meet the DD definition (due to lack of available and sufficient data, and the sheer number of different programs), and because cross-agency tracking of individuals using case identifiers proves cumbersome in terms of coordination, confidentiality issues and time burden on the agencies involved. Therefore, case file review data were supplemented with population prevalence estimates, based on existing population statistics for a sense of the total potential demand for DD services. It rapidly became apparent that these prevalence estimates are far larger than agency estimates of the number of developmentally disabled currently receiving services. If taken seriously as an indication of the potential demand for state-funded DD services, these estimates would suggest the possibility of up to a four-fold increase in the service demand.

These statistics make it clear that the actual demand for services at any given time falls far short of the total number of functionally limited individuals in the state and leads to the suppositions: (1) that individuals are being served by family, church, and other sources that are keeping them out of the public service system; and (2) that the demand for services waxes and wanes for a given individual over time, leading to a smaller proportion of the total population receiving services at any one time. We do not anticipate that the population estimates represent a latent demand that could be awakened by the implementation of the federal functional definition. Rather, these estimates must be analyzed in the context of utilization data, to be useful as a planning tool.

Primarily data from the 1976 Survey on Income and Education (SIE) for California collected by the Bureau of the Census.

DESCRIPTION OF STUDY COMPONENTS

The work performed as part of this study has been organized into four components: 1) a study design phase; 2) the development of estimates on the prevalence of developmental disabilities among California residents; 3) the development of estimates of the frequency with which DD individuals utilize a number of different state agency programs; and 4) an assessment of unmet service needs among different subgroups within the DD population.

Study Design

The study design phase consisted of three main components:

- the development of an operational definition;¹
- the design of case file review instruments² and
- the development of a needs assessment approach to follow in assessing unmet needs.³

The first of these, developing an operational definition for use in the study, was a critical step on which the rest of the design was built. The operational definition developed was designed to provide sufficient clarification of parameters in the definition to allow for developing case review instruments for determining retrospectively the preparation of agencies' caseloads meeting the definition. The operationalization for this purpose was necessarily different than would be required for determining eligibility of individuals through current assessment because of the data availability and level of data specifically decreases significantly using retrospective case file data. The case file review process relied to some extent on proxies or influences that could be made from existing data. In contrast, use of the definition during eligibility review requires specification of the specific measures that would be used in collecting client data, complicated by the following factors:

¹Included as Appendix A in Volume II, Technical Report.

²Included as Appendix H in Volume II, Technical Report.

³Included as Appendix J in Volume II, Technical Report.

- the need to apply different standards in defining substantial functional limitations for different age groups;
- the need to utilize different assessment procedures and tests for individuals with different types of impairments;
- the need to balance the desire for consistency of application of the operational definition across geographic service sites and across different impairment types with the desire to permit both individual site flexibility and professional discretion.

The operational definition used in this report is a study framework describing the different components of the definition of developmental disability set forth in PL 95-602. This framework includes a brief statement of each of the definitional criteria (all of which must be satisfied for an individual to meet the federal DD definition), followed by guidelines to be used in interpreting each criterion and in determining whether it has been satisfied. The same guidelines are appropriate for each of the different types of applications of the operational definition, though the procedures for testing whether each criterion has been satisfied will vary from application to application, depending on the availability of data, as described earlier.

This work built on previous work conducted by Elinor Gollay, Ph.D., and Morgan Management Systems, and incorporated comments received on the draft by a variety of sources including the National Association of Developmental Disabilities Councils. BPA's revision of the operational definition for use in California was presented to members of the State Council and the Project Review Group along with a list of issues for their consideration as a vehicle for focusing discussion and comments. The most notable modifications included:

- a change in the order in which the criteria are presented to reflect a more logical sequence;
- a broader interpretation of the age at onset criterion in which retrospective determination in the case of severely disabled adults requires the disability to have "manifested"

Elinor Gollay, Operational Definition of Developmental Disabilities, Gollay & Associates (June 1981).

itself (begun to limit functioning) prior to age 22 but not necessarily to have reached a "substantial" degree of limitation prior to age 22;

- an age-specific application of the substantial limitation criterion which reflects the different degree of relevance of each of the functional areas to different age groups (based, in large part, on a similar approach in the draft Gollay document), requiring only one of four limitations for the under-5 age group and two of five limitations for the 5-21 age group;
- a consideration of the hypothetical functional limitations the individual would have had without the support of any services that are currently being provided;
- an interpretation of the age-at-onset criterion to include manifestation of impairment with some functional limitation prior to age 22 without requiring functional limitations to have been substantial prior to age 22;
- the selection of 2.0 standard deviations and 2.5 standard deviations from the norm as alternate indicators of age-inappropriate functioning, rather than the three standard deviations proposed in the Gollay operational definition. (In fact, few standardized measures of functional limitations exist or are used consistently. For the purposes of case file review, "needs assistance" was a useful rule of thumb for substantiality in some of the functional areas.)

These aspects of the operationalized definition played an important role in the subsequent design of case file review instruments, in the training of the case reviewers. Instruments developed to collect case review data were pretested in the appropriate agency by double review of 5-10 cases by two reviewers. Inconsistencies in coding or recording of case information were discussed and resolved and, in some cases, the instruments themselves were revised. The review of Regional Center cases, which involved a high degree of reviewer judgment to determine age-appropriateness of functional data, were reviewed by the same study team in all four sites to ensure consistency across subsamples.

The Development of Prevalence Estimates

The primary data source used to develop prevalence estimates has been the California survey responses to the 1976 Survey of Income and Education (SIE), conducted by the U.S. Bureau of the Census. The availability of actual SIE data tapes for California has enabled this study to go beyond several previous efforts 1) because the data on DD prevalence are based on actual California responses, rather than applying nationally-derived population estimates to general California population statistics, and 2) because the availability of the actual tapes has made it possible to compare the impact of several alternate specifications of the DD definition. The description of preliminary findings from this study component in the next chapter addresses the following study issues:

- the prevalence of developmentally disabled in California as estimated using SIE data;
- characteristics of the developmentally disabled in California as described by SIE data; and
- a comparison of developmentally disabled, other severely disabled, and other disabled.

The Development of Estimates of Service Utilization

After a careful review of the programs administered by eight different state agencies – the Department of Social Services, the Department of Mental Health, the Department of Education, the Department of Developmental Services, the Department of Rehabilitation, the Department of Health Services, the Department of Alcohol and Drug Abuse, and the Employment Development Department – a group of programs was selected to be included in a case file review process used to estimate the extent of DD representation in existing agency caseloads. The programs were selected for case review on the basis of the sufficiency and availability of data and the likelihood that some number of the cases reviewed would be DD.

Five programs offered sufficient data to make reasonable determinations of DD status among a population sufficiently likely to include DD individuals. Those selected for case file review included Special Education

(Department of Education); California Children's Services (Department of Health); Regional Centers (Department of Developmental Services); In-Home Supportive Services (Department of Social Services); and Rehabilitation Services (Department of Rehabilitation).

The findings included in this Interim Report consist of the preliminary results from a univariate analysis of the information on 566 individuals whose case files were randomly selected for review.

Questions addressed by this component include:

- What proportion of all service recipients in these five programs meet the federal definition of developmental disability?
- What are the characteristics of the DD populations being served in these programs?

Additional bivariate analyses performed on the service demand data before the submission of the Final Report will include a look at the range of services received by developmentally disabled individuals enrolled in state agency caseloads, and will attempt to estimate the costs of these services relative to other client groups.

An Assessment of Service Needs and Service Gaps

The RFP expressed a hope that it would be possible to infer or develop an assessment of service needs from information in case files on service needs and gaps or from detailed information on the functional limitations of a particular individual. Unfortunately, little data on assessed needs, service utilization across agencies, and service gaps was available in case files, which would support the development of an individually derived service needs model. A deductive service needs model (inferring service needs from a description of functional limitations) is also not possible, since an individual's service needs at a given time are influenced not only by the existence of a particular functional limitation but also by the individual's living situation, service history, prognosis, ability of parents, friends, or relatives to assist in the provision of services, and the range of existing services available in the community.

Thus, the approach selected for assessing service needs among different subgroups of developmentally disabled depends on interviews with key

informed observers representing service program administrators, line service workers and casework supervisors, as well as advocacy groups and consumer representatives.

The following chapters provide a summary of the findings of each of these study components. The final chapter offers alternative scenarios for implementation of the definition through the state service system. Additional detail on study methodology, prevalence estimates, and case review findings can be found in the, Technical Report, Volume II of this Final Report.

II. ESTIMATES OF THE SIZE AND CHARACTERISTICS OF THE DP POPULATION IN CALIFORNIA

The data presented here are estimates, and thus are reported to the nearest thousand and, where applicable, confidence intervals (at the 95% confidence level) are given. All figures are derived from the 1976 Survey of Income and Education conducted by the Bureau of the Census, unless otherwise specified. The following pages present a summary of two different kinds of data, estimates of the prevalence of developmental disabilities, and descriptive information about the characteristics of the DD population.

ESTIMATES OF THE PREVALENCE OF DEVELOPMENTAL DISABILITIES

The SIE data indicate that approximately a quarter million individuals (245,000 ± 67,000) in California meet the federal definition of developmental disability. This represents just over 1% (1.17 ± .3) of the almost 21 million people in the state at the time of the survey. An additional 2.5 million (2,485,000 ± 202,000) are disabled (limited in a major life activity due to a limiting health condition), but not DD. Thus, according to these figures, the developmentally disabled represent approximately 9% of the total disabled population in the state. These figures differ slightly from the national SIE estimates in which the DD represent approximately 1.22% of the general population, but only 8.6% of the disabled.

For the purposes of this analysis, we have defined the severely disabled as those who frequently need help in at least one functional area or occasionally need help in at least two areas. Using this definition, about 28% of the disabled are severely disabled, representing an estimated three-quarters of a million (775,000 ± 115,000) people, or just under 4% (3.7% ± .5% of the state population. Thus, the developmentally disabled represent about 30% of the severely disabled population. Figures 1-3 illustrate the relationships of these subpopulations.

National figures are from Gollay, Estimates of the Size and Characteristics of the DD Population in the U.S., June 1981.

Figure 1
Estimated Prevalence of DD Among Total Population

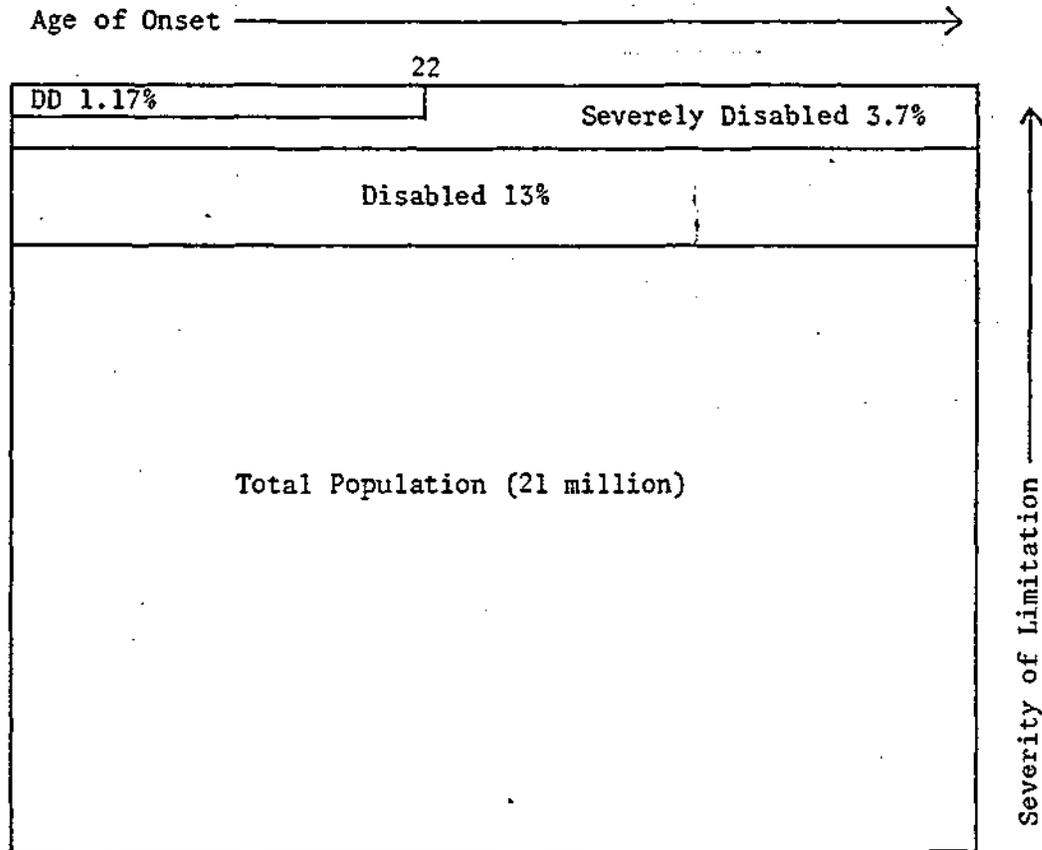


Figure 2
Estimated Prevalence of DD Among the Disabled

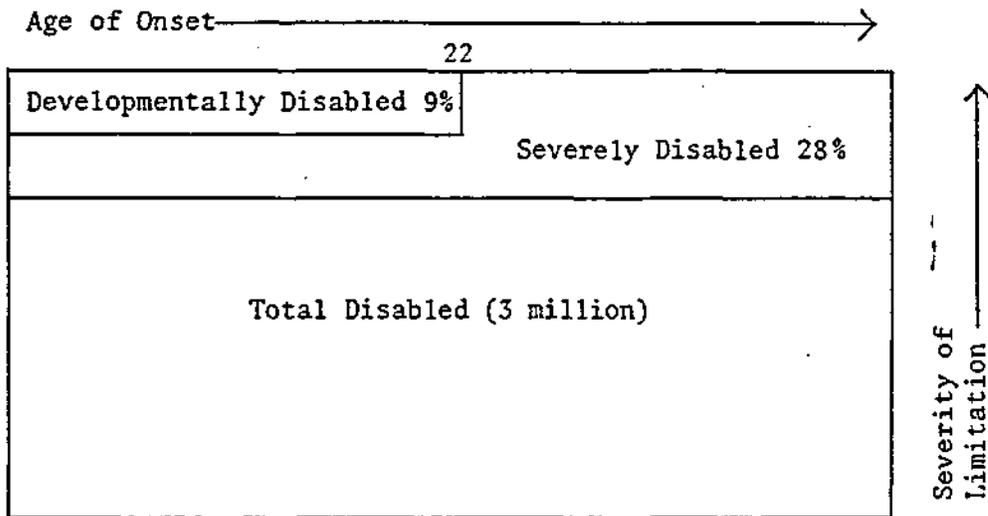


Figure 3
Estimated Prevalence of DD Among the Severely Disabled

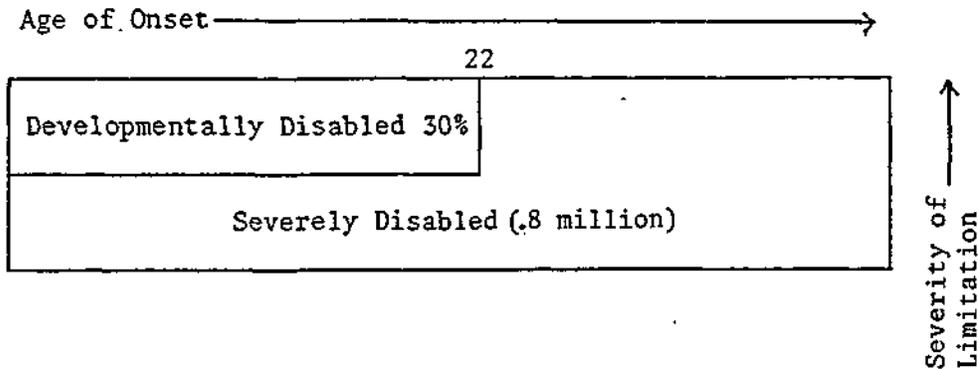


Table 1 illustrates the prevalence of developmental disabilities among different disability or impairment groups. Note that 100% of the mentally retarded are counted as developmentally disabled. It is assumed that the SIE estimate may tend to undercount the mentally retarded, partly due to the stigma attached to the label (disabilities are self- or family-reported) and partly to the fact that the SIE does not include institutions, nursing homes, or group homes. Thus, all reported as mentally retarded are counted in the DD estimate. This should not be interpreted to imply that all retarded persons, in fact, meet the federal definition. Note also the high proportion of speech impaired that are DD. The SIE did not count all individuals with speech impairments, only those with a condition limiting a major life activity. Thus speech impairments, which are less likely than other conditions to limit a major life activity, are probably generally reported for individuals who also have another, more disabling condition.

Perhaps the most interesting observations about the prevalence of developmental disabilities among specific disability groups as estimated by the SIE are the relatively high proportion of the emotionally disturbed considered to be DD (44%) and the relatively small proportion of developmentally disabled among the physical disabilities (2-10%). It is also interesting to note that, although the proportion of physically disabled who are DD is low, the number of physically disabled is so large that it still makes up the largest disability group within the DD population.

CHARACTERISTICS OF THE DD POPULATION

Age

As shown in Table 2, the largest group of developmentally disabled is the 6-17 age group representing approximately 46% of the population. This may be partly due to the fact that the age of onset criterion can be more clearly determined for this age group than for the older population. However, this is also consistent with the definition's focus on functional limitations, such that adults who have overcome their disabilities sufficiently to work would not be considered developmentally disabled even if they had a disabling condition that might have qualified them at a younger age. This is somewhat different from the "once DD, always DD" philosophy that has been previously common in the DD system.

Table 1
Prevalence of DD Among Disability Groups

Limiting Health Condition	Total Number With Impairments	Number of DD With Impairments	Percent
Mentally Retarded	70	70	100%
Emotionally Disturbed	77	34	44
Visually Impaired/Blind	153	23	15
Deaf	35	11	31
Orthopedic	257	26	10
Nervous Disorder	159	16	10
Respiratory	301	23	8
Hard of Hearing	117	12	10
Speech Impaired	44	30	68
Heart Trouble	488	30	6
Arthritis/Rheumatism	474	21	4
Back or Spine	552	11	2
Stomach Trouble	133	4	3
Other	775	26	3
Total Number of Impairments	3,634	337	9.3%
Total Number of Individuals	2,730	245	9.0%
Average Number of Impairments	1.3	1.4	

Table 2
Age Distribution Across Subpopulations

	DD Disabled	Severely Disabled	Total Disabled	Total Population
Infant (0-2) ^a	--	--	--	4%
Preschool (3-5)	4%	4%	1%	5
School Age (6-17)	46	31	11 ¹	21
Adult (18-64)	32	43	62	61
Elderly (65+)	17	21	26	9
Total	99% ^b	99%	100%	100%

^aDisability data was not collected on this age group.

^bTotal is less than 100% due to rounding error.

Source: Survey of Income and Education, Bureau of the Census, 1976 (California data).

In comparing the total disabled to the general population, one finds a disproportionately large number of disabled among the elderly, reflecting the many disabilities associated with aging. However, when looking at the more severely disabled, the distribution shifts to the younger age groups reflecting a higher proportion of those severe disabilities that occur in higher proportions in the younger age groups (e.g., mentally retarded, deaf).

Sex

As shown in Table 3 below, developmental disabilities appear to be relatively evenly distributed across males and females with a slightly higher proportion of males than found in other subpopulations or in the total population.

Table 3
Comparison of Sex Distribution Across Subpopulations

	Total Population	All Disabled	Severely Disabled	DD ..
% Male	48.7%	47.1%	47.1%	50.7%
% Female	51.3%	52.9%	52.9%	49.3%

When viewed across age groups, however, the difference is more apparent. Within the DD population, males account for 64% of the 18-64 age group; while 95% of the relatively small group of DD elderly are female. While it is true that females predominate in the older group of the general population, Table 4 shows that among the total population this effect is much less pronounced than among the DD.

Table 4
Sex Distribution by Age Group

	Total Population		DD	
	Male	Female	Male	Female
3-5	489 (51%)	472 (49%)	7 (68%)	4 (32%)
6-17	2,257 (51%)	2,167 (49%)	64 (37%)	48 (43%)
18-64	6,278 (49%)	6,468 (51%)	50 (64%)*	29 (36%)
65+	822 (41%)	1,167 (59%)	2 (3%)*	41 (95%)

* Difference between males and females is significant at the .05 level.

Source: Survey of Income and Education, Bureau of the Census, 1976
(California data).

Ethnicity

Given that the largest ethnic response category among all subpopulations was "other," little can be said about the ethnicity of the DD population. It is not known why so many respondents were categorized as "other," nor is any breakdown of the specific responses included in this category available. If one assumes the same response bias among the DD as the non-DD, Table 5 suggests that blacks are somewhat more likely to be DD than other groups. While the national SIE data suggest that blacks are more likely to be reported mentally retarded or DD physically impaired, and Native Americans are more likely to be reported as mentally retarded or DD sensory impaired (than the population as a whole), these data are subject to the same cautions regarding high response in the "other" category.

Educational Level

The SIE includes a number of data items related to educational status. The most simple and straightforward of these is "highest grade attended." As shown in Table 6, the DD are more likely than other subpopulations or the total population to have had no education. They are correspondingly less likely to have finished high school or continued on to college than are the other groups.

Functional Limitations

The functional areas in which the highest proportion of developmentally disabled are limited are economic self-sufficiency (94%), learning (78%), capacity for independent living (70%), and language (64%). Table 7 illustrates the prevalence of functional limitations across different age groups within the DD population. In addition to the high prevalence of limited economic self-sufficiency across all age groups, DD preschoolers show a high prevalence of learning and mobility limitations, DD school children show a high prevalence of learning and language limitations, DD adults show a high prevalence of language and self-direction limitations, and the DD elderly are all limited in capacity for independent living and mobility.

Gollay, Estimates of the Size and Characteristics of the DD Population in the U.S., June 1981.

Table 5
Comparison of Ethnic Distribution Across Subpopulations
(In Thousands)

Frequency: Row Percent:	DD	All Severely Disabled	All Disabled	Total Popula- tion
White	46 1.0%	171 3.8%	670 14.7%	4,557
Black	32 2.1%	92 6.0%	296 19.3%	1,535
Hispanic	30 0.9%	85 2.5%	318 9.5%	3,348
Asian/Pacific	6 0.8%	19 2.4%	48 6.1%	787
Native American	2 <0.1%	17 15.6%	31 28.4%	109
Other	129 1.2%	383 3.6%	1,337 12.7%	10,519
Unknown	-- --	7 5.2%	30 22.4%	134
Total	245 1.17%	774 3.69%	2,730 13.01%	20,987 100.0%

Source: Survey of Income and Education, Bureau of the Census, 1976
(California data).

Table 6
Comparison of Highest Grade Attended Across Subpopulations
(In Thousands)

Frequency: Column Percent:	DD	All Severely Disabled	All Disabled	Total Population
Children Under 14	60 26.8%	162 20.9%	217 8.0%	4,703 22.4%
None	40 16.4%	39 5.1%	69 2.5%	143 0.7%
Some Elementary	13 5.5%	45 5.9%	156 5.7%	444 2.1%
Finished Elementary	9 3.8%	24 3.2%	86 3.2%	335 1.6%
Junior High	36 14.8%	115 14.9%	474 17.4%	1,802 8.6%
Some High School	41 16.9%	126 16.2%	404 14.8%	2,152 10.3%
Finished High School	23 9.3%	144 18.7%	709 26.0%	4,786 22.8%
Some College	8 3.2%	74 9.5%	398 14.6%	3,891 18.5%
Finished College	8 3.3%	44 5.7%	216 7.9%	2,737 13.0%
Total	245 1.17%	774 3.69%	2,730 15.0%	20,987 100.0%

Source: Survey of Income and Education, Bureau of the Census, 1976 (California data).

Table 7
Activity Limitation by Age -- DD Persons Only
(In Thousands)

Activity Limitation	3-5 Years	6-17 Years	18-64 Years	65 and Over Years	TOTAL
<u>Self-Care</u>					
# Individuals	2	23	24	26	76
% Persons in Age Group	17.3%	20.7%	30.8%	61.9%	31.0%
<u>Language</u>					
# Individuals	6	97	57	6	165
% Persons in Age Group	51.1%	86.3%	72.2%	13.4%	67.4%
<u>Learning</u>					
# Individuals	9	110	68	3	191
% Persons in Age Group	82.7%	98.3%	86.3%	7.1%	77.8%
<u>Mobility</u>					
# Individuals	9	9	18	43	79
% Persons in Age Group	84.9%	7.8%	22.6%	100.0%	32.1%
<u>Self-Direction</u>					
# Individuals	4	33	62	3	102
% Persons in Age Group	36.0%	29.0%	79.1%	7.1%	41.7%
<u>Capacity for Independent Living</u>					
# Individuals	6	47	76	43	171
% Persons in Age Group	53.2%	41.7%	95.8%	100.0%	69.8%
<u>Economic Self-Sufficiency</u>					
# Individuals	11	112	72	35	231
% Persons in Age Group	100.0%	100.0%	91.8%	81.8%	94.2%
Total Limitations	47	431	377	159	1015
Total Individuals	11	112	79	43	245
Average # Limitations	4.5	3.8	4.8	3.7	4.1

Source: Survey of Income and Education, Bureau of the Census, 1976 (California data).

III. UTILIZATION ESTIMATES

Of the initial eight agencies considered for inclusion in the case review, three were eliminated because of difficulties experienced in obtaining sufficient data to determine DD status. These were:

- Employment Development Department;
- Department of Alcohol and Drug Abuse; and
- Department of Mental Health.

The Employment Development Department estimates that just over 3% of their 1.8 million applicants in FY 1982 were disabled, or approximately 60,000 individuals. The proportion of these who are developmentally disabled is unknown. However, it is reasonable to assume that the proportion who are DD would be somewhat less than the 9% suggested by the SIE data, since the developmentally disabled, most of whom are limited in economic self-sufficiency, are probably less likely than other disabled to be seeking employment.

The Department of Alcohol and Drug Abuse estimates that about 1,900 individuals 22 years of age or under will enter residential or prison drug programs during FY 1983. An estimated 1,000 youths of age 22 or under enter residential alcohol programs each year. In addition, some proportion of the 6,500 adult entrants into residential programs may have had onset prior to age 22, and some of the estimated 120,000 youths and adults who will enter detoxification or outpatient facilities may meet the definition. While the number is difficult to estimate, probably 2-5% of alcohol and drug abuse clients would meet the new definition.

The Department of Mental Health data suggest that approximately 16,500 youths under age 22 receive 24-hour care or partial day-care through state hospitals and community mental health services. While this may include some individuals with unknown chronicity and some double-counting of individuals who use both the state hospitals and community mental health

These figures represent admissions during the year, thus excluding longer term clients but double-counting individuals who are admitted more than once.

services, it probably still represents a conservative estimate since it does not include any adults who may have had early onset.

The remaining five agencies from which specific programs were selected for case review included:

- Department of Health Services, California Children Services;
- Department of Social Services, In-Home Supportive Services;
- Department of Rehabilitation, Vocational Rehabilitation Services;
- Department of Developmental Services, Regional Centers; and
- Department of Education, Special Education Services.

The nature of the client data available varied tremendously among programs selected for case review. This necessitated development of a different review instrument for each agency reviewed. Sampling procedures also varied across agencies. It is especially important to review the case review data in the context of the characteristics of each sample and the caseload from which it was selected. Table 8 offers a summary of the major differences between samples for reference in reviewing the findings.

CALIFORNIA CHILDREN SERVICES

Description of CCS Sample

Among the clients in our case file review sample, over one-quarter (26-30%) fall within the federal DD definition, an increase of 11 to 14 percentage points in relation to the proportion (15-16%) of clients meeting the current state DD definition. As shown in Table 9, over half (53%) of this sample are between the ages of 6 and 17, and over one-fourth (26%) are under age 6. This is consistent with the age distribution of the agency caseload. Males outnumber females by 56% to 42%. Race is unknown for a fairly large proportion (20%). Whites account for almost two-fifths (39%) of the group, and Hispanics just over one-fifth. No one in the sample is known to receive SSI, and in fact, for almost four-fifths (78%), SSI status is unknown. This is as might be expected, since most individuals would not receive SSI until after age 18.

The higher percentage includes those judged "likely" to meet the federal DD definition.

Table 8

Characteristics of Case Review Samples

Agency Program	% of Sample DD ^a	Age of Sample	Population Served by Agency	Groups Excluded From Sample	Agency Caseload Size	% of Agency Caseload DD ^g	Estimated Number of DD Individuals ^g
CCS	26-30%	0-21	Physically disabled	MFTU ^b (22% of caseload)	54,000	74% ± 10%	25,000 ± 5,300
IHSS	33-36%	60	All disabilities, all ages	Age 60+ (77% of caseload)	93,000	8% ± 5%	7,700 ± 4,600
Regional Centers	88-92%	All ages	Old DD	At-risk infants, cases open longer than two years	63,000	92% ± 4% of recent intakes ^c	58,000 ± 2,500
Special Education	14-45%	0-21	All disabilities	DIS ^d (32% of caseload) SCC and NPS ^e (31% of caseload)	358,000	48% ± 14%	171,000 ± 50,000
Vocational Rehabilitation	14-25%	Adults	All disabilities	Severe MR + other groups assumed DD (7.4% of caseload)	29,500 ^f	27% ± 9%	8,000 ± 2,600

^aUpper percentage includes those judged "likely" to be DD ("liberal" estimate).

^bMedical Therapy Unit participants are assumed to be DD.

^cPrevalence of non-DD among total caseload may be a little higher, but since the expectation is that they would be "grandfathered in," percentage of recent intakes is a more useful estimate.

^dDesignated Instruction and Services Program - assumed to be non-DD.

^eSpecial classes and centers and nonpublic schools - assumed to be DD.

^fTotal number of cases closed in status 26 or 28 over last two years.

^gBased on "liberal" estimate; range represents 95% confidence interval.

As shown in Table 10, physical disabilities are by far the most frequent among the CCS clients, occurring in 87% of the cases. The next most frequent in incidence, at only 15%, occurs for sensory impairments. Of those eligible under the old definition, cerebral palsy shows the greatest incidence (9%).

Clients who meet the federal DD definition are most frequently physically disabled (75%) and/or multiply disabled (50%). A significant minority of these DD individuals have sensory impairments (23%), are mentally retarded (23%), and/or have neurological impairments (17%) as a second disability. The developmentally disabled in the sample are more likely than other CCS clients to be mentally retarded or learning disabled, and multiply disabled.

Prevalence of DD in the CCS Caseload

As mentioned above, an estimated 26% to 30% of the cases sampled meet the DD definition. However, this sample only includes non-MTU participants, about 54,000. Thus, roughly 12,000 individuals were counted as DD from the outset. If 30% of the remaining 42,000 children are DD, then this means an estimated additional 12,600 individuals are defined as DD. The total estimated population of DD clients is then about 25,000, for a prevalence among CCS clients of roughly 45%.

The number of individuals served by CCS who meet the current (old) state definition of DD is unknown. However, it has been suggested that a reasonable proxy is the number of individuals with cerebral palsy (and related diagnoses) as the primary disabling condition. While it may be true that others would meet the categorical definition also, since they are identified by primary orthopedic impairment, it is impossible to determine how many that might be. CCS staff estimate the number potentially excluded by use of this proxy to be very small. Thus, we might estimate that 9,000, or 12% of the CCS caseload meet the "old" definition in contrast to 45% who are estimated to meet the federal definition.

The higher figure includes "likely" DD.

Table 9
California Children's Services
Demographic Characteristics of Sample
(N=100)

		Percent			Percent	
<u>Age</u>	0-2	12%	<u>SSI Status</u>	Not receiving	22%	
	3-5	14		Unknown	78	
	6-17	53		Total	100%	
	18-21	19		<u>Eligible Under Old Definition^a</u>		
	22-23	2		MR	7%	
<u>Sex</u>	Total	100%	CP	9		
			Male	56%		
			Female	42		
			Unknown	2		
<u>Race</u>	Total	100%	Epilepsy	3		
			CP and Epilepsy	1		
			Autism	0		
			Developmentally Delayed	1		
			Not Categorically eligible	89		
<u>Race</u>	Total	100%	^a Percents total more than 100% because of multiple disabilities.			
			White	39%		
			Black	16		
			Hispanic	21		
			Other	4		
Unknown	20					
Total	Total	100%	Total	100%		

Table 10
California Children's Services
Disability Type^a

Disability Type	Total CCS Sample (N=95)		DD Cases in CCS Sample (N=30)	
	n	(%)	n	(%)
Mental retardation	7	(7%)	7	(23%)*
Emotional disability	2	(2%)	1	(3%)
Sensory impairment	15	(16%)	7	(23%)
Physical disability	83	(87%)	29	(97%)
Neurological impairment	8	(8%)	5	(17%)
Learning disability	4	(4%)	4	(13%)*
Multiply disabled	18	(19%)	15	(50%)*

^a Percentages total more than 100 because of multiple disabilities.

* Disability categories in which the DD subset of all clients is significantly different from the non-DD subset at the .05 confidence level.

Service Utilization

The DD clients in the case review sample used more services on the average than did non-DD clients. The most dramatic difference was in the use of medication and treatment services where 75% of the DD were receiving the service compared to 25% of the non-DD.

IN-HOME SUPPORTIVE SERVICES

Description of IHSS Sample

Based on our case file review sample, the adoption of the federal DD definition would appear to increase the proportion of IHSS clients defined as developmentally disabled from 13% to 33-36%. As shown in Table 11, almost 95% of the IHSS sample fall within the "adult" years of 22-64, and almost two-thirds (65%) are female. Approximately half (46%) are white, with blacks and Hispanics accounting for about one-fifth additional each. Over four-fifths (81%) of the IHSS sample receive SSI. As with the CCS sample, physical disabilities exhibit the most frequent incidence among IHSS clients in our sample (83%), with emotional disabilities next most frequent at 17% (Table 12).

Of those eligible under the old definition, mentally retarded are the largest group, with 13% of the sample; epileptics are the next largest group, with 8% of the sample. The subset of the IHSS sample who meet the federal DD definition are most frequently physically disabled (72%) and mentally retarded (37%). In contrast to the total IHSS caseload sample, the DD recipients of IHSS services are more likely to be mentally retarded or neurologically impaired and less likely to be physically disabled.

Prevalence of DD in the IHSS Caseload

As mentioned above, an estimated 33% to 36% of the cases sampled meet the DD definition. However, this sample does not include the 60+ age group which accounts for 77%² of the total caseload. Thus, 36% of the 23% (under

The higher percentage includes those judged "likely" to meet the DD definition.

²State survey of IHSS recipients, April 1980.

Table 11
In-Home Support Services
Demographic Characteristics of Sample
(N=100)

	Percent		Percent
<u>Age</u>		<u>SSI Status</u>	
6-17	4%	Receiving	81%
18-21	2	Not receiving	11
22-64	94	Pending	2
65+	2	Unknown	6
Total	100%	Total	100%
<u>Sex</u>		<u>Eligible Under Old</u>	
Male	34%	<u>Definition^a</u>	
Female	65	MR	13%
Unknown	1	CP	3
Total	100%	Epilepsy	8
		Autism	0
		Developmentally delayed	0
		Not categorically eligible	78
<u>Race:</u>			
White	46%		
Black	21		
Hispanic	18		
Other	7		
Unknown	8		
Total	100%		

^a Percents total more than 100% due to multiple disabilities.

Table 12
In-Home Supportive Services
Disability Type^a

Disability Type	Total IHSS Sample (N=92)		DD Cases in IHSS Sample (N=35)	
	n	(%)	n	(%)
Mental retardation	13	(14%)	15	(37%)*
Emotional disability	15	(16%)	4	(11%)
Sensory impairment	7	(8%)	2	(6%)
Physical disability	79	(85%)	26	(72%)*
Neurological impairment	11	(12%)	9	(25%)
Learning disability	0	(0%)	0	(0%)*
Multiple disabled	25	(27%)	12	(33%)

^a Percentages total more than 100 because of multiple disabilities.

* Disability categories in which the DD subset of all clients is significantly different from the non-DD subset at the 95% confidence level.

60) of the total caseload is DD (8%), or roughly 7,700 clients, the majority of whom are assumed to be in the under-60 population.

Service Utilization and Service Costs for IHSS Clients

IHSS service utilization estimates based on a 1980 survey of 1,200 recipients conducted by the Department of Social Services indicate that by far the most frequently used services are domestic and related services followed by personal care. Transportation (primarily for medical appointments) is also a heavily used services. Protective supervision has the highest average number of hours per recipient, followed by personal care.

Approximately \$270 million annually is spent on IHSS services to about 93,000 recipients. This yields an average cost of \$242 per person per month. The average cost per participant in the case review sample of recipients under 60 is similar to that of the caseload as a whole. However, there is a clearly higher cost attributable to those determined to meet the DD definition. This is accounted for by a substantially higher use of personal care services among severely physically disabled. The utilization of other services does not appear substantially different between persons with and without developmental disabilities.

REGIONAL CENTERS

Description of Regional Center Sample

The great majority of Regional Center clients meet both the old and new definitions, though switching to the federal definition would generate a small drop in the proportion defined as DD from 95%¹ to 88-92%².

As shown in Table 13, the bulk of the sample falls within either the "adult years" of 22-64 (43.5%) followed by the "school years" of 6-17 (22%). Males outnumber females by 55% to 45%. Whites make up 65% of the sample, with the remainder relatively evenly split between blacks, Hispanics, and other races. Sixty percent receive SSI, which is the second-highest proportion (after IHSS) among the five agencies sampled.

By far, mental retardation has the largest representation among these clients, 85% of whom are mentally retarded. Significant proportions of the clients possess physical disabilities (37.5%) and/or neurological impairments (28.5%) (Table 14).

Prevalence of DD Among Regional Center Caseloads

The vast majority of Regional Center clients would continue to be defined as DD if the federal definition were adopted. Other states have experienced a dramatic decrease in the "old DD" population that is defined as DD under the federal definition. In some states, it appears that this decrease more than offsets the inclusion of new populations. However, in California, this is not the case. Because California Regional Centers take seriously the substantial handicap criteria of the current definition, few recently accepted clients would be excluded if the definition were adopted.

As mentioned previously, an estimated 88-92% of the recent intakes were judged to meet (or likely to meet) the DD definition. Of the current 63,000 cases, this would represent 57,960 individuals (using the 92% estimate) if the same prevalence were true among earlier intakes. In actual fact,

¹There were actually a number of clients judged by our reviewers as not meeting the current state definition of DD. However, rather than suggesting that Regional Centers are out of compliance with current state mandates, this probably reflects lack of adequate case file data.

²The higher percentage includes those judged "likely" to meet the definition.

Table 13
Regional Center
Demographic Characteristics of Sample
(N=200)

	Percent		Percent
<u>Age</u>		<u>SSI Status</u>	
0-2	8.5%	Receiving	60.0%
3-5	8.5	Not receiving	25.5
6-17	22.0	Pending	3.0
18-21	17.0	Unknown	11.5
22-64	43.5		
65+	.5		
Total	100%	Total	100%
<u>Sex</u>			
Male	55.0%		
Female	45.0		
Unknown	0.0		
Total	100%		
<u>Race:</u>			
White	65.0%		
Black	12.0		
Hispanic	14.0		
Other	8.5		
Unknown	.5		
Total	100%		

Table 14
Regional Center Disability Type^a
(N=200)

Disability Type	Total R.C. Sample (N=199)		DD Cases in R.C. Caseload (N=183)	
	n	(%)	n	(%)
Mental retardation	169	(85%)	161	(89%)
Emotional disability	9	(5%)	9	(5%)
Sensory impairment	12	(6%)	11	(6%)
Physical disability	74	(38%)	67	(37%)
Neurological impairment	57	(28%)	52	(29%)
Learning disability	18	(9%)	16	(9%)
Multiple disabled	101	(51%)	95	(52%)
Nondisabled or missing	2	(1%)	--	--

^aPercentages total more than 100 because of multiple disabilities.

* There are no disability categories in which the DD subset of all clients is significantly different from the non-DD subset at the 95% confidence level.

there may be a slightly higher proportion of non-DD among "old" cases. However, since it is anticipated that these individuals would retain eligibility for service through "grandfather" provisions, the estimate of prevalence among current intakes is more useful (and, in any case; "old" cases represent a relatively small proportion of the current caseload) .

Regional Centers are expected to spend \$205,866,000 during FY 1983, with 37% of this total going towards the operations of the Regional Centers themselves and the remaining 63% (\$129,545,000) used to purchase services for their clients. Of the purchase-of-service total, by far the largest portion is used to purchase out-of-home care for clients, with large amounts also devoted to the cost of day programs and "other" services.

During the sample month of June 1982, the Regional Centers purchased services for 30,535 different clients – nearly 50% of their total caseload. The most frequently purchased service was out-of-home care in a group home or family home (provided to 14,721 clients), followed, in decreasing order of frequency, by transportation services (11,068 clients), "other" services (6,607 clients), adult day activity programs (6,283 clients), in-home respite care (2,610 clients), and specialized out-of-home care services (2,358 clients).

The average monthly cost of different services ranged from a low of \$109 for transportation to a high of \$496 for specialized out-of-home care services. The total average monthly service cost per client for all Regional Center clients who received services that month was \$339.34.

The cost of supporting developmentally disabled clients in state hospitals is part of the budget of a separate State Hospitals division of the Department of Developmental Services. During FY 1984, it is expected that \$314,000,000 will be spent in the support of 7,600 developmentally disabled individuals in eight different state institutions. The per-client daily rates at these different state hospitals currently range from \$93 to \$231 for in-patient services, depending-on the facility and the type of treatment received (e.g., the most expensive daily rate is for a special project treating the mentally disordered). Supplementary charges are made for ancillary services received by state hospital patients, such as radiology, clinics, surgery, laboratory work, dentistry, physical therapy, and podiatry.

SPECIAL EDUCATION

Description of Special Education Sample

Our sample of special education clients suggests that adopting the federal definition will generate an increase in the proportion of special education clients meeting, or likely to meet, the DD definition from 11% to 14-45%.*

As shown in Table 15, all special education clients in our sample are under the age of 18, with 98.4% falling within the "school years" of 6-17. Males account for almost two-thirds of the sample (62.5%). Whites make up one-quarter of our case review sample, with blacks and hispanics accounting for about one-third each (35.9% and 31.3%, respectively). None of the special education clients in our sample were reported to receive SSI.

Eligibility under the old definition occurred primarily as a result of mental retardation (9.4% of the total sample), though the great majority (90.6%) were not eligible under the old definition. As Table 16 shows, learning disabilities were by far the most prevalent disability within our sample, occurring in 87.5% of the cases. Physical disabilities, the next most frequent, occurred in only 15.6% of the sample. The preponderance of learning disabilities reflects the method of sampling from the Resource Specialist Program only, which excluded the most severely disabled special education clients in special classes and special schools who might be more likely to possess other disabilities. Like the Special Education caseload sample as a whole, the DD subset of the sample were most likely to be learning disabled (79%) and/or multiply disabled (31%). Not surprisingly, the DD subset differs from the total sample because of a higher representation of the mentally retarded.

Prevalence of DD among the Special Education Caseload

An estimated 14-45% of the Special Education case review sample is DD, or 59,600 individuals (using the December 1981 estimate of pupils in the Resource Specialist Program). This estimate, combined with the estimated

*The higher percentage includes those judged "likely" to meet the federal definition.

Table 15
Special Education
Demographic Characteristics of Sample
(N=64)

	Percent		Percent
<u>Age</u>			
3-5	1.6%	<u>SSI Status</u>	
6-17	98.4	Receiving	--
		Not receiving	--
		Pending	--
		Unknown	--
Total	100%	Total	--
<u>Sex</u>		<u>Categorically Eligible in the Current Definition, Due to Disability</u>	
Male	62.5%	MIR	9.4%
Female	37.5	CP	0.0
Unknown	0.0	Epilepsy	1.6
Total	100%	Autism	0.0
<u>Race:</u>		Developmentally delayed	0.0
White	25.0%	Not categorically eligible	90.6
Black	35.9		
Hispanic	31.3		
Other	4.7		
Unknown	3.1		
Total	100%		

^Percents total more than 100 because of multiple disabilities.

Table 16
Special Education
Disability Type^a

Disability Type	Total Special Ed. Caseload (N=61)		DD Cases in Special Ed. Caseload (N=29)	
	n	(%)	n	(%)
Mental retardation	6	(10%)	6	(21%)*
Emotional disability	4	(7%)	1	(3%)
Sensory impairment	2	(3%)	1	(3%)
Physical disability	8	(13%)	5	(17%)
Neurological impairment	2	(3%)	2	(7%)
Learning disability	54	(89%)	23	(79%)
Multiple disabled	15	(25%)	9	(31%)

^aPercentages total more than 100 because of multiple disabilities.

* Disability category in which the DD subset of all clients is significantly different from the non-DD subset at the .05 confidence level.

107,000 in special classes and centers and 4,400 in nonpublic schools, yields an estimated total number of 171,000, or 48% of the total Special Education caseload. We suspect, however, that total inclusion of all special classes and exclusion of Designated Instruction Services clients in estimating the DD population may have been an oversimplification. Review of case files from these programs also would produce a more accurate estimate.

Service Utilization and Service Costs for Special Education Clients

Data provided by the Department of Education suggest that the mentally retarded, deaf, seriously emotionally disturbed, orthopedically impaired, deaf-blind, and multi-handicapped are more likely to use special day classes and special schools than other, more integrated settings, while speech-impaired and learning disabled are more likely to use the resource specialist program, and the visually-impaired and other health-impaired are more likely to use designated instructional services only. The lowest cost program is that in which clients receive designated instructional services only. The most expensive is that in which clients are served in special classes for more than half of the time.

VOCATIONAL REHABILITATION

Description of Vocational Rehabilitation Sample

Our sample of rehabilitation clients contained one of the smallest proportions meeting either DD definition among the five agencies sampled. The federal definition increases the proportion defined as DD from 10% to 14-25%*.

As shown in Table 17, the great majority (92%) are within the "working years" of 22-64. There is an approximately 50-50 split between males (53%) and females (47%). Almost seven-tenths are white (68%), about one-tenth are black (9%), and about two-tenths are hispanic (18%). Only 13% are known to receive SSI.

*The higher percentage includes those judged "likely" to meet the federal DD definition.

Table 17
Rehabilitation
Demographic Characteristics of Sample
(N=100)

	Percent		Percent
<u>Age</u>		<u>SSI Status</u>	
6-17	2%	Receiving	13%
18-21	4	Not receiving	86
22-64	92	Pending	1
65+	2	Unknown	0
<u>Total</u>	100%	<u>Total</u>	100%
<u>Sex</u>		<u>Eligible Under the OIG</u>	
Male	53%	<u>Definition</u>	
Female	47	MR	8%
Unknown	0	CP	0
<u>Total</u>	100%	Epilepsy	3
<u>Race:</u>		Autism	0
White	68%	Developmentally delayed	0
Black	9	Not categorically eligible	90
Hispanic	18		
Other	5		
Unknown	0		
<u>Total</u>	100%		

^A Percents total more than 100 because of multiple disabilities.

Ten percent of the rehabilitation sample are eligible under the old DD definition. Of these, 8% are mentally retarded and 2% are epileptics (1% are both retarded and epileptic). As shown in Table 18, the greatest representation among the total sample was found among clients with emotional disabilities (44%) and physical disabilities (37%). Other disabilities occurred in between 7% and 14% of the cases. At 16%, rehabilitation had the lowest proportion of multiply disabled among the five agencies sampled.

Prevalence of DD Among the VR Caseload

Of the 29,351 clients closed in statuses 26 or 28 from July 1981 through December 1982, 2,184 clients (7.4%) were excluded from sample selection because of having a diagnosis which could reasonably be assumed to meet the definition. The universe from which the sample was selected totaled 27,167 clients. Case review findings suggest that as many as 25% of these, or 6,800 clients, meet the DD definition. Together with those excluded from the sample, approximately 8,000, or 20% meet the DD definition

Service Utilization and Service Costs for Department of Rehabilitation Clients

The Department of Rehabilitation spent approximately \$90 million on vocational rehabilitation services in fiscal year 1982. The majority of these funds covered counselor time spent with clients and administrative costs. However, approximately one-fourth or 23 million was used to purchase services for individual clients. While the majority of services purchased were for vocational evaluation or training, transportation and other support services are also widely used. Like the Regional Centers, the Department of Rehabilitation will purchase needed support services unavailable to clients through other sources. While most of these are related directly to vocational preparation (e.g., tools, union dues, transportation to training, job seeking, skills training, job placement services), others are important to vocational success but not directly vocational in nature (e.g., physical restoration/medical, family counseling, independent living services, driver evaluation).

The most frequently provided service last year was diagnostic and evaluation services provided to 64% of the year's caseload. The average

Table 18
Rehabilitation
Disability Type^a

Disability Type	Total VR Sample (N=99)		DD Cases in Sample (N=25)	
	n	(%)	n	(%)
Mental retardation	8	(8%)	8	(32%)*
Emotional disability	43	(43%)	9	(36%)
Sensory impairment	14	(14%)	4	(16%)
Physical disability	37	(37%)	4	(16%)*
Neurological impairment	7	(7%)	4	(16%)*
Learning disability	7	(7%)	5	(20%)*
Multiple disabled	16	(16%)	8	(32%)*
Nondisabled or missing	1	(1%)	--	--

^aPercentages total more than 100 because of multiple disabilities.

* Disability categories in which the DD subset of all clients is significantly different from the non-DD subset at the .05 confidence level.

length of time as a client of 21.7 months suggests that approximately 45% of the caseload is carried over from the previous year. Thus, the high percentage receiving this service in one year suggests that virtually all clients receive this service at some time. It is also interesting to note the high utilization of transportation services such that more individuals use this service than receive vocational training services.

IV. SERVICE NEEDS OF THE
DEVELOPMENTALLY DISABLED

INTRODUCTION

The conceptual framework we propose for an analysis of the service needs of the developmentally disabled in California is a service taxonomy which examines six elements of a generic DD service network:

- services relating to service network access, i.e., case finding, case management, and information and referral;
- the selection of and access to appropriate residential placements (e.g., state hospital, skilled nursing facility, intermediate care facility, group home, family home, residential care by personal family members, or independent living);
- the selection of and access to appropriate day treatment placements (e.g., adult activity centers, educational programs);
- services aimed at enhancing individual functioning for individuals living in the community (e.g., educational and training programs, therapeutic services, medical treatment);
- services aimed at assisting an individual to perform daily living tasks which would otherwise be beyond his/her functional capacity (e.g., homemaker services or personal care services, adaptive physical devices, personal advocacy or protective services, and specialized transportation services); and
- family support services, such as family education and counseling, or respite services for family members caring for a relative with DD.

As described in the previous chapter on current service utilization patterns, there is no single coordinated comprehensive service system for the developmentally disabled in California, even for the current clients of the Regional Centers. Rather, clients find their way to services administered by a number of different state agencies, and paid for from multiple state and federal funding sources. What is unique about the current state-

funded DD service system is 1) its ability to provide long-term ongoing case management for Regional Center clients, as they move through different developmental and life cycle transitions, and 2) its ability to fill in some of the most important service gaps -- services that are necessary to maintain clients in a community setting, and that are not available from any other agency or funding source. Since there is no parallel system for other disability groups, there is concern that these gaps may not be filled for non-Regional Center groups. The extent to which the service needs of the "new" developmentally disabled population differ from those of current Regional Center clients and the extent to which their needs are already being met by other agencies will determine the potential impact of adopting the federal definition upon service demand.

SERVICES UTILIZED BY CURRENT REGIONAL CENTER CLIENTS

Table 19 summarizes the proportion of Regional Center clients for whom services were purchased in a sample month (June 1982). One can see that between the purchased services listed here and the case management services provided directly, the Regional Centers are providing services from every one of the six major service elements listed previously, although in several areas, services are provided to only a very few individuals. The most frequently purchased services are out-of-home community care, adult activity programs, in-home respite care, and transportation.

In addition, as shown in Table 19, mentally retarded who meet the DD definition (thus Regional Center eligibles) utilize services provided by other agencies including Special Education and California Children's Services where they make up a high proportion of the total agency caseload, and In-Home Supportive Services and Vocational Rehabilitation, where they are a smaller proportion of all clients served.

UNMET SERVICE NEEDS OF CURRENT REGIONAL CENTER CLIENTS

Through its role as the "provider of last resort," the Regional Center system does ensure that the developmentally disabled clients eligible for its services have access to the major services they need by purchasing

Table 19
Number of Regional Center Clients for Whom
Services were Purchased by the Regional Center
June 1982

Total Clients of Regional Centers: Approximately 60,000		
Services Purchased	Number Served	Approximate Percentage of Regional Centers' Caseloads
<u>Out-of-Home Care</u>		
Community Care Facility	14,721	25%
Skilled Nursing Facility	495	.8%
Specialized Services	2,358	4%
<u>Day Programs</u>		
Adult Activity Programs	6,283	10%
Day Nursery/Family Day Care	323	.5%
<u>Medical Services</u>		
Medical Programs	521	1%
Medical Equipment	83	.1%
Medical Professionals	1,043	2%
<u>Camp/Respite Care</u>		
In-Home Respite Care	2,610	4%
Out-of-Home Respite Care	723	1%
Camp	470	.7%
<u>Other</u>		
Home Care	116	.2%
Transportation	11,068	18%
Prevention	130	.2%
Other	6,607	11%
Total Clients for Whom Services Were Purchased	30,535	51%

Source: State Department of Developmental Services

directly services not available through other sources. This is not to say that there are not important service gaps remaining for those meeting the current state DD definition, nor that the Regional Centers have sufficient resources to respond to all individuals in need of their services. On the contrary, the Regional Centers cite resource constraints as a serious and increasing problem. Respondents associated with the Regional Centers contacted during this study cited the following specific service gaps for the "old DD" (state-defined) population:

- case management services for state hospital clients, if a proposed cutback of this service on the part of Regional Centers takes place;
- inadequate medical services available to those who no longer qualify for the Medi-Cal medically indigent program, since that program was abolished;
- inadequate psychological evaluations, since there is now pressure on the Regional Centers to save money by using outside evaluations;
- insufficient independent living services in the local communities;
- insufficient ability of community resources to respond to the needs of the mentally ill/mentally retarded subgroup; and .
- lack of space in local residential or day treatment facilities, in some geographical areas.

SERVICES UTILIZED BY NEW GROUPS WHO ARE DEFINED AS DEVELOPMENTALLY DISABLED UNDER THE FEDERAL DEFINITION

Like the mentally retarded, other developmentally disabled Californians also receive services across a variety of programs and agencies. The case file reviews conducted for four state agencies (in addition to the Regional Centers) permitted us to estimate the extent to which all developmentally disabled are currently receiving services from a variety of programs serving the disabled -- California Children's Services, Special Education, Vocational Rehabilitation, and In-Home Supportive Services. As shown in Table 20, the physically disabled represent the largest subgroup of DD individuals

Table 20
Current Utilization of the
State Service System by the Developmentally Disabled

Estimate of total number of agency clients who meet DD definition: Number/(Percent of Total Caseload)	Agency or Program				
	Regional Centers	Special Education	In-Home Supportive Services	Vocational Rehabilitation	California Children's Services
By Disability Group: ^a					
Mentally Retarded	51,500	40,000	2,500	2,100	5,500
Mentally Disordered	3,000	9,500	800	2,400	700
Sensorily Impaired	3,500	7,500	400	1,400	5,500
Physically Disabled	21,500	16,000	5,500	2,100	24,000
Neurologically Impaired	16,500	4,000	1,800	900	4,300
Learning Disabled	5,000	102,000	-0-	1,200	3,300
(Multiply Disabled)	30,000	23,000	2,300	2,600	12,500
	58,000 (92%)	171,000 (48%)	7,700 (8%)	8,000 (27%)	25,000 (45%)

^aDisability categories are not mutually exclusive.

Source: Population estimates are projected from sample case file review findings and other aggregate data on state agency caseloads.

currently receiving services from In-Home Supportive Services, Vocational Rehabilitation services, and California Children's Services, while, not surprisingly, the learning disabled are the largest DD subgroup receiving Special Education services, and the mentally retarded are the largest subgroup currently receiving Regional Center services.

Table 21, which compares the total estimated number of developmentally disabled individuals receiving services across the five agencies to the prevalence estimates for each disability subgrouping, shows that, in the five agencies reviewed, the number of DD clients within each subgroup currently receiving some public services ranges from a low of 60% of the estimated physically disabled DD population to a high of 162% of the estimated neurologically impaired DD population. The fact that the mentally retarded and neurologically impaired DD percentages exceed 100% is probably due to the fact that the Regional Center caseloads have close to complete penetration of these populations receiving services, so that the additional agency caseloads are "double-counted."

Table 21 also suggests that the mentally retarded, and possibly the learning disabled, are the two DD subgroups which receive a service share which is at or above their proportional representation in the DD population, while the mentally disordered and physically disabled DD may be substantially underrepresented in the current state service system.²

With the information available from our case file reviews, we cannot make the analytic leap from analyzing service utilization patterns to analyzing unmet service needs. One barrier is the absence of any data which would enable us to arrive at an unduplicated count of individuals currently receiving services. Another is the absence of any information on the total

This estimate assumes that the clients of the different agencies do not overlap. Since we expect that some overlap does occur (particularly for those subgroups where the percentage of the prevalence estimates receiving services exceeds 100%), these should be treated as liberal estimates.

² Several cautions are in order. First, the fact that an individual receives a single public service does not guarantee that all his/her service needs are met. Second, the mentally disordered are primarily represented in the mental health system, whose records were not reviewed as part of this study.

Table 21
Comparison of Estimated Prevalence of DD
by Disability Group with Service Utilization Patterns

	Prevalence Estimate	Subgroup as % of Total DD	Service Utilization Totals	Subgroup Served as % of Prevalence Estimate	Subgroup Served as % of Utilization Total
By Disability Group: ^b					
Mentally Retarded	70,000	29%	107,600	145%	38%
Mentally Disordered	34,000	14%	16,400	48%	6%
Sensorily Impaired	46,000	19%	18,300	40%	7%
Physically Disabled	141,000	58%	69,100	49%	26%
Neurologically Impaired	16,000	7%	27,500	172%	10%
Learning Disabled	Not available	from S.I.E.	111,500	N/A	41%
(Multiply Disabled) ^c	92,000	38%	70,400	77%	26%
Total Individuals	245,000	100%	269,700	110%	100%

^aThese numbers assume no overlap across the five agency caseloads we reviewed. Since we expect that some overlap does occur, these should be regarded as liberal estimates.

^bDisability groups are not mutually exclusive.

^cAssuming that no individual has three or more disabilities.

interagency package of services: currently utilized by any given individual. We suggest the need at some future date for a survey of a sample of developmentally disabled individuals to permit analysis of cross-agency service utilization as well as to understand the role of privately funded services and services provided by family members.

At any rate, in order to analyze unmet needs for the "new" DD population, we conducted a set of interviews with "informed observers" who consist of direct service workers, casework supervisors, program managers, and advocacy and consumer group representatives, in addition to obtaining review comments from experts who have studied the impact of the federal DD definition in other states.

UNMET NEEDS OF THE NEW GROUPS MEETING THE FEDERAL DEFINITION OF DEVELOPMENTAL DISABILITY

In the area of service network access, respondents suggested that groups such as the severely physically disabled, mentally disordered, and chronic alcohol and drug abuse program clients might benefit from the increased advocacy and coordination associated with a long-term case management approach. This approach would be in sharp contrast to the current crisis intervention mode of responding to emergency needs for mental health and substance abuse clients, and would fill a gap for the physically disabled for whom no agency currently has full responsibility. However, program staff cautioned that the "custodial" and "protective" overtones of long-term case management might be at odds with the desire for self-direction among the mentally alert, and the service philosophy of waiting for the client to take the initiative in seeking treatment among programs serving the mentally ill and drug addicts. Increased information and referral about service availability and increased advocacy to gain access to services were also seen as desirable for the new DD subgroups. Groups with a need for guidance and case management during the particular periods when they must make the transition from services for children and adolescents to adult services include "special needs" children in foster care and special education clients.

The service areas of residential and day treatment placements were not mentioned as areas of high unmet needs by our informants. In general,

it was assumed that if an individual is in need of a specialized residential setting, some agency (e.g., Department of Social Services, Department of Mental Health) is already paying for that service. Nevertheless, because the services currently offered by the Regional Centers to their clients frequently make independent or community-based living possible to sustain, there is a possibility of a pent-up demand for ICF/MR or community care placements among "new" DD subgroups.

In the area of individual enhancement services, it is generally perceived that each particular disability group (i.e., the physically disabled, the mentally disordered, the sensory impaired, and the learning disabled) already have access to therapeutic services or treatment services which are distinctive to that subgroup's particular need, and that unmet needs in these areas would not be well met by generic services designed for the developmentally disabled in general.

In contrast, services to assist with daily living tasks would be of more general application to severely functionally limited individuals, and might receive a substantially increased demand from new DD groups, particularly in light of funding constraints on the provision of Title XX-funded In-Home Supportive Services by county welfare departments, Specialized transportation, another of the services included within this category, would also probably be in great demand by "new" DD groups who have difficulty accessing public transportation (e.g., *the* physically disabled).

Family support services are widely mentioned as an unmet service need of a number of the different DD subgroups, whose parents are helping to care for them at home. Regional Centers are currently the only organizations which can purchase respite care for their clients.

In summary, agency representatives of service programs where the developmentally disabled make up only a small proportion of the total agency caseload tend not to be able to distinguish the service needs of the developmentally disabled from those of other clients, particularly other disabled clients. However, a number of these agencies did cite the need for services which they were not permitted to purchase for their clients, but which they were aware that Regional Centers could purchase for Regional Center clients.

Other service gaps mentioned focused on the need for services to ease the transition for DD individuals as they pass from one developmental or life cycle phase to another, particularly when such transitions involve leaving the jurisdiction of an agency which has been a major service provider (i.e., "graduating" from foster care or special education), or changing from one residential setting to another.

The foregoing suggests that the primary unmet needs of the new DD population relate to service network access, daily living assistance services, and family support services. However, one outside expert¹ has suggested that there may also be a "pent-up demand" for community residential placements and day treatment programs on the part of certain subgroups within the new DD population, e.g., mentally alert/physically disabled in nursing homes who would like support to be able to live independently; other institutionalized individuals who would like to be able to live in the community; learning disabled graduates of Special Education who would like to continue participating in day treatment programs. It is not clear to what extent an agency designated as case manager/service purchaser for the new developmentally disabled groups would have a responsibility to provide an expanded set of services such as these to its clients.

In the following chapter (Chapter V), we address a series of issues related to how the state might alter its DD service planning, funding patterns, and service coordination and delivery mechanisms in order to address the service needs of the total population meeting the federal definition. We also review the various scenarios that might be selected for implementing a revised DD definition and comments on the cost implications of each of these scenarios.

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V. ISSUES RELATING TO THE IMPLEMENTATION
OF THE FEDERAL DEFINITION OF DEVELOPMENTAL DISABILITIES

INTRODUCTION

The issue of whether California should adopt the federal definition of a developmental disability is not a single issue. Rather, it encompasses a series of implementation questions, each of which needs to be answered before it will be possible to determine what the impacts of adopting the definition would be. Some of these separate questions are:

- whether the federal definition should be used to define the target population in planning for a state system of DD services;
- whether the federal definition should be used to define a target population in need of cross-agency coordination efforts;
- whether the federal definition should be used to define a target population for advocacy and information and referral services;
- whether the federal definition should be used to define a target population for special state-funded services designated as "DD" services (currently these services include habilitation services administered by the Department of Rehabilitation and services administered by the Department of Developmental Services, i.e., the Regional Center services and state hospital care);
- whether a single version or multiple versions of an instrument applying an operational definition of DD should be used to determine the eligibility of specific individuals to receive DD services and, if so:
 - whether eligibility determination should be centralized or decentralized for different disability types, and
 - how much discretion should be left to the service provider/

intake screener in determining whether an applicant is eligible;

- if state-funded "DD" services were to be offered to all those who meet the federal definition, whether service delivery should be consolidated or decentralized to different agencies according to specific disability groupings; and
- if state-funded "DD" services were to be offered to all those who meet the federal definition, whether the same level of resources and types of services should be made available to each disability grouping.

Implementation of the federal DD definition by California is a politically and emotionally loaded issue primarily because of resource constraints. In theory, at least, service providers, casework supervisors, program administrators, and advocacy groups are all in sympathy with the intent of the federal PL 95-602 to focus scarce resources on that segment of the disabled population most in need of services, and to recognize and respond to the need of the developmentally disabled for comprehensive service planning, increased access to services, advocacy to ensure the above, and coordination of services to ensure that needs are met. The resistance to altering the current state system comes from a realistic desire to "conserve" what has been gained for those individuals who meet the state's categorical definition of developmentally disabled, and the desire to avoid further overloading that system or watering down the services it has been able to offer its mentally retarded, epileptic, cerebral palsied, and autistic clients.

Thus, in discussions of implementing the federal definition so that a broader range and increased number of disabled individuals can benefit from advocacy, service coordination and the opportunity to fill in critical service gaps, the state must clearly specify whether this substantially increased target population is to be served within the same level of resources currently devoted to those meeting the state definition of DD or whether additional resources will be made available. In addition, a careful distinction needs to be made between "no-cost" or "low-cost"

implementation activities and activities which imply substantial service or administrative costs.

In the previous sections of this report, we have tried to lay the groundwork for this discussion by 1) describing the estimated number of "old" (according to the state definition) and "new" (according to the federal definition) developmentally disabled individuals in the state and describing their characteristics; 2) examining the extent to which both "old" and "new" DD populations are currently utilizing services across a variety of state programs and agencies; and 3) exploring the extent to which "new" DD groups are experiencing unmet needs under the current system. Ultimately, however, we cannot offer a definitive answer to the question of what demand there would be for increased case management and/or specific purchased services if these were made available to all individuals meeting the federal DD definition. The level of increased demand would depend on what agency or agencies offered the services, the types of services made available, and the extent to which requesting designation as a developmentally disabled individual was seen as stigmatizing. It would also depend on whether agencies and providers who are presently serving these clients are enthusiastic about the notion of increased cross-agency coordination of services for their clients and whether they would tend to refer clients to the DD service system or subunit.

In the following sections, we first discuss some of the issues which arise in considering different implementation alternatives or scenarios, and second, review each of the implementation questions set forth at the beginning of this chapter, with suggestions about different ways the state might go about answering these questions.

ISSUES RELATED TO IMPLEMENTATION OF THE FEDERAL DEFINITION

The Character of the DD Service System as a "Protective Service" System Versus A System to Further Independent Living Goals

The current system of state-funded services for the developmentally disabled has a certain "protective service" orientation as a rationale for

Average Regional Center costs of operations suggest that providing case management and purchasing needed services to fill service gaps for approximately 60,000 clients costs \$206 million or \$3,433 per client per year. However, lower cost scenarios could also be devised as ways to respond to the unmet needs of "new" DD groups.

providing case management and service advocacy and coordination to its (primarily) mentally retarded clients, which grows out of current clients' frequent limitations in self-direction and limitations in independent living capabilities. Although concerned that clients receive therapeutic interventions that will enable them to develop to their full potential, Regional Center staff are more focused on stabilizing and maintaining clients in living situations and day programs that involve ongoing supervision than would be appropriate if the target population were expanded to include, individuals with physical, neurological, or sensory disabilities whose mental functioning and judgment was not impaired. Thus, one question raised by advocacy groups and service providers alike is how this difference should affect the implementation of the federal definition. On the one hand, some argue that it may be a healthy influence on the current service system for the mentally retarded to have an increased emphasis within this system on furthering independent living objectives. On the other hand, some respondents stated that this difference in service orientations indicates that the same caseworkers should not be expected to work with both types of clients, and that the case management systems for different disability groupings within the DD population should be distinct.

The Prevalence of Multiply-Handicapped Individuals

The case file reviews performed for this study, as well as the responses from the Survey on Income and Education (SIE), indicate that an extremely high percentage of developmentally disabled individuals are identified as having more than one type of disability (i.e., mentally retarded and physically handicapped, emotionally disabled and sensory impaired, etc.).¹ This situation suggests that dividing up the DD population for eligibility assessment and/or service delivery strictly according to disability type would leave the multiply-handicapped in an ambiguous category with respect

¹The SIE estimates that the 245,000 developmentally disabled individuals outside institutions in California account for 337,000 different impairments, for an average of 1.38 impairments per person. Our case reviews found that the number of multiply-handicapped individuals ranged from a low of 32% of all DD individuals receiving agency services (Department of Rehabilitation) to a high of 52% of all DD clients (Regional Centers).

to measuring severity of functional limitations and determining the appropriate agency to take responsibility for case management. Whatever implementation scenario is ultimately selected, it will need to provide for a way to adequately serve the multiply-handicapped.

Target Populations, Service Priorities, and Service Rationing

Even if the state decides to include the entire developmentally disabled population (according to the federal definition) as the target population for the state DD service system, it is not clear whether every individual who meets the definition is equally entitled to receive special DD services and to receive as many services as he or she needs, or whether the state or various state agencies may further restrict access to services by establishing client priority criteria and/or rationing the volume of services available. In the face of resource constraints and a demand for services which exceeds the supply, DD service providers would be forced to implement some kind of client prioritizing scheme (unless courts established that access to DD services was an entitlement), or rationing. If client prioritizing is determined to be feasible, a number of alternatives are possible (e.g., priority to the youngest, to those with the most severe functional limitations, to clients with functional limitations in learning or self-direction, to clients who need services in order to reside in the community, or first-come/first-served). If access to DD services is determined to be an entitlement for all those who meet the federal DD definition, the state would need to be much more cautious in expanding the eligible population.

The Possibility of Continuing to Target Service System Dollars to Categorical Disability Groups

If it is determined that the types of services needed by the mentally retarded versus the emotionally disabled versus the physically handicapped versus the learning disabled subgroups within the DD population are

An example of service rationing has been implemented by county welfare departments in assessing client needs for limited in-home supportive service resources. A ceiling of six hours of housekeeping support/month and an overall service maximum has been established.

substantially distinct, then it may make sense to do some planning for the developmentally disabled as a comprehensive group, while retaining distinct funding sources and service delivery systems for assessing and addressing service needs of specific disability groups. Thus, the current state funding for DD services might be relabeled "services for the mentally retarded, epileptic, cerebral palsied, and autistic," and limited to these categorical disability groups, even if centralized planning occurs for all those meeting the federal DD definition. Separate funding sources might be established for coordinating services for the physically disabled, emotionally disabled, or learning disabled. With respect to the physically-disabled and emotionally disabled where early age-of-onset is not a "given," services might be limited to the developmentally disabled (i.e., those with severe functional limitations which occurred early in life), or might be broadened to include all severely disabled. Under this approach, while service planning would use the DD definition, eligibility for state-funded services would no longer necessarily be linked to whether an individual met the federal DD definition.

Equity Between and Among Disability Groups

The issue of focusing special attention and resources to ensure that the developmentally disabled have access to needed services raises several different questions of equity between and among disability groups. The first question is whether the developmentally disabled who are currently receiving services under the state Regional Center system are entitled to special service priority as a result of their particularly limited ability to advocate for themselves. On the one hand, one could argue that without a particular emphasis on advocacy on behalf of the mentally retarded, the members of this disability group would be unable to secure needed services, and that other disability groups are not as handicapped in this regard. On the other hand, members of the other disability groups who also meet the federal definition can justifiably argue that the developmentally disabled as a group have been designated as deserving special attention to make sure they do not "fall through the cracks" of the service network, and that other DD subgroups should not be left out of state-funded DD services.

For disability groups such as the emotionally disabled and physically disabled, where only a portion of all severely disabled individuals meet the early onset requirements of the federal DD definition, the DD definition raises a second issue of equity of service access between those disabled at an early age and those disabled later in life. While the theory is that disabilities during the developmental years will result in more severe functional limitations than those experienced later on, others would argue that once adulthood is reached, there is not very much to justify differential treatment of the developmentally disabled and other disabled.

Which Agency(ies) Should Have Primary Responsibility for Serving the Developmentally Disabled?

As the agency designated to serve the mentally retarded and other groups meeting the current state definition of developmental disabilities, the Department of Developmental Services and its field service delivery mechanisms, the Regional Centers, are the natural service system to take primary responsibility for the mentally retarded. Similarly, for the emotionally disabled DD, it seems logical that the Department of Mental Health has a primary responsibility, although it may not be inclined to treat clients with early onset mental disorders differently from other agency clients.

For a number of other disability subgroups within the (federal) DD population, it is less clear whether the primary service agency concept makes sense. For example, although Special Education has a special responsibility to serve the learning disabled, this responsibility ends abruptly when clients turn 22. As a "lead agency," Special Education would not be able to follow its DD clients through the important life transitions when service coordination is so critical, i.e., through the transition from living at home with parents to independent living or living in a supervised setting away from one's parents, through the transition from school to adult day-time activities (ie., work, work activity, or training) and through the increasing functional limitations that accompany the aging process.

Physically handicapped DD individuals have even less of a primary agency responsible for their well-being. Although a number of physically disabled children become clients of California Children's Services, this

agency does not tend to broaden its focus beyond physical health issues nor to follow clients beyond the period of actual service intervention. After adulthood is reached, there is currently little effort made by service providers to distinguish between adult physically disabled with early onset (DD) and those who became disabled later in life (non-DD). In addition, rather than becoming the clients of a particular service program or agency, physically disabled tend to continue to need special support services (e.g., transportation, daily living supports) in order to access a broader range of mainstream services.

ALTERNATIVE SCENARIOS FOR IMPLEMENTATION

Should the Federal Definition of Developmental Disability Be Used to Establish a Target Population for Planning for DD Services?

To this degree, California has already implemented the federal definition. Because DD planning funds originate at the federal level, the state has been required to use the federal DD definition for planning purposes since PL 95-602 was passed in 1978. The organizational responsibilities for state planning have been assigned to the State Council on Developmental Disabilities and to the Local Development Disabilities Area Boards. These organizations have had the somewhat lonely jobs of estimating the prevalence of developmental disabilities (according to the federal definition) within local areas and for the state as a whole, and attempting to determine the extent to which developmentally disabled individuals are currently being served by Regional Centers as well as by other state agencies.

As we can attest, from conducting our reviews of other state agency caseloads, this can be a very frustrating task so long as those agencies responsible for direct service delivery to the developmentally disabled have no reason to keep track of DD clients separately from other clients and have no special services or service approaches that distinguish the developmentally disabled from other severely disabled clients or from the total client population. The case review instruments developed for specific agencies as part of this research project have provided the first readily available method for determining whether an individual agency client meets the federal DD definition and for estimating the extent to which the

developmentally disabled are represented across different state agency programs. Depending on the extent to which being identified as developmentally disabled becomes relevant in determining access to services (as described in later sections), service agencies and the state DD Council will have greater or lesser incentives to refine these estimation procedures.

Should the Federal Definition of Developmental Disability Be Used to Establish a Target Population in Need of Cross-Agency Coordination Efforts'?

One possible response to the multiple service needs of the developmentally disabled, and to their frequent need for advocacy and assistance in accessing existing services would be to attempt (1) to educate state agency personnel about the needs of the developmentally disabled; and, (2) to provide special state support to establish cross-agency service coordination mechanisms. If cross-agency coordination were to be effective, it would need to consist both of an inter-agency DD service delivery task force at the headquarters level, and regular case staffings with agency representatives at the local service delivery level to deal with particular problem cases for whom accessing services from several different agencies has proven problematic. While stopping far short of providing each DD individual with a permanent case manager, the implementation of a regular local "DD Round Table" might create a mechanism for dealing with the most difficult case coordination problems, provided they come to some service provider's attention. Alternatively, an "ombudsman" position could be established on an interagency basis to advocate for the developmentally disabled who are having difficulty accessing needed services. In this scenario, developmentally disabled individuals or their caretakers could initiate action themselves.

Although there would definitely be some costs associated with implementing either of these scenarios for cross-agency coordination, such coordination would be relatively inexpensive compared to either duplication of the Regional Center case management service for all DD individuals, or purchase of services to fill service gaps' for the developmentally disabled.

Should the Federal Definition of Developmental Disability Be Used to Establish a Target Population for Advocacy As Well as Information and Referral Services?

This level of response to the service needs of the developmentally disabled suggests a slightly more than routine provision of advocacy, and information and referral services, in contrast to the crisis-oriented coordination described in the preceding section.

Scenarios for this level of service response could include either centralized service delivery for all developmentally disabled, or service decentralized by agency affiliation or disability type. Under the advocacy and I & R model, a client would have to initiate a request for services (differentiating this response from generalized case management) and case activity would be short-term and oriented to problem-solving, rather than long-term, as in Regional Center case management. The costs of implementing an advocacy, and information and referral service system would vary, depending on whether these activities could be assigned to existing staff within certain state agencies (including as one possibility current Regional Center staff), or whether new staff positions would have to be added within one or more "lead" agencies.

Should the Federal Definition of Developmental Disability Be Used to Determine Who is Eligible for Special State-Funded Services for the Developmentally Disabled?

Currently, individuals who meet the state's categorical definition of developmentally disabled are eligible not only for the assessment and long-term case management services offered directly by the Regional Centers, but also for Regional Center purchase of necessary services that are not available from any other source. Approximately 60,000 individuals are ongoing clients of the statewide system of Regional Centers, and, during FY 1982, an average of 30,000 Regional Center clients received purchased services each month. The purchase-of-service budget for the Regional Centers for FY 1983 is \$129 million.

They are also eligible for special "habilitation" services from the Department of Rehabilitation.

If the state were to decide to extend eligibility for state-funded "DD" services to all individuals meeting the federal definition of developmental disability, there would be major cost questions and major service delivery design questions to be answered. The major cost questions would be:

- Would there be an increased level of state funds to devote to the delivery of case management and purchased services to the developmentally disabled residents of California, or would the same approximate level of funding be expected to "go further"?
- Would funding be generalized for all developmentally disabled, or would there be separate "set-asides" for different disability subgroupings within the target population (e.g., the mentally retarded, the physically disabled, the emotionally disabled) to ensure that each group received its "fair share"?

The major service delivery design questions are:

- Would the same set of services be available to all developmentally disabled state residents, or would the set of purchasable services differ according to the particular functional limitations of different disability groupings?
- Would assessment, case management, and approval of purchased services for all developmentally disabled occur in a centralized service delivery system, or would "lead" responsibility for serving different disability groupings be assigned to different agencies?

Table 22 summarizes alternative scenarios for the delivery of state-funded DD services. Although it is not possible to predict with certainty the increased demand for case management and purchased services among the "new" DD (i.e., those who would become newly eligible for state-funded DD services if the federal definition were used to define service eligibility), it is highly likely that there would be significant costs associated with any meaningful expansion of the state-funded DD service system to address currently unmet needs.

As described in Chapter IV, the services for which there is likely to be an increased demand include, among others, respite care, transportation services, prevocational services, and placement in community care facilities as an alternative to more restrictive settings.

Table 22

Alternative Scenarios for Providing Case Management and Purchased "Services of Last Resort" for the Developmentally Disabled

Available Resource Level	Centralized Lead Agency Responsibility	Centralized Lead Agency Responsibility	Different Lead Agencies for Different DD Subgroups
Current	Same Services Available to all DD	Differentiated Service Packages or Budgets for Different DD Subgroups	Differentiated Service Packages
Some Increase	(1) Extend case management to new DD population, but water down, ration, or eliminate purchased services	(2) Limit case management and purchased services to current state-defined DD population	
Substantial Increase	(4) Expand Regional Center system to accommodate those who meet federal DD definition	(3) Offer centralized case management for all DD individuals; differentiate services available to different disability groups	(5) Same as (4), but with separate funding allocations or quotas by disability group
			(6) Creation of a separate service assessment, case management, and purchased services system for different disability types, with a different "lead agency" for each type

Thus, if there is not a very real commitment on the part of the state to devoting an increased level of resources to meeting the needs of the developmentally disabled, then the alternatives scenarios to be considered - (1) through (3) on Table 22 - need to be devoted to somehow rationing services or limiting eligibility to arrive at a reasonable set of priorities describing how the limited resources should be expended.

Scenario 1 on Table 22 is the scenario most feared by current Regional Center staff - that the Regional Centers would be assigned responsibility for serving all individuals who meet the federal DD definition without any substantial increase in funding. The result, they warn, would be the inability of the Regional Centers to serve anyone adequately, and a resulting watering-down of both direct and purchased services: case management would be reduced to "paper pushing," and purchased services would have to be limited and/or rationed. Scenario 1 would have the virtue of serving all developmentally disabled individuals equitably.

Scenario 2, on the other hand, would attempt to preserve the progress made by the Regional Center system in meeting the needs of the mentally retarded, and would limit eligibility for Regional Center services to the mentally retarded (with or without the additional disability groups currently included in the state definition of developmental disability). This could be accomplished in two ways. First, the state could decide to retain its current state DD definition for all but federally funded planning efforts. Alternatively, the state could "adopt" the federal DD definition for advocacy, service coordination, and information and referral activities, as described previously, but could relabel the Regional Center service system as a system to serve a narrower target population -- e.g., persons with mental retardation.

Scenario 3 would designate the delivery of case management services as the key element in a DD service system, and would attempt to extend this service to all developmentally disabled individuals with only a moderate increase in total state resources allocated to the developmentally disabled. In order to ensure that the demand for purchased services remained within resource constraints, Scenario 3 would probably require that services be rationed. This might be done by treating all DD individuals equitably and providing everyone a reduced range or volume of

services, as in Scenario 1, or it might be done by designating a different set of available services for different disability groups.

Scenarios 4 through 6 describe alternative organizational approaches for addressing the needs of all individuals meeting the federal DD definition, where resource constraints are not the overriding consideration. Under Scenario 4, the state would decide to expand the system of Regional Centers to accommodate the unmet case management and purchased service needs of all those who meet the federal definition of developmental disability. One can imagine a variety of staffing patterns that might be used to accomplish this expansion. Under some patterns, caseworkers might specialize in serving individuals with particular types of disabilities (e.g., the mentally retarded, the emotionally disabled); under others, caseworkers might be specialists in particular types of services, which would be useful to individuals with a variety of disabilities (e.g., transportation, respite care).

Scenario 5 is similar to Scenario 4 in assigning the responsibility for delivery of case management services and filling service gaps for the entire DD target population to a single agency. However, under Scenario 5, the state would pay more attention to the extent to which individuals with different types of disabilities (e.g., mentally retarded, physically disabled, emotionally disabled, learning disabled, sensory impaired, multiply handicapped) actually make use of the DD service system, either through prospective budget ceilings for different disability types or through retrospective monitoring of service utilization. As in Scenario 3, the services available to each disability category might vary.

Scenario 6 would involve the most extensive changes from the current service system, by designating and funding more than one "lead agency" to offer case management and to authorize and arrange for the delivery of services not available from other sources. Such designated lead agencies might include: the Department of Education (for learning disabled youth); the Department of Mental Health (for emotionally disabled youth and adults); the Department of Health (for the physically handicapped); and the

It would remain to be seen whether this type of deliberate differential access could withstand a legal challenge.

Department of Developmental Services (for the mentally retarded). To meet the needs of individuals who have multiple disabilities or who do not fit neatly within a disability category, one agency would need to be designated as a generalized case management agency. The decentralized service system implied by Scenario 6 would probably have significant variations from agency to agency and thus from disability group to disability group in the range and intensity of services provided. Supporters of this scenario would emphasize that this decentralized pattern builds on existing agency expertise in serving individuals with specific disabling conditions, and thus permits the service response to be sensitive to the needs of the particular group.

The case management and purchase-of-service arrangements described in Scenarios 1 through 6 are compatible with, and are envisioned as being supplemented by, the less expensive advocacy, coordination, and information and referral activities described previously. It is perhaps important to emphasize once again that the state-funded DD service system is not a comprehensive service system, but is, instead, a strategy for filling the gaps left by a variety of mainstream state programs for social and health services. For this reason, state agency coordination and inter-agency troubleshooting should be seen as an essential part of the state implementation of the definition, even if special DD services are also provided.

Should the Federal Definition of Developmental Disability Be Used to Focus the Attention of Mainstream State Agencies and Programs Toward the Needs of This Target Group?

Because the developmentally disabled receive the majority of their services from mainstream agencies or programs or from programs that target a broader disabled client population than just DD (e.g., all severely disabled, all emotionally disabled), the federal definition might also be used to focus attention on the extent to which developmentally disabled individuals are successfully accessing mainstream services. In a mild

While the purpose of this activity is to ensure that DD individuals are able to access services on the same basis as other state residents, there is a danger that increased visibility of the extent to which DD are served across a variety of state agency programs might lead to a demand that state agencies be reimbursed by the state DD system for the cost of these services.

form, this use of the federal definition would lead to a request (or requirement) that state agencies keep track of the extent to which they are serving developmentally disabled individuals. In a stronger form, it might lead to the establishment of quantified service goals for serving DD individuals, or to a specific request that some percentage of funds be set aside for serving the developmentally disabled. Most state agencies would be likely to resist formal DD "set asides," unless the DD system itself was providing a separate source of funding. Just such a separate funding arrangement supports the current "habilitation set-asides" for the developmentally disabled within the state Department of Rehabilitation.

If the State Decides It Wants to Use the Federal Definition of Developmental Disability to Establish Eligibility for Special DD Services or to Keep Track of the Extent to Which the Developmentally Disabled Are Being Served by Mainstream State Agencies, How Should Individual Eligibility Be Established?

We found in designing and implementing our case file review of current service utilization and DD eligibility patterns across five state agencies that it was necessary to refine the operational definition of a developmental disability each time it was applied to a different type of client with a different service history and different disabling condition. Partly this was due to the fact that we were dependent on reviewing written information already present in the case file, and that this data set varied from agency to agency. More important, however, the types of functional limitations assessed as well as the measures of severity of limitations varied from agency to agency and from disability to disability. This suggests that it would be difficult to arrive at a single eligibility assessment tool that could be applied to all developmentally disabled individuals to certify that they met the requirements of the federal definition.

Even with multiple assessment tools, the state could choose between a centralized eligibility assessment process, whereby a central agency would assess the DD status of all applicants for DD-funded services, and a decentralized process whereby individual agencies would determine

whether their own clients or prospective clients met the federal definition.

SUMMARY AND RECOMMENDATIONS

The study findings discussed in previous chapters of this report can be summarized as follows:

- 1) Contrary to the expectations in some other states that the adoption of the federal definition would not substantially increase the total number of individuals labeled as DD," California can expect an increased total target population to result from the adoption of the federal DD definition. This is largely due to the fact that the state has already focused attention on the most severely disabled among those categorical disability groups meeting the state DD definition, leaving little room for "trimming away" the less severely impaired.
- 2) The adoption of the federal definition of developmental disability would result in a reorientation of the DD target population, with the largest representation from the physically disabled (who would comprise approximately 58% of the total DD population), the second largest representation from the mentally retarded (who would comprise 29% of the total), followed by the sensory impaired (19%), the emotionally disabled (14%), and the neurologically impaired (7%).²
- 3) Although new groups of individuals would be labeled as developmentally disabled if the federal definition were adopted, these groups are already accessing services from one or more state agencies, for the most part. The areas of anticipated increased demand (where needs may not be

¹Due to a balance between the exclusion of the less severely impaired mentally retarded and the inclusion of those severely impaired at an early age with other types of disabilities. See U.S. DHHS, Special Report on the Impact of the Change in Definition of Developmental Disabilities, Washington, D.C., May 1981.

²These numbers do not control for double-counting those with multiple handicaps; thus they sum to more than 100%.

adequately met under current service delivery arrangements) include:

- long-term case management services, for those who are not currently eligible for services from the Regional Centers;
 - family support services, such as respite care, and education of family members about specific disabilities and specific functional limitations;
 - prevocational services for the emotionally disabled;
 - transportation, for all severely disabled groups; and
 - community-based placements, for those who would be able to live in community settings, if additional community supports were available.
- 4) In the absence of services targeted specifically to the developmentally disabled, most state agencies have little incentive to identify what specific clients are developmentally disabled or even what proportion of all agency clients fall into this category.

The previous description of the different options available to the state relative to the adoption of the federal definition of developmental disabilities is intended to emphasize that adoption of the federal definition is not a simple "yes-no" decision, but encompasses a range of different possible responses. While it is not within the scope of this study to recommend what action the state should take on this issue, we do hope that we have provided a framework which will help clarify discussion on the part of policymakers. Furthermore, we would urge the state to acknowledge and respond to the needs of all (federally-defined) developmentally disabled, at least to the extent that interagency coordination and advocacy activities can meet those needs, even if the state decides it is not able to or desirable to offer a full case management/purchase-of-services option to all developmentally disabled state residents. Otherwise, it will be difficult to justify continuing a state service response which focuses on only one discrete portion of the developmentally disabled population.

In estimating the potential unmet service need/latent service demand among the "new" DD population subgroups, this study has raised as many

questions as it has been able to answer. Among the unanswered questions are the following:

- To what extent do "new" DD subgroups need the long-term case management approach currently provided to mentally retarded individuals by the Regional Centers? and
- To what extent would "new" DD subgroups seek out and access case management services if they were made available?

In designing service responses to meet the needs of the "new" DD population, the state needs to be able to assess the need for case management in general, as well as to distinguish between 1) the need for short-term cross-agency coordination of multiple services, and 2) the need for ongoing long-term case management to ease major life transitions for the developmentally disabled (e.g., leaving school, transitioning from living with parents to independent or supervised living situations, growing old and infirm, etc.).

In order to better assess the case management needs of several new DD subgroups, we recommend that the state undertake additional data collection and analysis on three topics. The first topic recommended for further study is an exploration of the service needs, service access and utilization, and perception of unmet needs among the adult physically disabled DD population in the state. This is one group which has no obvious state agency which might take "lead agency" responsibility for case management or service provision.

A second topic recommended for further study is an exploration of the transition that occurs when developmentally disabled youth who have been served by the special education program "graduate" from special education and enter the adult service system. This transition is reputed to be one of the most difficult transitions to make in the absence of case management to ensure service continuity. By observing whether special education "graduates" are currently able to access the services they need, the state will be able to better estimate the extent of unmet needs among this population.

The third topic area in which we recommend further study concerns the extent to which there is an unmet need for long-term case management services on the part of the emotionally disabled DD subgroup. While client surveys are probably not appropriate for this last group, case file reviews

and in-depth discussions with selected service providers should shed light on both the need for long-term case management, as well as the likelihood that clients would take advantage of this option if it were offered.

In the final analysis, we believe that projections of the increased demand for DD services by the expanded target population must remain guesses, in the absence of actual implementation. One approach to developing more accurate projections might be implementation of the new definition in one or more pilot counties. With careful selection of counties where both population mix and service mix are fairly representative of the state as a whole, much could be learned about how the complex system of services and case management might best be coordinated to serve the needs of persons with developmental disabilities as defined in P.L. 95-602.

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