ASSESSMENT OF THE INCIDENCE AND PREVALENCE OF DEVELOPMENTAL DISABILITIES IN NEW MEXICO AND ASSOCIATED NEEDS FOR RESIDENTIAL SERVICES

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I. INTRODUCTION

A. Scope

Though the strategic planning process sponsored by the Developmental Disabilities Planning Council is directed at the need for residential services in New Mexico, such needs cannot be considered in isolation from other integrally-related support service requirements. Save their particular handicaps, individuals with developmental disabilities are no different than anyone else. All require shelter, food, and clothing. In the event they become ill, they require the services of health practitioners. To the extent that their impairments limit their ability to care for themselves (self-care skills), move about (mobility skills), and carry on activities of daily living, education and vocational pursuits, they require supervision and support. At the same time, in the interests of both the individual and society, persons with disabilities should be afforded the opportunity to learn those skills necessary to increase their independence and reduce their dependence on others.

Stated in terms of particular service requirements, this translates into six general classifications of services, of which residential services is only one.

1) Case Coordination Services -- Case coordination services include needs assessment, planning, service coordination, and follow-up services necessary to make the delivery system work well for clients.

2) Residential Services -- Residential services include the provision of food, clothing and shelter, the basic level

of supervision necessary to insure the safety and well-being of clients, and the provision of training in self-care and community living skills. The residential services are divided into three subcategories for purposes of this needs assessment:

* <u>Residences-High Supervision</u> -- Residential arrangements where extra supervision is required to manage clients with behavior problems or to assist physically handicapped clients in activities of daily living. This category includes residents who must be carried, wheeled or led from the building by others in emergency situations. Direct staff/client ratios range from 0.5:1 to 1:1.

* <u>Residences-Moderate Supervision</u> -- Residential arrangements where 24-hour supervision is provided by staff (live-in or shift), residents are capable of basic self help skills only under continual supervision. Residents require reminding, verbal instructions or gestures in order to depart from the residence within a reasonable period of time when warned of danger by a signal device. This may include residents who are deaf, if the home is equipped with special visual warning devices. Staff client ratios range from 1:3 to 1:6.

* <u>Residences-Minimum Supervision</u> -- In semi-independent living programs, residents have their own living quarters (apartments, small homes) with staff nearby and on-call in the same building or building complex. Residents take care of their own housekeeping needs, but some may need intermittent training or supervision in certain areas of domestic activity or community independence (e.g., meal preparation, use of public transportation, banking, etc.) Daytime activities are most likely to be vocational in nature and to be in group-supervised work centers, supervised work placements, or independent job placements.

  Residents do not require any reminding, verbal instructions, gestures or physical assistance from staff or other residents to depart from the residence within a reasonable period of time when warned of danger by a signal device (e.g., a fire alarm).

  While living quarters should not exceed three persons, minimum supervision (less than 24-hour) programs may include as many as 10-20 living quarters for 30-60 clients. Direct staff/client ratios range from 0:7 to 1:16.

3) Health Services -- Health services include services for evaluating the health status of individuals, for identifying and aleviating acute conditions, and for managing those chronic disabling conditions to the point where clients can function at the levels at which they would be able to function were it not for those conditions

4) Educational and Vocational Services -- Educational and vocational services are designed to enhance the physical, communicative, social, affective and congnitive development of persons in order that they achieve and sustain the behaviors and skills necessary for them to maintain a lifestyle as culturally normative and as free of outside support as possible.

5) Client Support Services -- Special client support services include services designed to ameliorate chronic and disabling physical and behavioral conditions to the point where clients can function at the levels at which they would be able to function were it not for those conditions.

6) Caretaker Support Services -- Caretaker support services include the provision of those services that are necessary for residential, habilitative and health programs to work efficiently and effectively.

Thus, while this needs assessment and the residential services plan [to follow] concentrate on persons with developmental disabilities who can not be expected to live independently (in unsupervised residential arrangements), it can not and does not confine the scope of services needed to residential services alone.

B. Types of Demand

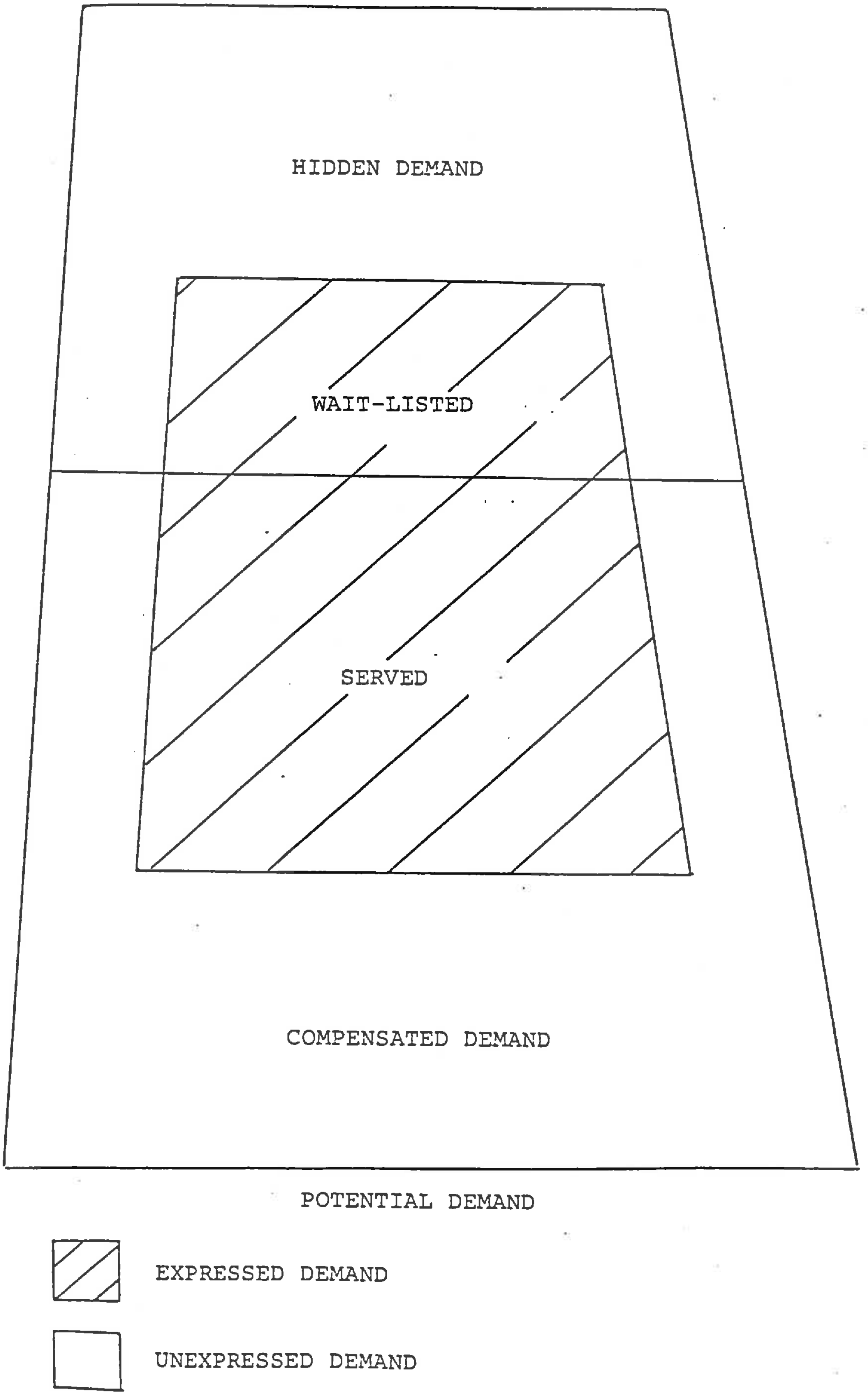
In assessing the probable demand for services to the target population, one must distinguish among the components of the total **potential demand for services** (i.e., all persons meeting the target population definition) including **expressed demand** (i.e., the number of these persons actually participating in developmental disabilities programs), and **unexpressed demand**

latent demand part of which is expressed on **waiting lists** (i.e., persons now demanding but not receiving service), and part of which is **[hidden] or unexpressed**, (i.e., persons not now demanding service but who would demand appropriate services if they had access to them; and **compensated demand** (i.e., persons relying on private supports and who would not presently demand public services even were they made accessible). These categories of demand are illustrated in Figure 1.

We believe that planners could profit by devoting less attention to refining estimates of potential demand and more to improving estimates of latent demand. The proportion of the developmentally disabled population receiving publicly-supported services varies markedly from state to state in spite of the fact that the prevalence rates per se do not vary significantly from area to area. For instance, according to 1982 Census of Residential Facilities for mentally retarded citizens (Hauber, Bruininks, Hill, Lakin and White, 1984), Nevada reports only 34.2 beds per 100,000 population, while North Dakota reports 104.2. This distinct difference lends support to the notion that the level of utilization of publicly-funded residential alternatives is less affected by changes in the overall size of the developmentally disabled population (potential demand) than by changes in the supply of acceptable residential alternatives.

FIGURE 1

Demand for Services: A Conceptual Diagram



C. Organization of the Report

Section II of this report presents estimates of the prevalence of developmental disabilities (potential demand for residential and related support services) in 1985, 1990 and 1995.

Appendix A describes the methodology used to estimate the size of the developmentally disabled population in New Mexico using the 1976 Survey of Income and Education data. Appendix B describes the procedure used to estimate the number of developmentally disabled adults on the SSI/SSDI rolls in the state. Appendix C lists the service providers surveyed by HSRI and Appendix D contains the provider survey for.

Section III analyzes the expressed demand for residential and related support services in the state as of March 31, 1985. This includes active clients in appropriate state-funded residential programs, and persons awaiting residential placement -- both those presently residing and those not residing in state-funded residential facilities. The plan also includes discussion of the unexpressed demand for residential and related support services in New Mexico. The analyses of expressed and unexpressed demand are elaborated in the _Plan for the Development and Improvement of Residential Services for Persons with Developmental Disabilities_.* The references used in preparing this report are included in the bibliography.

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* Prepared for the New Mexico Developmental Disabilities Planning Council by the Human Services Research Institute (May, 1986).

II. POTENTIAL SERVICE DEMAND

A. General

The size of the developmentally disabled population can be represented in terms of the incidence or prevalence. **Incidence** refers to the number of new cases that are manifest during a specified period of time. Incidence rates represent the number of new cases occurring during a specified period of time relative to the number of persons at risk during the same period of time.

Prevalence refers to the number of cases (whether old or new) that are present in a population for a designated time interval or point in time. Prevalence rates represent the total number of cases present in the population relative to the total population.

Incidence and prevalence are interrelated. Prevalence rates vary as a function of the incidence and duration of cases. Theoretically one could estimate the prevalence of disorders (cases) indirectly from estimates of case incidence and duration. However, reliable information is scant on the expected duration or life expectancy of persons with mental retardation and related developmental disabilities, and thus prevalence rates are the measures of choice.

Few if any states can afford to mount epidemiologic surveys or registries comprehensive enough and of sufficient size to arrive at valid and reliable estimates of the incidence and prevalence of most developmental disabilities. In order to obtain these data, New Mexico, like other states has had to fund studies designed to make use of the results of existing epidemiological data.

HSRI made use of the results of several of these studies using other data sources as well to complement and verify these figures.

Specifically, HSRI used:

(1) national and state estimates of the prevalence of the developmentally disabled population with no mental retardation for persons ages 6-64 and of the entire developmentally disabled population above age 64, derived by Gollay and Associates, Inc. based primarily on the 1976 Survey of Income and Education (Gollay, 1980 and 1981);

(2) area wide estimates derived primarily from studies compiled by Kiely and Lubin (1983), Farber (1970), Abramowicz and Richardson (1975), and Kiely, Lubin and Kiely (1984);

(3) estimates based on epidemiologic data on the incidence and mortality of selected medical conditions that lead to developmental disabilities;

(4) state estimates of the size of the mentally retarded population in New Mexico based on the records of adults receiving Supplemental Security Income payments and Social Security Disability Insurance benefits by reason of mental retardation;

(5) counts of the number of infants and preschoolers (ages 0-5) on high risk infant registries in those states having mandates to serve disabled children from birth.

As is apparent in our discussion of these estimates, they are all of limited validity, reliability and scope. However, by analyzing these estimates in combination, it is possible to arrive at a more complete picture of the developmentally disabled population in New Mexico than would otherwise be possible, and to validate concurrently these independent estimates (i.e., to assess the probable validity and reliability of independent estimates according to their degree of consistency).

The estimates of the prevalence rates of mental retardation and other developmental disabilities in New Mexico are shown in

Table 1. The prevalence rates for severe mental retardation are estimated to be slightly higher than the median values reported in Table 4.

Estimates of the number of persons statewide and by planning districts are shown in Table 2. These projections are based on the prevalence rates in Table 1 and general population projections. The first three sources noted above were used to arrive at the estimates, and the latter two, to check the estimates.

B. Estimates Based on the 1976 Survey of Income and Education (SIE)

Table 3 presents SIE-based estimates of the prevalence of the developmental disabilities in New Mexico, among the civilian noninstitutionalized population ages three and above. Persons were identified as developmentally disabled according to the "functional" definition operationalizing the definition as much as possible in terms available in the survey. The identification criteria are defined in Appendix A.

HSRI used the 1976 Survey of Income and Education-based prevalence rates to estimate the numbers of persons with developmental disabilities other than mental retardation for persons ages 6-64. The survey based estimates for persons aged three to four in New Mexico appeared spurious, and national rates were used instead. The survey based estimates for persons ages

TABLE 1

AGE-ADJUSTED PREVALENCE RATES (PER 1,000 GENERAL POPULATION) OF PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES IN NEW MEXICO, 1985*

Age		Prevalence rate per 1,000 general population(age-adjusted)			
	Total population(a)	MR severe(b)	MR mild(b)	Other DD(c)	Total DD
Infants & pre-school(d):					
0 - 2	81,022				5.5
3 - 5	78,097				10.2
0 - 5	159,119				7.8
School age					
6 - 17	261,387	4.0	4.6	5.9	14.5
18 - 21	100,114	3.5	4.0	2.6	10.1
6 - 21	361,501	3.8	4.4	5.0	13.3
Adults					
22 - 64	800,518	2.2	2.6	2.0	6.8
65 +	142,646	0.6 (c)	0.7	0.3	1.5
22 +	943,164	2.0	2.2	1.7	6.0

a. Source: Wombold (1985).

b. Source: Epidemiologic studies in areas other than New Mexico.

c. Source: Gollay (1980 & 1981).

d. Source: HSRI-- Based on survey of state high risk infant registries and incidence/mortality estimates of selected disabling conditions from epidemiologic studies in areas outside New Mexico

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* The rates are based on the size of the general population within each age group.

TABLE 2

ESTIMATED NUMBER OF PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, BY AGE IN NEW MEXICO: 1985

AGE GROUP	STATE DEV DISABILITIES ALL	STATE MR	STATE OTHER	DISTRICT 1 DEV DISABILITIES ALL	DISTRICT 1 MR	DISTRICT 1 OTHER	DISTRICT 2 DEV DISABILITIES ALL	DISTRICT 2 MR	DISTRICT 2 OTHER	DISTRICT 3 DEV DISABILITIES ALL	DISTRICT 3 MR	DISTRICT 3 OTHER	DISTRICT 4 DEV DISABILITIES ALL	DISTRICT 4 MR	DISTRICT 4 OTHER	DISTRICT 5 DEV DISABILITIES ALL	DISTRICT 5 MR	DISTRICT 5 OTHER	DISTRICT 6 DEV DISABILITIES ALL	DISTRICT 6 MR	DISTRICT 6 OTHER	DISTRICT 7 DEV DISABILITIES ALL	DISTRICT 7 MR	DISTRICT 7 OTHER
INFANTS/PRESCHOOL																								
0-2 YEARS	449			66			57			160			26			16			84			40		
3-5 YEARS	799			115			103			285			47			29			149			71		
0-5 YEARS TOTAL	1,248			181			160			445			73			45			233			111		
SCHOOL AGE																								
6-17 YEARS	4,133	2,451	1,682	540	320	220	571	339	232	1,497	888	609	236	140	96	159	94	65	727	431	296	403	239	164
18-21 YEARS	1,011	751	260	120	89	31	133	99	34	388	288	100	62	46	16	35	26	9	156	116	40	117	87	30
6-21 YEARS TOTAL	5,144	3,202	1,942	660	409	251	704	438	266	1,885	1,176	709	298	186	112	194	120	74	883	547	336	520	326	194
ADULTS																								
22-64 YEARS	5,281	3,727	1,554	536	378	158	742	524	218	2,172	1,533	639	293	207	86	180	127	53	866	611	255	492	347	145
65+ YEARS	226	184	42	15	12	3	31	25	6	86	70	16	16	13	3	12	10	2	44	36	8	22	18	4
22+ TOTAL	5,507	3,911	1,596	551	390	161	773	549	224	2,258	1,603	655	309	220	89	192	137	55	910	647	263	514	365	149
TOTAL ALL AGES	11,899	7,113	3,538	1,392	799	412	1,637	987	490	4,588	2,779	1,364	680	406	201	431	257	129	2,026	1,194	599	1,145	691	343

65 and above in both the United States and New Mexico were inexplicably high either as an artifact of the survey design or estimation method. Therefore, prevalence rates based on area-wide epidemiological studies were used instead for this age group.

The Survey of Income and Education estimates are based on a 1976 sample survey of 151,170 households containing 160,975 families and 440,815 individuals. It is the largest survey by far conducted in the past decade that contains the basic information necessary to identify adults and children who are developmentally disabled. The overriding problem with the Survey of Income and Education, as with all national surveys, is the large sampling error associated with estimating the size of the developmentally disabled population and subpopulations, particularly within less populous states (such as New Mexico) and substate areas, and particularly by age and sex -- two variables known to be associated with significant differences in the prevalence of particular developmental disabilities. The limited reliability of the state estimates by age is indicated by the large confidence intervals associated with estimates of the developmentally disabled population in New Mexico as shown in Table 3.

Other design limitations are that the Survey of Income and Education does not cover those infants and children under age three, and covers only the civilian noninstitutionalized population.

Information on the chronicity of disabling conditions is limited, and there is no breakout available by type of developmental disability (e.g., cerebral palsy, autism, epilepsy, or spina bifida). These and lesser limitations notwithstanding, the Survey of Income and Education is the only reasonably current national survey with a state-sensitive sampling scheme that allows for state-specific estimates, and that includes a wide range of information on activity limitations.

TABLE 3

ESTIMATED PREVALENCE RATES (PER 1,000) OF DEVELOPMENTAL DISABILITIES IN NEW MEXICO, BY AGE: CIVILIAN NONINSTITUTIONALIZED POPULATION, 1976

	Age (years) at time of interview						
Type of individual	All ages	3-4	5-17	18-25	26-45	46-64	65+
DD/MR							
Prevalence	3.2	4.8	5.2	4.0	2.1	1.8	1.7
67% range*	7.4	13.0	2.5-7.9	0.1-7.8	4.5	4.5	5.3
95% range**	11.5	21.8	10.7	11.8	6.8	7.1	9.0
DD/non-MR							
Prevalence	5.1	19.0***	5.9	2.3	0.7	4.3	17.7***
*	0.9-9.2	1.1-37.0	2.7-9.0	5.3	2.0	0.5-8.1	7.5-27.9
**	13.4	55.0	12.2	8.2	3.2	11.9	38.2
Total DD							
Prevalence	8.3	23.8***	11.1	6.2	2.8	6.0	18.8***
*	5.4-11.2	4.0-43.6	7.0-15.2	1.3-11.1	0.1-5.5	1.5-10.6	7.3-30.2
**	2.5-14.1	63.6	2.8-19.3	16.1	8.3	15.2	41.8

* 67% probability that the "true" number falls within this range.
** 95% probability that the "true" number falls within this range.
*** Inexplicably high.

SOURCE: Based on estimates prepared by Gollay and Associates (1980).

Note: Rates are based on the size of the general population within each age group.

C. Estimates Based on Epidemiological Studies

HSRI used epidemiologic study-based prevalence rates for estimating the size of the severely mentally retarded population ages six and above and for estimating the size of that segment of the mildly mentally retarded population likely to require public or private support services over the long term. These studies could not be used to derive estimates of the numbers of other developmentally disabled persons since the studies focus only on the major mental retardation-related disabling conditions, and undercount significantly the size of the non-mentally retarded developmentally disabled population (e.g., persons with severe hearing or orthopedic impairments). Moreover, unlike the Survey of Income and Education, these studies do not capture or report sufficient information to distinguish the level of disability associated with these conditions and thus the extent to which they might be considered developmentally disabled according to the functional definition.

These surveys vary in sample design, size, and identification procedures. Most are also limited in terms of the information available on the extent or severity of the disabling condition and on its duration. Nonetheless, they do provide prevalence estimates by type of disabling condition, and considered together provide a picture of how varied the prevalence of different developmental disabilities can be. Large differences are generally attributable to differences in the case finding procedures or to variations in the survey or registry methods used. Many also provide reasonably reliable estimates of age- and sex-specific, prevalence rates.

Knowing that the prevalence of developmental disabilities -- particularly those disabilities associated with low birthweight and premature births, maternal infections, and psychosocial factors -- varies with socio-economic status, the preferred "synthetic" estimation technique would have been to apply prevalence rates specific to socio-demographic subpopulations in the source study areas to like subpopulations in the New Mexico planning areas. HSRI employed a less exacting, but more practical method given the paucity of data on the sociodemographic characteristics of the epidemiologic study populations. HSRI developed age-specific prevalence rates assuming that age-specific prevalence rates are reasonably stable across areas/populations. Because the validity of this assumption cannot be established, these "synthetic" estimates carry a uniform and inestimable bias.

HSRI, in synthesizing the studies reported in the literature, drew heavily from the compilations prepared by Kiely and Lubin (1983), Farber (1968), Abramowicz and Richardson (1975), and Kiely, Lubin and Kiely (1984). The age-specific prevalence rates employed are summarized according to four types of developmental disabilities: mental retardation, epilepsy, cerebral palsy, and autism.

1. Mental Retardation

Mental retardation refers to significantly subaverage (two standard deviations below the mean) general intellectual functioning according to intelligence Quotient (IQ) tests, and concurrent deficits in adaptive behavior (according to age-appropriate standards of personal independence and social responsibility), and manifested during the developmental period (prior to age 18) (American Association for Mental Deficiency, 1977).

Most epidemiologic studies of mental retardation confine the measures of mental retardation to the intelligence dimension; few studies examine the adaptive behavior dimension. This is a major drawback for planners since the adaptive behavior scores tell more about the need for support services than do the intelligence scores. In fact, most epidemiologic studies report only two categories of intelligence: mild mental retardation and severe mental retardation, the latter encompassing persons with IQ's below 50 or 55.

a. Severe Mental Retardation (Table 4)

Table 2 summarizes the high, low and median age-adjusted rates (per 1,000) of severe mental retardation reported in those community epidemiologic studies judged reliable based on the reviewers' evaluations of the methods used for case finding and for enumerating the general population.

Persons with severe mental retardation, as opposed to mild mental retardation, require considerable support since these individuals have severe activity limitations (Baird and Sadovnik, 1985). Because severe mental retardation appears to be less subject to socio-economic influences and to demographic differences than does mild mental retardation, prevalence rate estimates for severe mental retardation tend to be more

TABLE 4

ESTIMATED PREVALENCE RATES (PER 1,000) OF SEVERE MENTAL RETARDATION, BY AGE, AND SEX, POPULATION, BASED ON EPIDEMIOLOGIC SURVEYS AND REGISTRIES OF IN AREAS OUTSIDE NEW MEXICO

Age/sex	Low	Median	High
0 - 4 years	0.5 Kushlick & Cox, 1967	0.9	3.1 Wing, 1971
5 - 9	1.4 Kushlick, 1961	3.6	4.1 Wing, 1971
10 - 14	2.3 Innes, Kidd & Ross, 1968	3.5	4.4 Lewis, 1929
15 - 19	1.1 Goodman & Tizard, 1962	3.6	4.0 Scally & Mackay, 1964
20 - 29	2.1 Lewis, 1929	2.9	3.9 Scally & Mackay, 1964
30 - 39	1.3 Lewis, 1929	2.1	3.2 Kushlick, 1961
40 - 49	1.2 Lewis, 1929	1.8	2.3 Kushlick, 1961
50 - 59	0.9 Lewis, 1929	1.3	1.8 Kushlick, 1961
60+	0.5 Lewis, 1929	0.6	1.3 Innes, Kidd & Ross, 1968
Male	53% Scally & Mackay, 1964	57%	59% OR State Bd. of Health, 1962
Female	40% OR State Bd. of Health, 1962	43%	46% Scally & Mackay, 1964

Note: Rates are based on the size of the general population within each age group.

consistent (Birch et. al., 1970; Abramowicz and Richardson, 1975).

The observed prevalence rate for severe mental retardation varies markedly with age with the highest rates occurring in the early teens (Kiely and Lubin, 1983). There is a consistently higher rate of mental retardation among males than among females owing in part to the role of the "X" chromosone in genetically linked disorders (Kiely and Lubin, 1983; Turner and Oppitz, 1980; Baird and Sadovnik, 1983).

b. Mild Mental Retardation

Estimates of the prevalence of mild retardation vary widely. Unlike the prevalence of severe mental retardation, the prevalence of mild mental retardation appears to be strongly associated with socioeconomic status (Kiely and Lubin, 1983; Richardson & Abramowicz, 1975; Birch et al., 1970; Jackson, 1965). Differences may also be explained by variations in the case identification procedures employed.

Prevalence rates of mild mental retardation based largely on health registers and medical records tend to be relatively low because they exclude a large segment of the mentally retarded population with minimal medical involvement. Prevalence estimates of mild mental retardation based largely on education records and household surveys tend to be much higher since they include the sizeable learning disabled subpopulation, as well as persons with behavior problems -- problems that color rater judgement of the learning ability (Stanford Research Institute, 1978; Mercer, 1973).

Estimates of the prevalence of mild retardation range from 21 to 25 per thousand (Farber, 1968; Kaufman and Payne, 1975; Maloney and Ward, 1979). However, most of these individuals, while they have IQs from 55-69 (have relatively low scholastic aptitude), are able to achieve independence and personal self sufficiency in their adult years (Charles, 1953; Richardson, 1978), and thus will not demand extraordinary public or private supports.

Tarjan (1970) estimates that only about 20% of these people have some organic impairment. It is only this segment which is likely to show adaptive deficits throughout life and to warrant continuous classification as mentally retarded (Baroff, 1982). According to these judgements, HSRI's estimates of potential demand include only 20% of the mildly retarded population.

2. Epilepsy (Table 5)

Epilepsy is defined to include chronic conditions of the nervous system characterized by recurrent seizures (involuntary motor activity or change in consciousness and behavior) for purposes of estimating the prevalence of rates of the disability (Blackman, 1983). Not included are febrile seizures (precipitated by fever) or single nonrecurrent seizures. Most studies report that 60% to 80% of the cases of epilepsy are grand mal or petit mal seizures which are generalized throughout the body. Less common are local seizures which occur in particular areas of the body (Kiely and Lubin, 1983).

In reviewing the dozens of studies compiled by Kiely and

TABLE 5

ESTIMATED PREVALENCE RATES (PER 1,000) OF EPILEPSY, BY AGE AND SEX BASED ON EPIDEMIOLOGIC SURVEYS AND REGISTRIES IN AREAS OUTSIDE NEW MEXICO

Age/sex		Low	Median	High
All ages	(n = 13)	2.6 Wajsbort, 1967	4.8	6.2 Hauser & Kurland, 1975
0 - 9 years	(n = 10)	1.1 Wajsbort, 1967	3.5	5.8 Kurland, 1959
10 - 19	(n = 8)	3.5 Wajsbort, 1967	4.6	6.5 Stanhope, 1972
20 - 29	(n = 10)	3.0 Wajsbort, 1967	5.3	14.0 Stanhope, 1972
30 - 39	(n = 11)	2.7 Wajsbort, 1967	4.4	8.2 Brewis, 1966
40 - 59	(n = 10)	2.3 Wajsbort, 1967	3.8	7.3 Hauser & Kurland, 1975
60+	(n = 9)	1.2 Kurland, 1959	3.8	10.2 Hauser & Kurland, 1975
Male		50% deGraaf, 1974; Hauser & Kurland, 1975	54%	65% Kurland, 1959
Female		35%	46%	50%

Note: Rates are based on the size of the general population within each age group.

Lubin (1983), no noteworthy age or sex specific patterns of occurrence can be found. However, we did find wide variation in age-specific prevalence rates from study to study. This can be attributed to sampling error, case finding differences, and possibly to actual differences in the prevalence of epilepsy in different geographic areas. Table 5 presents the range of age-specific prevalence rates found in the surveys and registries reviewed by Kiely and Lubin (1983).

3. Cerebral Palsy (Table 6)

Cerebral palsy is a chronic disorder of muscle control or coordination resulting from injury to the brain during fetal, perinatal or early childhood stages of development. Incidence is strongly associated with low birth weight, intra-uterine growth retardation and adverse prenatal factors. As Table 6 illustrates, there is a wide variation in the prevalence of cerebral palsy found in different areas probably due to incomplete case identification (e.g, Hansen, 1960), inconsistent case definitions and actual regional differences. U.S. rates appear higher than rates found in other countries; according to Kiely, Lubin and Kiely, (1984), this may be partly a function of more complete case identification procedures in the U.S studies and partly a function of etiologic differences such as low birthweight.

Most studies of the prevalence of cerebral palsy are limited to children. The highest rates appear to be among children five to 14 years of age. The few studies done on adults show rates declining with age -- perhaps a function of age-specific

TABLE 6

ESTIMATED PREVALENCE RATES (PER 1,000) OF CEREBRAL PALSY, BY AGE AND SEX, BASED ON EPIDEMIOLOGIC SURVEYS AND REGISTRIES IN AREAS OUTSIDE NEW MEXICO

Age/sex		Low	Median	High
0 - 4 years	(n = 5)	1.5 CT State Dept. of Hlth.,1951	2.2	2.9 Wishik, 1956
5 - 9	(n = 5)	1.4 Hansen, 1960	2.3	8.8 Wishik, 1956
10 - 14	(n = 5)	1.3 Hansen, 1960	2.9	8.4 Wishik, 1956
15 - 19	(n = 5)	1.4 Hansen, 1960 (ages 15-18)	1.7	6.5 Wishik, 1956 (ages 15-20)
20 - 29	(n = 11)	-	1.1 Hansen, 1960 (one estimate)	-
20 - 49	(n = 1)	-	0.7 Gudmondsson, 1967	-
25 - 34	(n = 1)	-	0.8 Levin, 1949	-
35 +	(n = 1)	-	0.3 Levin, 1949	-
> 50	(n = 1)	-	0.2 Gudmondsson, 1967	-
Male	(n = 4)	53% Lagergren, 1970	57%	61%
Female	(n = 4)	39% Lagergren, 1970	44%	47%

Note: Rates are based on the size of the general population within each age group.

mortality among adults with cerebral palsy. Most studies found a higher rate of prevalence among males than females. Only one study looked at the prevalence of cerebral palsy by race and found a higher prevalence among white children (Nelson and Ellenberg, 1978) -- a surprise given that low birth weight and perinatal mortality are higher among black neonates (Niswander and Gordon, 1972). Kiely, Lubin and Kiely (1984) could identify no clear secular trends in cerebral palsy -- trends that have been hypothesized by some researchers in light of recent advances in newborn intensive care.

4. Autism

Autism is a developmental disorder with severe distortions of social and language development that begin at an early age. According to the American Psychiatric Association, a child is diagnosed as having infantile autism only if all of the following features appear during the first 30 months of life (Schora, 1983):

- lack of responsiveness to other people;
- grossly impaired development of language;
- peculiar speech patterns, when speech is present, such as echolalia (repeating the speech of others); pronominal reversal (e.g., the use of "you" and "I"); or metaphorical language (e.g., the repetition of words or sound with unclear or "private" meanings);
- bizarre interactions with, or responses to, the environment, such as extreme fascination with unusual objects; resistance to even minor changes; and behavior rituals (often involving repetitive acts such as flicking the fingers) which, if interfered with, lead to great distress or tantrums;
- absence of hallucinations, delusions, and other features of schizophrenia.

Based on a review of five studies, Kiely and Lubin (1983) found the reported prevalence of rates of autism among persons below 19 years of age to vary from 0.21/1000 to 0.48/1000. They found approximately three times as many males as females with a diagnosis of autism.

5. Other Less-Prevalent Developmental Disabilities

Some of the less prevalent developmental disabilities are generally accompanied by mental retardation and thus are counted as part of the larger mental retardation population. These include bronchopulmonary dysplasia, stroke, severe cranio-facial disfigurement, deaf-blind, Huntington's disease, hereditary progressive muscular dystrophy, spina bifida, systemic Lupus ery-themotosus and tuberus sclerosis (Gollay, 1981(2)). Reasonably reliable estimates of the age-specific prevalence of most of the less-prevalent developmentally disabling conditions are not available. They are too few in number to support the calculation of age-specific prevalence rates from completed surveys and registries.

The incidence of some of these conditions can be identified at birth. Still others can be identified in early infant monitoring and screening programs. However, while the duration and disabling effects of some of these conditions can be predicted, the duration and disabling effects cannot be predicted for most others. Consequently, it is not possible to derive reliable prevalence rates for most of these conditions, particularly lifetime prevalence estimates (Gortmaker and Sappenfield, 1984).

6. Multi-Handicapped

Persons who have one developmental disability are likely to have others. Consequently, in order to obtain an unduplicated count or estimated prevalence of developmental disabilities, one cannot simply total the categorical prevalence estimates. One must first factor out the numbers of persons who have multiple disabling conditions.

The predominant area of overlap is between mental retardation and other developmental disabilities. Cerebral palsy, epilepsy and autism also co-occur (Pond, 1979; Hopkins, Bice and Colton, 1954; Jacobson and Janicki, 1983). In their analysis of approximately 50,000 persons in New York known to be receiving or known to need specialized interventions or developmental disabilities services during the period November 1978 through June 1982, Jacobson and Janicki (1983) found that persons with mental retardation accounted for 68% of the persons with autism, 71% of the persons with cerebral palsy, and 91% of the persons with epilepsy were mentally retarded. Thirty-five percent of adults (age 22 and above) and 25% of children (under age 22) with mental retardation also had epilepsy, cerebral palsy, and or autism.

Baird and Sadovnik, (1985) report even higher rates of multiple handicaps among severely and profoundly mentally retarded persons: from 71.7% to 91.6% of severely mentally retarded persons registered in the British Columbia Health Surviellance Registry from 1952 through 1966 had other disabling conditions including cerebral palsy, epilepsy and autism. The proportion of retarded persons with multiple handicaps was found to increase dramatically with the degree of retardation. Fifty-six percent of children with profound mental retardation as opposed to 21% with mild mental retardation had multiple handicaps. Thirty-seven percent of adults with profound mental retardation as opposed to 25% of adults with mild mental retardation had multiple handicaps (Jacobson and Janicki, 1983).

Other researchers report generally lower estimates. For instance, the Oregon State Board of Health (1962) reports that 15.75% of severely mentally retarded children were found to have cerebral palsy and 17.27% had epilepsy. Drillien et al. (1966) found 22.94% of mentally retarded persons with cerebral palsy and 8.72% with epilepsy. Lindberg (1979) found that 21.3% of persons with mental retardation also had epilepsy and 4.7% also had cerebral palsy, and Pond (1979) found that 33% of severely mentally retarded persons had epilepsy and three to six percent of mildly mentally retarded persons had epilepsy.

In estimating the prevalence of multi-handicapped persons as shown in Table 7a, HSRI assumed that Jacobson and Janicki's figures* (Table 7b) are an accurate reflection of the co-occurrence of mental retardation, cerebral palsy, epilepsy and

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Note: Because Jacobson's and Janicki's figures represent persons served or awaiting developmental disabilities services in New York, and do not include developmentally disabled persons who have chosen not to enter or have previously exited the system (who as a general rule would probably be more capable and have a lower proportion of multiple handicaps), the figures probably represent a higher rate of co-occurence than would be true were the population to include those unserved as well as those served or awaiting services.

TABLE 7a

ESTIMATED PREVALENCE RATES (PER 1,000) OF SEVERE MENTAL RETARDATION, CEREBRAL PALSY, EPILEPSY, OR AUTISM ALONE OR IN COMBINATION, BY AGE BASED ON EPIDEMIOLOGIC SURVEYS AND REGISTRIES OUTSIDE NEW MEXICO

Age	Severe mental retardation	Epilepsy	Cerebral palsy	Autism	Total	Multiply-handi-capped	Grand total*
0 - 19 years				0.12**	0.12	0.06	0.18
0 - 9		0.28			0.28	0.13	0.41
0 - 4	0.59		0.46		1.05	0.49	1.54
5 - 9	2.34		0.48		2.82	1.33	4.15
10 - 19		0.37			0.37	0.17	0.54
10 - 14	2.28		0.61		2.89	1.36	4.25
15 - 19	2.34		0.36		2.70	1.27	3.97
20 - 49			0.10		0.10	0.05	0.15
20 - 29	2.18	0.37			2.55	1.20	3.75
30 - 39	1.58	0.31			1.89	0.89	2.78
40 - 59		0.27			0.27	0.13	0.40
40 - 49	1.35				1.35	0.63	1.98
50 - 59	0.98				0.98	0.46	1.44
50 +			0.03		0.03	0.01	0.04
60 +	0.45	0.27			0.72	0.09	0.81

---

* Not including mental illness and less prevalent developmental disabilities.

** By way of explanation: this statistic indicates that of every 1000 persons in the general population ages 0-19, an estimated .12 are autistic. Put another way, it is estimated that one person in every 12,000 (ages 0-19) is autistic.

Note: Rates are based on the size of the general population within each age group.

TABLE 7b

PERCENT OF CASES OF SELECTED DEVELOPMENTAL DISABILITIES OCCURRING ALONE OR IN SOME COMBINATION (MULTI-HANDICAPPED), BY TYPE OF DISABLING CONDITION AND AGE: NEW YORK STATE, 1978-1982

Disabling condition		Children (under age 21)	Adults (age 22 +)
a	Autism	65%*	89%
b	Cerebral palsy	79%	86%
c	Epilepsy	92%	93%
d	Mental retardation	35%	25%
e	Multi-handicapped	47%	32%

SOURCE: Jacobsen and Janicki (1983).

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* By way of explanation: this statistic indicates that 65% of the persons in New York State under age 21 with autism had autism alone and not in combination with any of the other four major developmentally disabling conditions(a-d).

autism generally. Accordingly, HSRI first reduced the generalized prevalence rates for mental retardation, epilepsy, cerebral palsy and autism presented earlier by the percentages shown in Table 7b (rows a through d) in order to arrive at the prevalence of cases of each condition alone. Then HSRI multiplied the sum of these prevalence rates by 47% in order to obtain the prevalence rates for multiply handicapped persons.

D. Estimates Based on the Incidence, Associated Mortality, and Probable Disability Associated with Selected Pre- and Post-natal Medical Conditions (Table 8)

For purposes of developmental disabilities planning these children are commonly termed medically fragile. Medically fragile children considered at risk of being developmentally disabled are infants and preschool-aged children up to 36 months of age who have a high probability of manifesting in childhood a sensory or motor deficit and/or mental handicap. This group includes:

- children with syndromes that are known to result in later mental retardation and other developmental disabilities;
- children with identified developmental delays, as determined by a standard assessment.

Identifying these children, however, is difficult. As Arango (1983) points out, "physicians are reluctant to call a child disabled' until they are certain that what is obviously a developmental delay is not simply a case of slow growth" (p. 19). About the best one can do is to rely on the available condition-specific incidence and mortality data and the educated guesses of pediatricians, neonatologists and other practitioners in the field on the probability of associated disability.

TABLE 8a

PREVALENCE OF SELECTED DEVELOPMENTAL DISABILITIES AMONG CHILDREN AGES 0-5 BASED ON THE INCIDENCE, ASSOCIATED MORTALITY, AND PROBABLE DISABILITY ASSOCIATED WITH SELECTED MEDICAL CONDITIONS: NEW MEXICO

Condition	Incidence (Number per 10,000 live births)	Estimated number affected (assuming 27,000 live births/year)	Probable mortality	Likelihood that developmental disability will occur	Estimated number of children with developmental disability per year
1. Hereditary causes					
A. Inborn errors of metabolism					
1. PKU [ASTHO, 1984]	0.7	2		99% +	
2. Hyperthyroidism [ASTHO, 1984]	2.1	5		42% +	2
3. Histidinemia (Galactosemia, TaySach's, Batten's, Hurler's syndromes) [Fryers, 1984]	0.4	1		10% +	
B. Structural/functional					
1. Cystic fibrosis [Warwick, Pogue, Gerber & Nesbitt, 1975]	5	14	80%	100%	3
2. Muscular dystrophy	1 (boys ages 3-5)	3		100%	3
C. Blood					
1. Rh factor	11	30		10%	3
					11
2. Early influence on embryonic development					
A. Chromosomal abnormality					
1. Down's syndrome [Birth Defects Monitoring Program, 1985]	10	27	26%	100%	20
2. Other autosomal anomalies [Fryers, 1984]	20	54	26%	10%	4
3. Sex chromosome disorders (mostly Klinefelter's) [Fryers, 1984]	30	81	26%	10%	6
4. Non-specific disorders (recessive, X-linked) [Fryers, 1984]	15	41	26%	50%	15
B. Open neuro-tube disease					
1. Spina bifida [Birth Defects Monitoring Program, 1985]	10	27		50%	14

(Continued)

This is the approach taken by HSRI in estimating the number of developmentally disabled children under age six who will be identified as developmentally disabled each year (Tables 8a & b). The approach is modeled upon earlier work done by Arango, Price and Krchmar (1983). As shown in Table 8b, most of these cases are expected to be identified by age three.

The chief limitations of this method are:

- the incidence and mortality rates have not been adjusted for ethnicity and socio-economic status (SES) even though the incidence of developmental disabilities and related mortality rates associated with maternal infections and diseases, fetal alcohol syndrome, birth complications and acquired postnatal factors are known to vary by race and SES (Public Health and Preventive Medicine, 1985; Mayre, 1982; Morris and Heady, 1955; Morrison, Heady and Matrix, 1959). Race specific and SES specific rates would yield more reliable estimates.
- Some conditions are omitted or underrepresented. Included are mostly those conditions having some associated mental deficiency.
- More accurate representations of the incidence and mortality associated with developmental disability related conditions could be made by subdividing these categories and conditions (e.g., conditions associated with obstetric complications such as cerebral palsy from conditions such as idiopathic seizure disorders).

Obtaining sizeable samples of children under four years of age with particular developmental disabilities can be especially difficult. Many disabilities are not easily detected until a child enters school (e.g., mild mental retardation, learning disabilities), and early diagnostic signs may be attributed to normal developmental lags rather than to disability. As a result, epidemiologists are forced to deal with few identifiable cases in this age range, and sampling error becomes a major issue (Sower and Covert, 1975; Baird and Sadnovnik, 1985).

E. Validity and Reliability of these Estimates

1. Validity and Reliability

The **validity** (i.e., the extent to which prevalence estimates truly represent the prevalence of developmental disbilities) is largely a function of how developmental disabilities are defined. If the definitions are relatively loose, the prevalence estimates will be relatively high. If the definitions are relatively tight, the prevalence estimates will be relatively low.

As Kiely and Lubin (1983) explain, one of the reasons for the relatively wide variations in the reported prevalence rates is that different researchers employ different definitions. For instance, a study of the prevalence of mental retardation that focuses on individuals with I.Q.'s below 50 or includes measures of adaptive behavior will result in a prevalence rate that is considerably lower than a study that defines mental retardation solely on the basis of an I.Q. below 70.

The **reliability** of estimates of the prevalence of developmental disabilities is heavily a function of the size of the survey sample upon which the prevalence estimates are based. To understand the role of sample size in the determination of reliability, the notion of "sampling error" must be addressed. Such error is the difference between the characteristics of a sample and the characteristics of the population from which the sample was drawn. This is because a particular sample used in a survey is one of a large number of possible samples of the same size that could have been selected using the sample design. Likewise, an estimate of some parameter (e.g., the number of persons having cerebral palsy) derived from a particular sample is one of many estimates that could have been derived from other possible samples from the same population. These estimates form a distribution that is centered around the true value for the given parameter. Most estimates, therefore, differ from the mean value of the estimate by some amount. The deviation of a sample estimate from the mean or average of all possible sample estimates is defined as the sampling error.

Sampling error is represented or measured by a statistic called the standard error. Hence, the standard error of an estimate is a measure of the precision with which an estimate from a sample measures the true value of the parameter, the true value being the mean of all possible sample estimates, assuming no unsuspected bias or nonsampling error. The precision of an estimate in turn is affected by the size of the sample from which the estimate is based. Specifically, the size of the standard error is inversely related to the square root of the size of the sample upon which an estimate is based.

Because the prevalence of developmental disabilities is relatively low, the size of the sample must be quite large in order to derive reasonably reliable estimates of the prevalence of most developmentally disabling conditions. This is particularly so in the case of those disabling conditions ocurring infrequently such as Tourette's syndrome, spina bifida and neurofibromotosis. For this reason, even the larger surveys must group such low incidence disabilities as "other."

As was seen in Table 3 the standard error of the estimates of the prevalence of developmental disabilities generated from even the largest surveys is too high to use these estimates unchecked. Standard errors of the prevalence estimates derived from many of the smaller area surveys done in other areas of the country and the world are relatively low when generalizing only to the areas studied. However, the inestimable error involved in assuming, as one must, that these area estimates can be generalized to New Mexico and to its planning districts is probably equally as great as or greater than the sampling error indicated for the 1976 Survey of Income and Education.

For these reasons, HSRI checked these estimates against three independent estimates, two of which are based on state-specific data -- specifically, (a) estimates based on the numbers of adults participating in the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) Programs for reason of mental retardation, (b) counts of the numbers of children participating the special education programs in the state as prepared by the Department of Special Education, and (c) estimates based on prevalence rates of disabled infants and pre-schoolers ages 0-5 as reported in high risk infant registries in other states.

2. Estimates Based on Social Security Data

Estimates based on Social Security data are shown in Table 9 along with estimates based on other methods. The quadrant method is so named because it uses known estimates of the size of three segments (quadrants) of the adult mentally retarded population in

TABLE 9

ESTIMATED SIZE OF THE DEVELOPMENTALLY DISABLED POPULATION IN NEW MEXICO, USING DIFFERENT ESTIMATION METHODS

Age (a)	1976 Survey of Income and Education (b) MR, severe			Epidemiologic studies: Prevalence MR, severe	Prevalence MR, mild	Prevalence Other DD	Prevalence All DD	Incidence/ Mortality All DD	Registries: High-risk Infants All DD	SSI/SSDI records (quadrant method): Severe MR
	MR, severe	Other DD	All DD							
Infants & pre-schoolers										
0 - 2								721	462	
3 - 5	373	395 (c)	768					1250	781	
0 - 5				234	269	160	663	1971	1243	
School age										
6 - 17	1,370	1,554	2,924	1,038	1,194	312	2,544			
18 - 21	457	263	720	347	399	91	837			349
6 - 21	1,827	1,817	3,644	1,385	1,593	403	3,381			
Adults										
22 - 64	1,797	1,592	3,389	1,789	2,057	390	4,236			3,696
65 +	242	242 (d)	484	82	94	45	221			
22 +	2,039	1,734	3,873	1,871	2,151	435	4,457			

(a) Age divisions in the source data were interpolated when necessary to make the age divisions agree with the age divisions established for planning purposes.

(b) Civilian noninstitutionalized population only.

(c) U.S. prevalence rate used instead of inexplicably high rate derived for New Mexico.

(d) The estimation method produces an artificially high estimate of the number of elderly persons who have developmental disabilities other than mental retardation; therefore, the rate was lowered to equal the rate for mental retardation.

NOTE: The mental retardation categories include all persons with mental retardation as a secondary and tertiary as well as a primary condition.

a state to estimate a size of the fourth unknown quadrant.* As shown in Figure 2, the quadrants are divided according to SSI and SSDI participation and participation in state-funded developmental disabilities services.

The signal feature of the method involves estimating the size of that segment of the mentally retarded population in the state that is neither participating in the SSI or SSDI programs nor in state funded services for developmentally disabled persons (Figure 2, quadrant D) based on the assumption (or variation thereof) that adults with mental retardation participate in the SSI/SSDI entitlements at the same rate regardless of whether they are known or unknown to the state developmental disabilities system. More specifically, in the case of New Mexico, it is assumed that the ratio of the number of these non-developmental disabilities system clients not participating in the SSI or SSDI programs (quadrant D) to the number of non-developmental

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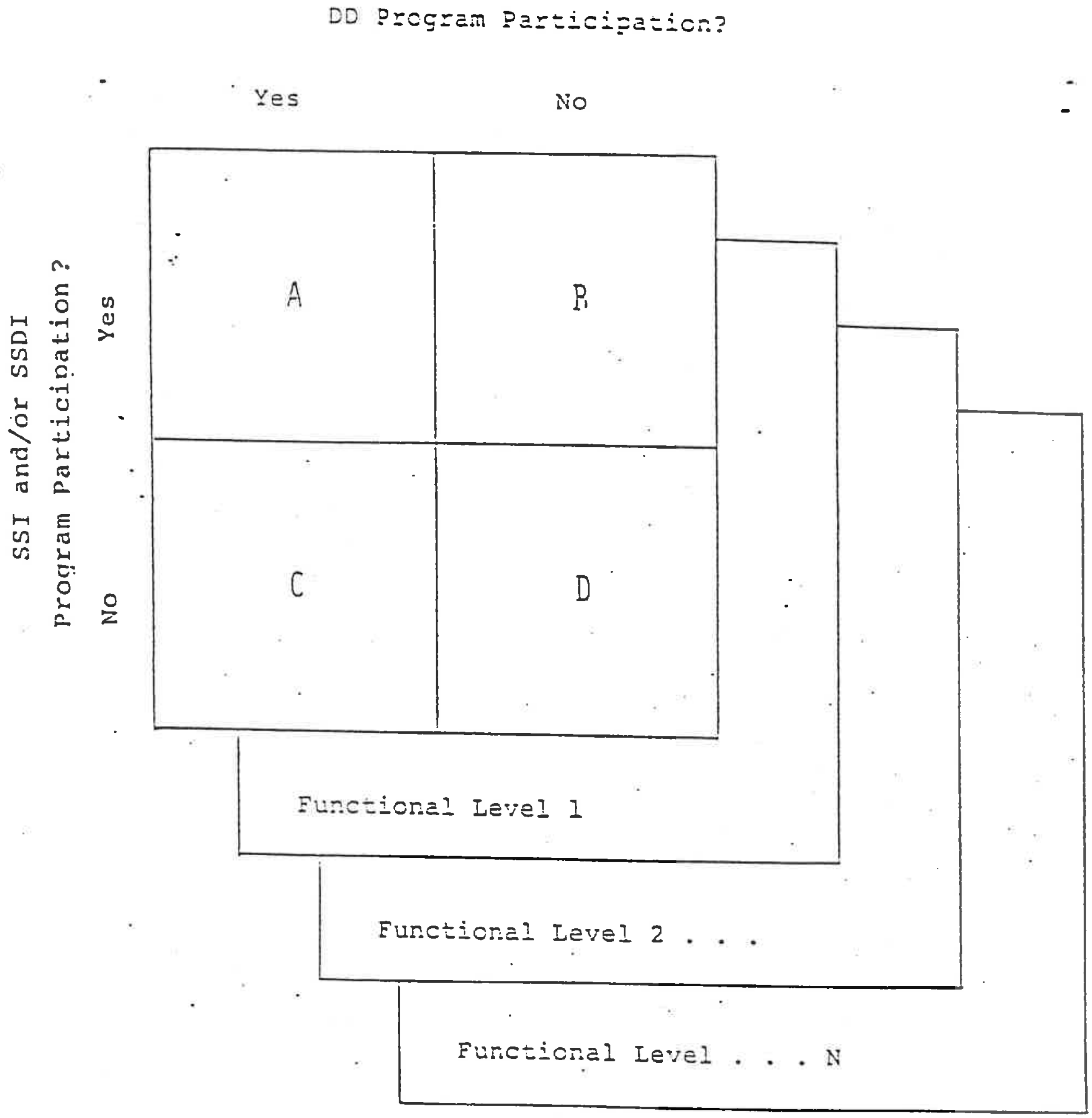
*Note: Because eligibility determination procedures are known to differ to some extent from region to region in the case of Social Security Disability Insurance, and from state to state in the case of Supplemental Security Income, the quadrant method can only be applied on a state by state basis. In this way the estimates are not affected by whether a state or region has relatively strict or liberal SSI or SSDI eligibility requirements. The formula is such that liberal jurisdictions will show more individuals with developmental disabilities as participating the SSI and SSDI programs (quadrants A and B) and fewer not participating (quadrants C and D). In conservative jurisdictions, fewer individuals with developmental disabilities would be identified as participating in SSI or SSDI (quadrants A and B), while more would be indicated as not participating (quadrants C and D).

ESTIMATING THE SIZE OF ADULT POPULATION WITH DEVELOPMENTAL DISABILITIES

QUADRANT METHOD



BASIC ASSUMPTION

$$B/D = A/C$$

$$D = B(C/A)$$

Figure 2

disabilities system clients participating in the SSI or SSDI program (quadrant B) is the same as the ratio of the number of developmental disabilities system clients not participating in the SSI or SSDI programs (quadrant C) to the number of developmental disabilities system clients participating the SSI or SSDI programs (quadrant A).* The sum of quadrants A and C, the number of clients by SSI and SSDI status, was obtained from a survey of state-funded providers of residential and day services to developmental disabled adults in New Mexico conducted by HSRI in May and June of 1985, and from the Client Option Oriented Profile (COOP) management information system. Quadrant B was calculated by subtracting the number of developmental disabilities system clients participating in the SSI or SSDI programs (quadrant A) from the total number of mentally retarded adults estimated to be participating statewide (quadrants A and B). These estimates were calculated for New Mexico by the Human Services Research Institute using data obtained from the Social Security Administration. This procedure is explained in Appendix B.

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* This assumption leads to a conservative estimate of the developmentally disabled population. This is because the rates of SSI and SSDI participation among developmental disabilities system participants are generally higher than, not equal to, the rates of participation among non-developmental disabilities system participants; most states assist or at least encourage clients to apply for SSI and/or SSDI benefits at the time they first apply for service as a means of helping defray the cost of care to the state and/or the client.

3. Estimates Based on State High Risk Infant Registries (Table 10)

In order to obtain prevalence rates for the 0-5 age group, HSRI conducted a telephone survey of those states having high risk infant registries and having mandates to serve disabled children from birth. It was assumed that the registries in these states would have cause to be more complete than would any registries existing in other states.

The results of HSRI's survey of high risk infant registries are shown in Table 10.

4. Concurrent Validity

Table 9 compares the developmentally disabled population estimates by age and disability category. As shown in Table 9, the number of adults with severe mental retardation as estimated using the Survey of Income and Education, and as estimated using the median prevalence rates from area wide epidemiologic studies are in close agreement. Likewise, the number of adults with mental retardation (severe and mild) as estimated using the median prevalence rates from area wide epidemiologic studies and as calculated using the quadrant method are in close agreement. Accordingly, we would judge that these estimates are reasonably valid and reliable.

The Survey of Income and Education estimates are the only acceptable estimates of the number of adult non-mentally retarded, developmentally disabled persons. These estimates do not include persons residing in institutions and other group

TABLE 10

AGE-ADJUSTED PREVALENCE (RATES PER 1,000 GENERAL POPULATION) OF DISABLING CONDITIONS AMONG CHILDREN AGES 0-5

	Ages	
State	0-2	3-5
Iowa	6.0	
Massachusetts		10.0
Maryland	4.7	
Michigan	4.5	10.0
Nebraska	7.3	15.3
New Jersey		
Rhode Island		10.0
South Dakota	5.7	
Median	5.7	10.0

Source: State High Risk Infant Registries.

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* The rates are based on the size of the general population within each age group.

quarters, and thus must be considered under-estimates. The estimates based on area-wide epidemiologic studies include only mental retardation-related developmental disabilities and thus reflect only a small portion of the "other" developmentally disabled population.

The size of the developmentally disabled population age five and under as estimated from the high risk infant registries is about the same as the size estimates based on available epidemiologic data on the incidence and mortality associated with selected potentially disabling conditions, and expert judgment of the probability of their resulting in a disability. As earlier explained both sources must be considered to yield under estimates or at least conservative estimates of the prevalence of developmental disabilities among this age group, though not nearly as conservative as estimates based on prevalence rates reported in epidemiologic studies. Arango (1983) came up with higher estimates using incidence data, and (as shown in Table 10) Nebraska's registry likewise reported a higher prevalence.

Officials responsible for these registries invariably reported that the registries were incomplete; their systems have not yet evolved to the point of 100% participation. Also many disabilities are simply not easily detected and diagnosed. Some states such as Iowa, in fact, postpone formal diagnoses until the child reaches age three.

The prevalence rates for children in the next age bracket (ages six through 17) according to the Survey of Income and Education child counts is roughly 15 per thousand -- a rate slightly lower than the prevalence rate for children ages three through five.

F. Developmental Disabilities Population Trends

The principal feature that distinguishes between those developmentally disabled persons who can not be expected to ever live independently in unsupervised residential arrangements, and other developmentally disabled persons, appears to be the level of mental dysfunction that inhibits the ability to learn independent living skills and to exercise that judgement necessary to apply these skills. This is to be expected. A very high proportion of persons in residential placements in all states for which HSRI has statistics show similar proportions. In New Mexico, according to COOP, over 90% of the persons in out-of-home community-based residential arrangements have some degree of mental retardation and over 99% of persons in the two institutions are likewise disabled.

Thus in projecting changes in the potential demand for residential and related support services in New Mexico, the most significant segment of potential demand comes from those with mental retardation and associated handicaps of biologic origin, 90% of which are manifest at birth or early infancy (Grossman, 1983). The causal factors include infectious disease, genetic disease, birth complications associated with low birth weight, and other biomedical causes. Some of the factors are on the increase, some on the decrease, but the incidence of most is relatively steady (Birth Defects Monitoring System, unpublished data, 1981).

According to unpublished statistics compiled as part of the Birth Defects Monitoring Program, there has been little significant change in the incidence of mental retardation-associated birth defects over the past decade. At the same time, the incidence of total congenital anomalies (nervous system) has declined very slightly. The incidence of Down's Syndrome appears relatively steady; the effects of advances in prenatal diagnostic capabilities are likely being offset by increases in maternal age and improved intensive neonatal care.

Exceptions are the incidence of anencephaly (brain defects) and spina bifida, which have declined about 40% from 1970-73 to 1984. The incidence of congenital rubella has also declined dramatically and the incidence of hemolytic newborn disease has been halved during this period.

In contrast the incidence of hip dislocations with central nervous system defects has increased threefold, and the recognized incidence of autosomal abnormalities (excluding Down's Syndrome) has doubled (though this may be a function of increased recognition rather than increased incidence).

There has been only a slight decline in the prevalence of premature births and low-weight births (under 1,500 grams) over the past decade. In past years low birth weight infants accounted for a substantial proportion of all developmental handicaps. In the 1950s and early 1960s infants weighing less than 2000 grams accounted for about 10-15% of all severe mental retardation (Drillien, 1968; Birch et al., 1970; Gustavson et al., 1977) and about 30-40% of all cerebral palsy (Lillenfield and Parkhurst, 1951; Childs and Evans, 1954; Eastman and DeLeon, 1955; Foster, Guy and Perry-Jones, 1956; Fuldner, 1957). The risk of cerebral palsy was 6.5% in McDonald's survey of infants under 1800 grams (McDonald, 1967), and 9% in the Collaborative Perinatal Project's survey of infants under 1500 grams (Ellenberg and Nelson, 1979).

However, while the incidence of premature and low-weight births and of most biological factors associated with mental retardation and associated nervous system disorders have remained relatively steady, survival rates continue to increase. Philip, et al. (1981) estimate, based on a survey of neonatal care centers throughout England and North America, that the neonatal survival of infants weighing less than 1500 grams at birth has increased from about 38% in the 1960s to 51% in the 1970s to about 69% in the late 1970s (Gortmaker and Sappenfield, 1984). Elwood and Elwood (1980) report an increase in the survival of children with spina bifida from four to eight years owing to advances in surgical treatment. As Grossman (1983) observes "much progress has been made during the past two decades in developing facilities and treatment for the intensive care of such high-risk infants. Biochemical abnormalities such as hypoglycemia and hypoxia can now be diagnosed readily and treated effectively. Respiratory distress and anoxia, once major causes of brain damage, are now also subject to treatment without consequent morbidity in most cases."

What is unknown is the net affect of these advances on the prevalence of neurologic impairments. According to reports by

Shapiro, McCormack and Stanfield (1983), and Hack, Faranoff and Merkatz (1979), overall rates of severe impairment among surviving low birthweight infants currently appear to be less than 20% (Gortmaker and Sappenfield, 1984). While some suspect that these advances are leading to decreases in the prevalence of neurologic impairments (Gortmaker and Sappenfield, 1984; Grossman, 1983), others (Drillien, 1958; Hold, 1970) suspect that an increased number of handicapped children are surviving. Still others (Kiely, Paneth and Susser, 1981) are uncertain.

The positive advances in stemming the prevalence of lead encephalopathy (mostly among low income children) are being offset to some degree by increases in the incidence of other acquired postnatal factors such as bacterial meningitis (Underman, Overturf, Leedmon, 1978).

There is increasing evidence that the extent to which mental retardation and associated neruologic impairments of biologic origin result in adaptive and maladpative behavior is heavily influenced by biosocial and psychosocial factors. Children in supportive and stimulating environments appear to be able to compensate for the biologic defects to a greater extent than children not having such benefits (Grossman, 1983). The beneficial affects of early intervention programs are well documented.

Studies of handicapped infants and their parents (Moore, 1979; Stedman, 1977) as well as of "high risk" children (Lazar, 1979; Weikart, Bond and McNeil, 1978) have shown that early intervention can produce gains in children in all developmental areas -- motor, language, social/emotional, cognitive, and self help. Gains were even produced in such traits as intelligence (as measured by standardized tests) which were once thought to be "fixed" at birth. Another study (Garland, Stone, Swanson and Woodruff, 1980) has shown the obverse: delaying intervention may aggravate a child's handicap by creating secondary conditions, such as emotional disturbance" (Arango, 1983).

Considering the relative stability of most biologic factors leading to mental retardation and associated neurologic impairments and the unsettled question of the increased survival of low birthweight infants on the prevalence of mental retardation and neurologic impairments, HSRI can only assume that the prevalence of moderate, severe and profound mental retardation and other developmental disabilities will continue at the same rate in future years. **This assumption is reflected in our projections of the size of the developmentally disabled population (potential demand) in New Mexico statewide and by planning district in the years 1990 and 1995.** (Tables 11 and 12).

TABLE 11

ESTIMATED NUMBER OF PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, BY AGE IN NEW MEXICO: 1990

AGE GROUP	STATE DEV DISABILITIES ALL	STATE MR	STATE OTHER	DISTRICT 1 DEV DISABILITIES ALL	DISTRICT 1 MR	DISTRICT 1 OTHER	DISTRICT 2 DEV DISABILITIES ALL	DISTRICT 2 MR	DISTRICT 2 OTHER	DISTRICT 3 DEV DISABILITIES ALL	DISTRICT 3 MR	DISTRICT 3 OTHER	DISTRICT 4 DEV DISABILITIES ALL	DISTRICT 4 MR	DISTRICT 4 OTHER	DISTRICT 5 DEV DISABILITIES ALL	DISTRICT 5 MR	DISTRICT 5 OTHER	DISTRICT 6 DEV DISABILITIES ALL	DISTRICT 6 MR	DISTRICT 6 OTHER	DISTRICT 7 DEV DISABILITIES ALL	DISTRICT 7 MR	DISTRICT 7 OTHER
INFANTS/PRESCHOOL																								
0-2 YEARS	479			68			60			168			27			16			96			44		
3-5 YEARS	879			125			112			310			49			30			173			80		
0-5 YEARS TOTAL	1,358			193			172			478			76			46			269			124		
SCHOOL AGE																								
6-17 YEARS	4,557	2,703	1,854	619	367	252	607	360	247	1,630	967	663	253	150	103	165	98	67	855	507	348	428	254	174
18-21 YEARS	986	732	254	120	89	31	125	93	32	373	277	96	57	42	15	35	26	9	166	123	43	110	82	28
6-21 YEARS TOTAL	5,543	3,435	2,108	739	456	283	732	453	279	2,003	1,244	759	310	192	118	200	124	76	1,021	630	391	538	336	202
ADULTS																								
22-64 YEARS	5,977	4,219	1,758	615	434	181	840	593	247	2,465	1,740	725	312	220	92	197	139	58	977	690	287	571	403	168
65+ YEARS	277	225	52	17	14	3	36	29	7	110	89	21	18	15	3	15	12	3	54	44	10	27	22	5
22+ TOTAL	6,254	4,444	1,810	632	448	184	876	622	254	2,575	1,829	746	330	235	95	212	151	61	1,031	734	297	598	425	173
TOTAL ALL AGES	13,155	7,879	3,918	1,564	904	467	1,780	1,075	533	5,056	3,073	1,505	716	427	213	458	275	137	2,321	1,364	688	1,260	761	375

TABLE 12

ESTIMATED NUMBER OF PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, BY AGE IN NEW MEXICO: 1995

AGE GROUP	STATE DEV DISABILITIES			DISTRICT 1 DEV DISABILITIES			DISTRICT 2 DEV DISABILITIES			DISTRICT 3 DEV DISABILITIES			DISTRICT 4 DEV DISABILITIES			DISTRICT 5 DEV DISABILITIES			DISTRICT 6 DEV DISABILITIES			DISTRICT 7 DEV DISABILITIES		
	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER
INFANTS/PRESCHOOL																								
0-2 YEARS	492			71			59			172			26			17			101			46		
3-5 YEARS	914			131			111			320			48			31			188			85		
0-5 YEARS TOTAL	1,406			202			170			492			74			48			289			131		
SCHOOL AGE																								
6-17 YEARS	5,023	2,979	2,044	702	416	286	649	305	264	1,780	1,056	724	273	162	111	167	99	68	988	586	402	464	275	189
18-21 YEARS	1,040	773	267	136	101	35	128	95	33	385	286	99	58	43	15	36	27	9	188	140	48	109	81	28
6-21 YEARS TOTAL	6,063	3,752	2,311	838	517	321	777	480	297	2,165	1,342	823	331	205	126	203	126	77	1,176	726	450	573	356	217
ADULTS																								
22-64 YEARS	6,596	4,657	1,939	708	500	208	919	649	270	2,710	1,913	797	331	234	97	208	147	61	1,088	768	320	632	446	186
65+ YEARS	321	260	61	21	17	4	41	33	8	128	104	24	20	16	4	17	14	3	62	50	12	32	26	6
22+ TOTAL	6,917	4,917	2,000	729	517	212	960	602	278	2,838	2,017	821	351	250	101	225	161	64	1,150	818	332	664	472	192
TOTAL ALL AGES	14,306	8,669	4,311	1,769	1,034	533	1,907	1,162	575	5,495	3,359	1,644	756	455	227	476	287	141	2,615	1,544	782	1,368	828	409

III. EXPRESSED DEMAND

A. Source Data

In order to make a reasonable assessment of the service and related resource requirements of developmentally disabled persons receiving services and awaiting services in New Mexico, HSRI divided the population into seven level-of-functioning categories: (1) seriously medically and physically disabled, (2) moderately medically and physically disabled, (3) endangering behavior (4) disruptive behavior (5) minimally adaptive (6) moderately adaptive and (7) highly adaptive. Each of these categories was further divided into three age groups (1) 0-5, (2) 6-21, and (3) 22 and over. Individuals were assigned to one category only.

Data were collected on the number of persons receiving services in each of the seven planning districts and at the two state institutions by level-of-functioning and age and by the type of residential and day (training) service(s) in which they were participating as of March 31, 1985. These data were obtained from two sources: (1) HSRI's mail/phone survey of 30 providers with contracts with the Developmental Disabilities Bureau (Health and Environment Department); (2) the state's Client Oriented Option Profile (management information system). Public forums in each of the seven planning districts provided information that served as a check and complement to these data.

An individual could be assigned to one category only. Persons fitting into more than one category were assigned to the lowest (most dysfunctional) division.

1. Provider Survey

A list of the 30 service providers surveyed is shown in Appendix C. The survey form is shown in Appendix D.

The survey served two purposes: (1) to obtain information that were not available from COOP, most importantly:

- a more detailed breakout of residential and training services;
- an assessment of the relative urgency of the situations of persons on waiting lists for services;
- the number of full time equivalent staff;
- the number of clients not registered in COOP.

(2) to verify information available in COOP specifically:

- the client levels of functioning (defined globally) -- the client level-of-functioning definitions and service definitions are shown as part of Appendix D.
- the number of clients receiving Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits

2. Client Oriented Option Profile (COOP) Data

The COOP data were used in lieu of the HSRI survey for those few providers not responding to the HSRI survey, and for the two institutions. Clients were categorized into one of the seven levels-of-functioning using indicators available in the COOP data base. The indicators used in assigning individuals to the level-of-functioning categories are presented in Appendix E.

Where COOP data and HSRI survey data were inconsistent, HSRI contacted the providers by phone for explanations. Twenty two of the 29 providers responded to the survey. Not all responses were complete, and missing data could not always be obtained by phone.

3. District Planning Meetings

During the initial phases of the preparation of the residential plan, HSRI conducted public forums in the seven state planning districts. The forums, which were intended to attract family members, professionals, and others interested in the provision of services to persons with developmental disabilities, were held to solicit information regarding local needs for residential services. Participants were also asked to rank service needs in terms of their priority locally. The areas most commonly mentioned included the following:

- increased and improved residential opportunities for persons with severe and profound mental retardation, persons who are non-ambulatory and individuals with both mental retardation and behavior problems;
- adequate salaries to attract and retain residential staff;
- respite care for families who have maintained a family member with developmental disabilities at home;
- increased staff training opportunities;
- expanded "real world" work opportunities and job training programs for persons with developmental disabilities;
- increased vocational training programs in the public schools;
- training and support programs for families with developmentally disabled family members;
- greater public awareness of the needs and capabilities of persons with developmental disabilities.

Though attendance at the forums varied from district to district, the information gained provided a useful foundation for further data gathering. In order to augment and build on the information, forum reports were sent to an expanded group of district planning participants, an overview of the New Mexico developmental disabilities system was prepared and circulated, and district by district profiles were prepared which included information on current service utilization and demand and projections for future service requirements. These subsequent activities reinforced the need for increased living arrangements with a capacity to serve persons with more serious disabilities, and the need to provide expanded family support services, in addition to other system reforms.

4. Data Validity and Reliability

While the Provider Survey and COOP data on individuals in and awaiting developmental disabilities services in New Mexico are the best data available at this time, are somewhat problematic. The method used to classify clients in this study has important limitations worth noting. The classification scheme as designed force fits clients with severe behavior, medical and physical disabilities into categories other than the categories distinguishing clients by adaptive skill level when in fact a client could fit into both types of categories. This was purposely done in order to identify the principal problem(s) that dictate client service requirements. However, resource limitations did not allow for the training of provider staff on how to complete the survey, and providers could not afford the time or were not inclined to spend a lot of time studying the written instructions. The resulting confusion, coupled with the inherent difficulty associated with making global judgments on client levels of functioning, put the validity of client classifications in some question.

Fortunately, the survey ratings of client levels of functioning could be checked against the ratings computed from the COOP data were found to be quite consistent. The global survey ratings of clients were only slightly higher than the level-of-functioning ratings derived from the COOP data.

B. Persons Served

New Mexico has relatively few persons in out-of-home residential placements, 1,037 (Table 13), just over eight percent of the developmentally disabled population in the state. In 1982, New Mexico ranked 42nd among the 50 states in terms of the number of publicly supported residential beds per 100,000 population.* New Mexico had 62 beds per 100,000 population; the average of all states was 105 per 100,000 population (Hauber, Bruininks, Hill and White, 1984). Based on our informal reading of the pace of residential program development in New Mexico and other states in the three years since, we expect that New Mexico's rank today would be about the same, perhaps slightly higher.

We suggest that there are several reasons for New Mexico's relatively low level of out-of-home placement:

- the rural character of the state inhibits efforts to identify families in need, and families tend to be more self reliant;
- as with many rural states, the rate of admissions to institutional programs in years past was relatively low. In 1982 New Mexico's rate of persons in large

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* Residential options are defined to include: Parent/ret/guardian's home, Independent home or apartment, Dual residence (home/other), Foster care, Boarding home, Nursing home, Group home, and State institution.

residential facilities (over 64 beds) was little more than half that of the other states (Hauber, Bruininks, Hill, Lakin and White, 1984)

- The supply of residential placement alternatives has been limited.

Thus, relative to most other states, New Mexico relies heavily on private, family-based care. Nearly 92% of the estimated 12,600 persons requiring long term supervised residential arrangements or 11,500 persons with mental retardation and other organic impairments reside at home. Clearly this is to the considerable economic advantage to the state. Were New Mexico to have as many persons in out-of-home placements as the average state, another 600 beds would be required. At an ICF-MR institutional rate of $100 per day, this would add 22 million dollars to the annual cost of care for these individuals, almost $7 million dollars of which would by borne by the state. At the average community ICF-MR rate of $75, it would add another 16.5 million dollars to the annual cost of care, five million dollars of which would be borne by the state.

Yet the state provides little support to these families. Only .6% (71) of these families receive family support services and then only respite care; most of these families live in the Albuquerque area and utilize the Los Lunas respite program. Respite care and other family support services such as: adaptive equipment, educational/therapeutic services, transportation, medical or dental services, home barrier removal, special clothing, special diets, diagnosis and assessment, medication, home health care, attendant care, recreational services, information and referral, temporary relief/respite, family counseling, parent/sibling education, homemaker services, chore

TABLE 13

EXPRESSED DEMAND FOR RESIDENTIAL BEDS IN NEW MEXICO, BY AGE GROUP AND CURRENT LIVING ARRANGEMENT, 1985

		AGE GROUP		
NT RESIDENTS	ALL AGES	0-5	6-21	22+
TAL	1,037	40	229	768
COMMUNITY	564	32*	111	421
FT. STANTON	127	0	13	114
LOS LUNAS	346	8	105	233
TING LISTS				
TAL	377	13	91	273
COMMUNITY	312	4	50	258
FT. STANTON	--	--	--	--
LOS LUNAS	65	9	41	15
AL EXPRESSED DEMAND	1,414	53	320	1,041

* All foster care.

services, housekeepers, cash assistance, future financial planning are not offered.

Even day program slots are rationed in many districts to persons in out-of-home residential arrangements, which in some cases has had the perverse effect of leading families to place their dependents out of the home solely in order to get them into structured day activities.

The largest number of publicly-supported residential placements are in institutional facilities and community group homes, 124 in community ICF-MRs 230 in group homes and another 473 in institutional settings. Other residential models (such as minimally supervised apartments and companion homes are limited or nonexistent in most districts). As one might expect, the lack of a residential continuum is most apparent in less populous districts such as District 1 and District 7.

Overall there appears to be a satisfactory balance between the level of functioning of clients in residential placements and the level of supervision provided. In some districts, however, the initial profiles suggest that some less severely disabled individuals are being served in overly restrictive supervised settings.

As shown in Table 14, while group home staff/client ratios and day program staff/client ratios appear adequate compared to staffing standards and norms of like programs in other states, these care givers, like the families, are reportedly provided few supports (e.g., staff training, specialist consultations on how to manage clients with behavioral, physical, and medical

TABLE 14

STAFF TO CLIENT RATIOS BY TYPE OF PROGRAM

PROGRAM TYPE	New Mexico Programs (Median)[1]	Program Standards and Models (Range)[2]
Residential		
ICF-MR (N=2)	2.7	2.0 - 8.0
Residential -- Moderate Supervision (N=5)	2.1	1.2 - 10.6
Residential -- Minimum Supervision (N=7)	8.5	8.0 - 17.3
Day		
Work Activity Centers	7.2	5.0 - 20.0
Adult Day Habilitation	5.0	4.0 - 5.0
Sheltered Workshops	5.2	5.0 - 20.0

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[1] Source: HSRI Provider Survey

[2] Source: HSRI Multi-State Survey of Program Staffing Standards and Models

problems; funds for structural adaptions to accommodate persons with physically impairments; specialized diagnostic and evaluation services; and crisis support services in the event of unmanageable behaviors.

1. Urgent or Inadequate Situations

Three hundred and twelve persons were identified by community providers as needing a group home placement as of June 1985. However, information on the level of functioning of these individuals is insufficient to judge the level of residential supervision and supports required, and no information is available on the relative urgency of their situations -- that is, reflective of the burden being placed on the private care givers and the present adequacy of these supports considering the clients health, safety and welfare.

Though responses to HSRI's provider survey relating to the urgency of residential placement requests were incomplete, those 11 providers completing this part of the survey indicated that 15% of the non-institutionalized persons wait-listed were in urgent situations, that is, judged to be in circumstances posing an immediate threat to their health or safety. Another 28% were in inadequate residential situations -- inadequate in terms of the quality of the food, shelter, clothing, care and treatment, privacy afforded, and in terms of the dignity and respect shown them. Assuming that these 11 providers are representative of all group home providers, 48 of the 312 clients were in urgent situations and 87, in inadequate situations.

2. Inappropriate Placements

The majority (57%) or 177 were living in residential situations considered to be age inappropriate, too restrictive, not sufficiently accessible, or for whom alternative circumstances were desired or necessary for reasons than the above.

a. For Reason of Overly Restrictive Care

The least restrictive alternative principle requires that a living situation should reflect an age and culturally appropriate environment that can also meet the persons needs for supervision and training without compromising personal rights. Assuming that persons with overriding severe medical, physical, and behavioral problems or minimum self care skills require high supervision, and others, moderate to minimum supervision, most individuals are in appropriately supervised residential and day activities in New Mexico. However, by our analysis, approximately 50 clients (those with disruptive behaviors and moderate or high activities of daily living skills) now in ICF-MR or other high supervision facilities could benefit from moderately supervised arrangements*.

b. For Reasons of Size and Segregation

As a rule, the impersonal, bureaucratic organizational structures and management procedures associated with large, centralized providers of care, tend to impede rather than promote

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* A small number of these persons should be counted in the 158 persons identified by providers as inappropriately placed and on the community waiting list (above).

the personal interaction, support, flexibility, and esprit de corp necessary for motivated and effective residential caregivers. As important, larger programs tend to be more standardized and uniform compared to smaller settings where staff can be more sensitive to individual client needs. Counteracting factors that argue in favor of large versus small programs for particular types of clients are absent; moreover, there are few economies of scale associated with large, labor-intensive developmental disabilities services (Ashbaugh, 1984).

Accordingly, in the Institute's judgment, the 127 clients at Fort Stanton and 346 clients at Los Lunas are inappropriately placed. Eighty three of these persons are currently wait-listed for community programs. Table 15 summarizes the number of additional out-of-home residential placement requirements presently known.*

3. Estimate Qualifications

While the COOP data, data from the HSRI survey, and information gathered at the district planning meetings were sufficient to identify the obvious and immediate demand for residential and support services, they provide an inadequate base for ongoing long term planning. The waiting-list data are incomplete. Such lists will be representative and complete only when all prospective applicants for residential services in New Mexico are aware of the lists and understand that they must be listed as a prerequisite to receiving service. At present the

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* Referenced on page 6.

TABLE 15

CONSERVATIVE ESTIMATE OF ADDITIONAL OUT-OF-HOME RESIDENTIAL BEDS REQUIRED IN NEW MEXICO COMMUNITIES, BY DISTRICT AND LEVEL OF RESIDENTIAL SUPERVISION

			DISTRICT/LEVEL OF SUPERVISION REQUIRED													
	TOTAL		1		2		3		4		5		6		7	
CURRENT STATUS	HIGH	MOD.	HIGH	MOD.	HIGH	MOD.	HIGH	MOD.	HIGH	MOD.	HIGH	MOD.	HIGH	MOD.	HIGH	MOD.
COMMUNITY WAITING LIST (URGENT SITUATIONS)	14	34	0	7	3	6	4	8	1	2	1	3	5	6	0	2
LOS LUNAS WAITING LIST	60	5	7	0	11	1	31	2	0	0	8	2	3	0	0	0
COMMUNITY WAITING LIST (INADEQUATE SITUATIONS)	28	59	1	13	6	10	8	14	2	5	3	3	8	11	0	4
COMMUNITY WAITING LIST (INAPPROPRIATE SITUATIONS)	57	120	2	27	12	20	16	29	4	10	6	6	16	22	1	8
TOTAL	159	218	10	47	32	37	59	53	7	17	18	14	32	39	1	14

NOTES: High supervision - clients with severe medical or physical problems, endangering behavioral problems, or minimum self-care skills.

Moderate supervision - clients with disruptive behavior problems and at moderate or high skill levels.

Community waiting lists distributed by district according to relative size of district waiting list (CO-OP).

The supervision needs of persons on community waiting lists are assumed to be the same as those currently in residence.

information on the clients is not sufficient to discriminate individuals by level of functioning and corresponding service requirements, nor by the urgency of their present situations.

Accordingly, the Institute strongly recommends that the Developmental Disabilities Planning Council, in fulfilling its legislated mandate to assess the need for developmental disabilities services in New Mexico, design, develop, and implement a system as described below.

(1) All persons seeking placement in state funded Institutions or community living facilities or day services be required to:

- complete an application for services. The application should seek information on the urgency of the client's situation as well as on the clients level-of-functioning
- consent to more thorough evaluation upon selection for placement, with placements made according to an established set of state priority criteria reflecting both client need and the urgency of the caregiver/client situation.

(2) Persons currently served should also be evaluated periodically (preferably annually) in order to assess their level of functioning and service needs (logically as part of the individual habilitation planning process).

(3) The level of functioning evaluations should be done using a standardized individual client evaluation instrument such the Individualized Client Assessment Profile (ICAP).

(4) These evaluation scores should be incorporated as part of the COOP information system in order to allow for ready analysis in support of Developmental Disabilities Bureau Planning.

(5) Over time these data will allow the Developmental

Disabilities Planning Council to identify trends in service demand, and to better gauge the extent of unmet service needs in New Mexico.

IV. UNEXPRESSED SERVICE DEMAND

The developmentally disabled population includes a number of persons who have not demanded publicly supported services, some of whom would demand appropriate services if they to were available (latent demand). Some however, would not (compensated demand). The latter group is presently relying on private residential services or supports.

It is important to recognize that such demand will surface as new residential and related support services, designed to satisfy known or expressed demand, are established. This additional demand is generated by virtue of the added visibility and accessibility of these services, and the implicit message that such alternatives represent available and acceptable alternatives to family caregivers. In other words, the level of hidden versus compensated demand is not only a function of the adequacy of private residential services and supports, but of the availability of acceptable alternatives.

The state, as a marketer of residential services, has the ability to generate and shape residential demand. Forty years ago demand for residential services was channeled into institutions. More recently New Mexico, like most other states, has channeled this demand into community residences. In future years, respite care and other family support services hold promise to redirect some of this residential service demand into residential supports for those families seeking relief and support rather than separate residential arrangements for their disabled dependents.

Reasonably accurate estimates of the hidden demand associated with different service alternatives are best made from studying service supply/demand relationships over a period of years using the eligibility determination system (described earlier). In the absence of these data it is possible only to make outside estimates of hidden demand using comparative demand figures from other states. Under the conservative assumption that the ratio of expressed demand plus hidden demand to potential demand in New Mexico equals the average ratio of expressed demand (number of persons in service or wait listed) to potential demand in the other 49 states, the hidden demand would be 336. Under the liberal assumption that the ratio of expressed demand plus hidden demand to potential demand in New Mexico equals the average ratio of expressed demand to potential demand in that state reporting the highest such ratio, the hidden demand would be 1657.

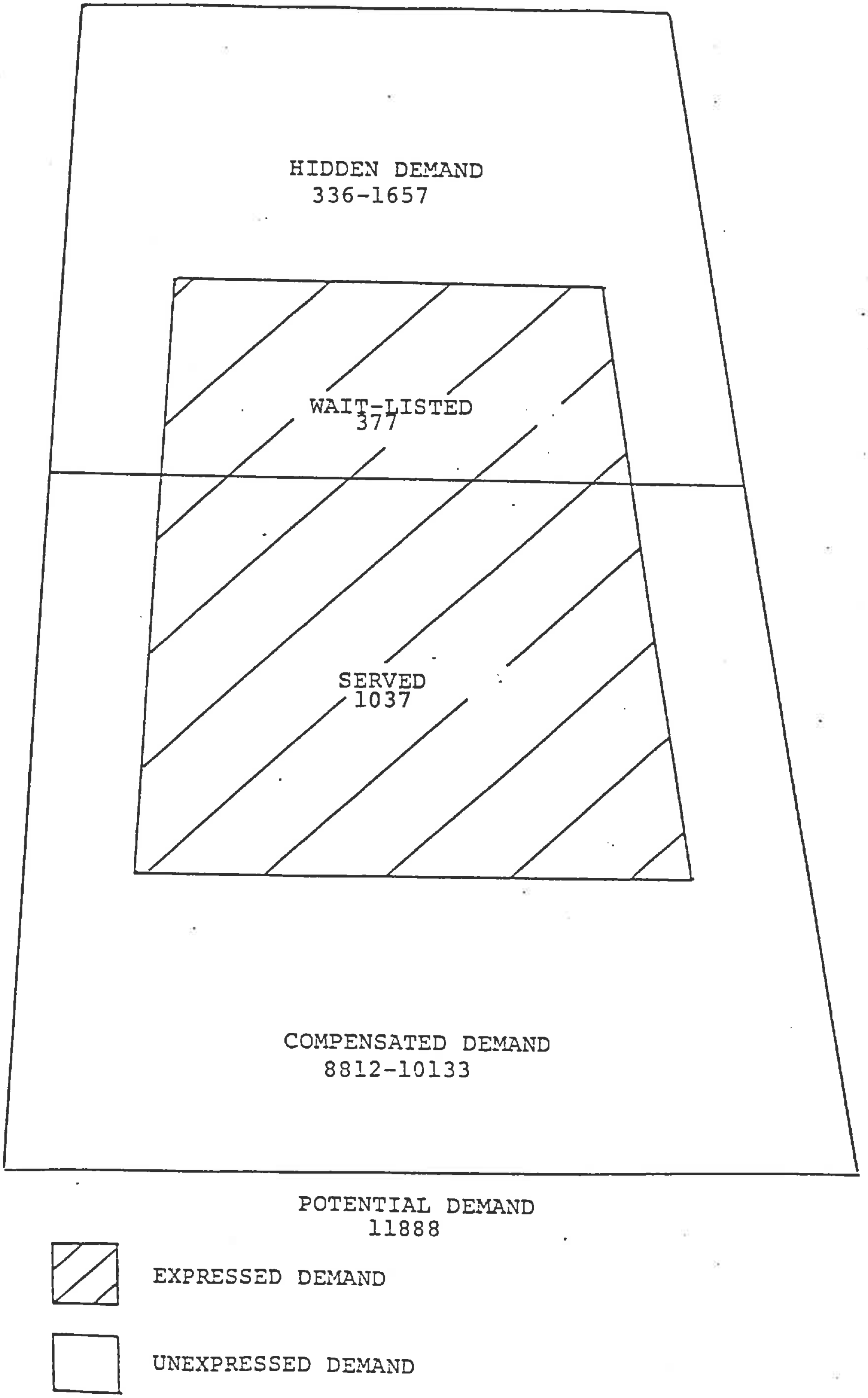
These comparative data are based on the 1982 National Census of Residential Facilities (Hauber, Bruininks, Hill, Lakin and White, 1984).

V. SUMMARY

Figure 3 illustrates the breakdown of demand for residential and related day services by category of demand.

FIGURE 3

Estimated Demand for Residential Services
in New Mexico



BIBLIOGRAPHY

Abramowicz, H.K. & Richardson, S.A. 1975. Epidemiology of severe mental retardation: Community studies. *American Journal of Mental Deficiency*, *80*, 18-19

Agosta, J., Bradley, V., Rugg A. & Covert, S. August 1985. *The needs of families: Results of a statewide survey in Virginia*. Boston: Human Services Research Institute.

American Association on Mental Deficiency. 1977. *Manual on terminology and classification in mental retardation*. Washington: American Association on Mental Deficiency.

Andersen, B. 1954. Cerebral palsy. J. Oslo City Hospital, *4*, 65-87

Arango, John. 1983. *The early years. A plan for New Mexico's developmentally disabled children*. Final report prepared by Rio Grande Associates for the New Mexico Developmental Disabilities Planning Council.

Association of State and Territorial Health Officials (ASTHO). 1984. Services for mothers and children. *Public Health Agencies 1982*, *3*. Association of State and Territorial Health Officials.

Baird, P.A. & Sadovnick, A.D. 1985. Mental retardation in over half-a-million consecutive livebirths: An epidemiological study. *American Journal of Mental Deficiency*, *89*, (4), 323-330.

Barker-Toms, L. & Kogan, D. June 1983. *Study of the federal definition of developmental disability: Final Report, Volume 1 Summary of findings*. Health and Welfare Agency, Sacramento, CA.

Baroff, G. June 1982. Predicting the prevalence of mental retardation in individual catchment areas. *Mental Retardation*, *20*, (3) 133-135, AAMD.

Baumann, R.J., Marx, M.B. and Leonidakis, M.G. 1977. An estimate of the prevalence of epilepsy in a rural Appalachian population. *American Journal of Epidemiology*, (106), 42-52.

Baumann, R.J., Marx, M.B. 1978. Epilepsy in rural Kentucky: Prevalence in a population of school age children. *Epilepsia*, *19*, 75-80.

Birch, H.G., Richardson, S.A., Baird, D., Horobin, G. and Illsely R. 1970. *Mental subnormality in the community, a clinical and epidemiologic study*. Baltimore: Williams & Wilkins.

Bird, A.V., Heinz, H.J., and Klintworth, G. 1962. Convulsive disorders in Bantu mine-workers. *Epilepsia*, *3*, 175-187.

Brewis, M., Poskanzer, D.C. Rolland, C., and Miller, H. 1966 Neurological disease in an English city. *Acta Neurologica Scandanavica*, *24*, 9-89.

Brewis, M. Poskanzer, D.C., Rolland, C., and Miller, H. 1966. Neurological disease in an English city. *Acta Neurologica Scandanavica*, *42*, (24), 9-89.

Bureau of Educational Planning and Development, University of New Mexico. 1984. Population estimates and projections of New Mexico's developmentally disabled for the years 1980-2000. Santa Fe: Developmental Disabilities Planning Council.

Cavazzuti, G.B. 1980. Epidemiology of different types of epilepsy in school age children of Modena, Italy. Epilepsia, 21, 57-62.

Centers for Disease Control. February 1982. Congenital malformations surveillance report - January - December 1982. Washington: U.S. Department of Health and Human Services.

Childs, B. and Evans, P.R. 1954. Birthweights of children with cerebral palsy. Lancet, 1, 642.

Chiofalo, H. Kirschbaum, A. Fuentes, A., Cordero, M.L., and Madsen, J. 1979. Prevalence of epilepsy in children in Melipilla Chile. Epilepsia, 20, 261-266.

Colvez, A. & Blanchet, M. May 1981. Disability trends in the United States Population 1966-76: Analysis of reported causes. American Journal of Public Health, 71, (5), 464-470.

Comptroller General. September 1985. Disparities still exist in who gets special education. United States General Accounting Office

Connecticut State Department of Health. 1951. The study of cerebral palsy in Connecticut. Hartford, CT:

Cooper, J.E. 1965. Epilepsy in a longitudinal survey of 5,000 children. British Medical Journal, 2, 1020-1022.

Crombie, D.L., Cross, K.W., Fry, J. Pinsent, J.F.H. and Watts C.A.H. 1960. A survey of the epilepsies in general practice. British Medical Journal, 2, 416-422.

Davie, R., Butler, N., Goldstein, H. 1972. From birth to seven: The second report of the National Child Development Study (1958 Cohort). London: Longmans.

deGraff, A.S. 1974. Epidemiological aspects of epilepsy in Northern Norway. Epilepsia, 15, 291-299.

Drillien, C.M. 1958. Growth and development in a group of chidren of very low birthweight. Archives of Disabled Children, 33, 10.

Drillien, C.M. 1968. Studies in mental handicap. II. Some obstetric factors of possible etiological signficance. Archives of Disabled Children, 43, 283.

Eastman, N.J. & Deleon, M. 1955. The etiology of cerebral palsy. American Journal of Obsterics and Gynecology, 69, (950).

Ellenberg, J. & Nelson, K. 1979. Birthweight and gestational age in children with cerebral palsy or seizure disorders. American Journal of Disabled Children, 133, (1044).

Elwood, J.M. & Elwood, J.H. 1980. Epidemiology of Anencephalus and Spina Bifida. New York: Oxford University Press.

Enterline, P.E., & Capt, K.G. February 1959. A validation of information provided by household respondents in health surveys. American Journal of Public Health, 49, (2), 205.

Freeman, John (ed.). April 1985. Prenatal and perinatal factors associated with brain disorders. Bethesda, MD: National Institute of Health, National Institute of Child Health and Human Development.

Foster, D.W. Guy, A. & Parry-Jones, A. 1956. Infantile cerebraly in Cardiff. Medical Officer, 96, (181).

Foster, J.E. Nov 1980. Using natality data in health planning. Statistical Notes for Health Planners, 12. Washington: U.S. Department of Health and Human Services.

Fuldner, R.V. 1957. Labor complications and cerebral palsy. American Journal of Obstetrics and Gynecology, 74, (159).

Gallin, R.S. & Given, C.W. Dec 1976. The concept and classification of disability in health interview surveys. Inquiry. 13, 395-407.

Garland, C., Stone, N.W., Swanson, J., & Woodruff, G. (eds). 1981 Early intervention for children with special needs and their families. Western States Technical Assistance Resource (WESTAR). University of Washington.

Giel, R. 1970. The problem of epilepsy in Ethiopia. Tropical and Geographical Medicine, 22, 439-442.

Gollay and Associates. April 1980. Estimates of the size and characteristics of the developmentally disabled population in New Mexico. Santa Fe: New Mexico Developmental Disabilities Council.

Gollay and Associates. 1980. Statewide comprehensive assessment of needs and services. Santa Fe: Division of Vocational Rehabilitation, New Mexico Department of Education.

Gollay, Elinor, Ph.D. June 1981. Estimates of the size and characteristics of the non-institutionalized developmentally disabled population in the United States based primarily on an analysis of the 1976 Survey of Income and Education. Santa Fe: Gollay and Associates.

Gomez, J.G., Arciniegas, E., & Torres, J. 1978 Prevalence of epilepsy in Bogota, Columbia. Neurology, 28, 90-94.

Goodman, N., & Tizard, J. 1962. Prevalence of imbecility and idiocy among children. British Medical Journal, 216-219

Gortmaker, S.L., Ph.D., Sappenfield W.S., M.D. February 1984. Chronic childhood disorders: Prevalence and Impact. Pediatric Clinics of North America, 31, (1).

Griffiths, M.I., Barrett, N.M. 1967. Cerebral palsy in Birmingham. Developmental Medicine and Child Neurology, 9, 33-46.

Grossman, H. 1983. Classification in mental retardation. Washington: American Association on Mental Deficiency.

Grossman, J. 1977. Manual on terminology and classification in mental retardation. Washington: American Association on Mental Deficiency.

Gudmundson, G. 1966. Epilepsy in Iceland: A clinical and epidemiologic investigation. Acta Neurologica Scandanavica, 25 1-124.

Gudmundson, K.R. 1967. Cerebral palsy in Iceland. Acta Neurologica Scandanavica, 43, Suppl 34.

Hack, M., Fanaroff, A., & Merkatz, I. 1979 The low-birthweight infant-evolution of a changing outlook. New England Journal of Medicine, 301, 1162-1165.

Hansen, E. 1960. Cerebral palsy in Denmark: A discussion of its occurrence, disease types, etiology and social aspects based of material on 2621 patients born in the period 1925-1953. Acta Psychiatrica Neurologica Scandanavica, 146.

Hauser, W.A., and Kurland, L.T. 1967. The epidemiology of epilepsy in Rochester, Minnesota, 1935 through 1967. Epilepsia, 16, 1-66.

Herlitz, G. Redin, B. 1955. The prevalence of cerebral palsy. Acta. Paediatrica (Uppsala), 44, 146-154.

Holt K.S. 1970. The quality of survival for birth and life. Maternal and Child Care, 6, (211).

Ingram, T.T.S. 1955. A study of cerebral palsy in the childhood population of Edinburgh. Archives of Disabled Children, 30, 85-98.

Innes, G., Kidd, C., & Ross, H.S. 1968. Mental subnormality in Northeast Scotland. British Journal of Psychiatry, 114, 35-41.

Jacobson, John, W., & Janicki, Matthew, P. June 1983. Observed prevalence of multiple developmental disabilities. Mental Retardation, 21, (3), 87-94.

Kauffman, J.M. & Payne, J.S. 1975. Mental retardation: Introduction and personal perspectives. Columbus, OH: Merrill.

Kiely, J.L., Paneth, N., Stein, Z. Susser, M. 1981. Cerebral palsy and newborn care I: Secular trends in cerebral palsy. Developmental Medicine and Child Neurology, 23.

Kiely, M., Lubin, R.A., Ph.D. & Kiely, J.L., Ph.D. 1984. Descriptive epidemiology of cerebral palsy. _1984 Public Health Review_, _954_, (12), 79-101.

Kiely, M., Lubin, R.A., & Kiely J.L. 1983. _Estimating the prevalence of persons with developmental disabilities in New York state_. Staten Island: New York State Institute for Basic Research in Developmental Disabilities.

Kiely, M., Lubin R. & Kiely, J. 1984. _The descriptive epidemiology of cerebral palsy_.

Kiely, J.L., Paneth, N., & Susser, M. 1981. Low birthweight, neonatal care, and cerebral palsy: An epidemiological reveiew. In P. Mittler (ed) Frontiers of knowledge in, _Mental Retardation, Vol II - Biomedical aspects_. Baltimore: University Park Press.

Kirchner, C., Peterson, R. & Suhr C. Nov 1979. Trends in school enrollment and reading methods among legally blind school children, 1963-1978. _Visual Impairment and Blindness_, Statistical Brief #6.

Krantz, G.C., Bruininks, R.H. & Clumpner, J.L. _Mentally retarded people in state-operated residential facilities_. University of Minnesota, Department of Psychoeducational Studies.

Krohn, W. 1961. A study of epilepsy in Northern Norway: Its frequency and character. _Acta Psychiatrica Neurologica Scandanavica_, _150_, 215-225.

Kurland, L.T. 1957. Definitions of cerebral palsy and their role in epidemiologic research. _Neurology_, _7_, 641-654.

Kurland, L.T. 1959. The incidence and prevalence of convulsive disorders in a small urban community. _Epilepsia_, _1_, 143-161.

Kushlick, A. 1961. Subnormality in Salford. In M.W. Susser & A. Kuslick, A. _A report on the mental health services of Salford for the year 1960_. Salford England Health Department.

Lagergren, J. 1981. Children with motor handicaps: Epidemiological medical and socio-paediatric aspects of motor handicapped children in a Swedish county. _Acta Paediatrica Scandnavica_, Supp 289.

Langergren, J. 1970. Motor handicapped children: A study from a Swedish county. _Developmental Medicine and Child Neurology_, _12_, 56-63.

Last, John (ed.). 1986. _Public health and preventive medicine, 12th edition_. Norwalk, CT: Appelton-Century-Crofts.

Layde, P.M., Erickson, J.D., Dooley, K., et al. February 1980. Is there an epidemic of ventricular septal defects in the U.S.A.? _The Lancet_, 407-408.

Lazar, I. 1979. Invest early for later dividends. _The Interstate Compact for Education_, _28_, 12-13.

Lessell, S., Torres, J.M., and Kurland, L.T. 1962. Seizure disorders in a Guamian village. Archives of Neurology, 7, 37-44.

Levin, M.L., Brightman, I.J., Burtt, E.J. 1949. The problem of cerebral palsy. The New York State Journal of Medicine. 49, 2793-2799

Levinson, E. 1962. Retarded children in Maine. Orno, ME: University of Maine Press.

Levy, L.F., Forbes, J.I., and Parirenyatwa, T.S. 1964. Epilepsy in Africans. Central African Journal of Medicine, 10, 241-249.

Lewis, E.O. 1929. Report of the mental deficiency committee, being a joint committee of the board of education and board of control, Parts, I, II, III, IV. London, England: H.M. Stationery Office.

Liebowitz, U. and Alter, M. 1968. Epilepsy in Jerusalem, Israel. Epilepsia, 9, 187-105.

Lillenfield, A.M. & Parkhurst, E. 1951. A study of the association of factors of pregnancy and parturition with the development of cerebral palsy. American Journal of Hygiene, 53, 262-282.

Lubin, R. 1980. Report of the subcommittee on definition of neurological impairments. New York State Advisory Council on Mental Retardation.

Lubin, R., Jacobson, J.W., & Kiely, M. 1982. Projected impact of the functional definition of developmental disabilities: The categorically disabled population and service eligibility. American Journal of Mental Deficiency, 87, (1), 73-79.

MacEachron, A. & Krauss, M. 1983. A national survey of handicapped children receiving public social services: Prevalence rates and service patterns in 1977. Children and Youth Services Review, 5, 117-154.

Maloney, M.P. & Ward, M.P. 1979. Mental retardation and modern society. New York: Oxford University Press.

Mathai, K.V., Dunn, D.P. Kurland, L.T., and Reeder, F.A. 1968. Convulsive disorders in the Mariana Islands. Epilepsia, 9, 77-85.

McCurely, R., Mackay, D.N., and Scally, B.G. 1972. The life expectancies of the mentally subnormal under community and hospital care. Journal of Mental Deficiency Research, 16, 57-66.

McDonald, A.D. 1967. Children of very low birthweight. London: William Heinmann Medical Books Ltd.

McDonald, A.D. 1961. Maternal health in early pregnancy and congenital defect. Final report on a prospective inquriy. British Journal of Prevalence in Social Medicine, 15, 154-166.

McGreal, D.A. 1966. A survey of cerebral palsy in Windsor and Essex County. Ontario: Canadian Medical Association Journal, 95, 1237-1240.

McNeil, J.M. March 1985. Selected materials on the prevalence of disability. Washington: United States Bureau of the Census.

Meighan, S.S., Queener, L. and Weitman, M. 1976. Prevalence of epilepsy in children of Multhnomah County, Oregon. Epilepsia, 17, 245-256.

Mercer, J. 1973. The myth of 3% prevalence. In R.K. Eyman, C.E. Meyers & G. Tarjan (eds), Sociobehavioral studies in mental retardation: Papers in honor of H.F. Dingman. American Association on Mental Deficiency, 1, 1-18.

Miller, C. and Eyman, R.K. 1978. Hospitals and community mortality rates among the retarded. Journal of Mental Deficiency Research, 22, 137-145.

Moore, W.G. , Personal Interview 1981. The long range effects of early childhood education on the trainable mentally retarded population. Efficacy studies in early childhood specical education, 4.

Nagi, S.Z. Fall 1976. An epidemiology of disability among adults in the United States. Health and Society, 439-467.

National Center for Health Statistics. December 1983. Advance report of final natality statistics, 1981. Monthly Vital Statistics Report, 32, (9). Washington: U.S. Department of Health and Human Services.

National Institute of Neurological and Communicative Disorders and Stroke. November 1980. The national head and spinal cord injury survey. Anderson, D.W. and McLaurin, R.L. (eds.). Supplement to the Jounral of Neurosurgery.

Nelson, and Ellenberg, J.H. 1978. Epidemiology of cerebral palsy In: B.S. Schonberg (ed), Advances in Neurology, 10, 28-36. New York: Raven Press.

Oregon State Board of Health. 1962. Mental Retardation prevalence in Oregon. Portland: Oregon State Board of Health.

Overboe, C.J. & Wang, Y.Y. Oct 1978. Behavioral and physical characteristcs of developmentally disabled individuals. Washington: U.S. Dept. of Health, Education and Welfare.

Phillip, A.S. et al. July 1981. Neonatal mortality risk for the eighties: The importance of birth/weight gestational age groups. Pediatrics, 68, 122-130.

Pond, D.A., Bidwell, B.H. and Stein L. 1960 A survey of epilepsy in fourteen general practices I. Demographic and medical data, Acta Psychiatrica Neurologica, 63, 217-236.

Rehab Group, Inc. May 1979. Digest of data on persons with disabilities. Washington: Congressional Research Service, Library of Congress.

Richardson, S.A. 1978. Careers of mentally retarded young persons: Services, jobs, and interpersonal relations. American Journal of Mental Deficiency, 82, 349-358.

Richardson, W.P. & Higgins, A.C. 1965. The handicapped children of Alamance County, North Carolina. Wilmington, DE: Neumors Foundation.

Rose, S.W., Penry, J.K., Markush, R.E., Radloff, L.T. & Putnam P.L. 1973. Prevalence of epilepsy in children. Epilepsia, 14, 133-152.

Ross, E.M., Peckham, C., West, P.B.and Butler, N.R. 1980. Epilepsy in childhood findings from the National Childhood Development Study. British Medical Journal, 1, 207-210.

Rutter, M., Graham, P. & Yule, W. 1970. A neuropsychiatirc study in childhood. Spastics International Medical Publications. London: Longman Group Limited.

Sachs, M., Smull, M. Beverly, B. September 1985. Selected demographic and need characteristics of respondents to the community needs survey for persons with mental retardation. Baltimore: University of Maryland, School of Medicine.

Scally, B.G. & Mackay, D.N. 1964. Mental subnormality and its prevalence in Northern Ireland. Acta Psychologica, 40, 203-211.

Shapiro, S. McCormick, M.C., Stanfield, B.H., et al. 1983. Changes in infant morbidity associated with decreases in neonatal mortality. Pediatrics, 72, 408.

Sillanpaa, M. 1973. Medico-Social prognosis of children with epilepsy: Epidemiological study and analysis of 245 patients. Acta Paediatrica Scandanavica, 237.

Sower, R. & Covert, R. 1975. Identifying preschoolers with special needs: A county-wide project to help plan future special services in the public schools. Education and Training of the Mentally Retarded, 10, (2).

Stanford Research Institute. 1978. Studies of handicapped students. Whom do teachers identify as handicapped?, 1. Menlo Park: Stanford Research Institute.

Stanhope, J.M., Brody, J.A., and Brink, E. 1972. Convulsions among the the Chamorro people of Guam, Mariana Island I. Seizure disorders American Journal of Epilepsy, 95, 292-298.

Wing, L. 1971. Severely retarded children in a London area: Prevalence and provision of services. Psychological Medicine, 1, 405-415.

Wishik, S.M. 1956. Handicapped children in Georgia: A study of prevalence, disability, needs, and resources. American Journal of Public Health, 46, 195-203.

Woods, G.E. 1963. The lowered incidence of infantile cerebral palsy. Developmental Medicine and Child Neurology, 5, 449-450.

Wright, F.H., Blough, R.R., Chamberlin, A., Ernest, T., Halstead, W.C., Meir, P., et al. 1972. A controlled follow-up study of small prematures born from 1952 through 1956. American Journal of Diseases of Children, 124, 506-521.

APPENDIX A

METHODOLOGY USED TO ESTIMATE THE SIZE OF THE DEVELOPMENTALLY DISABLED POPULATION USING THE SIE DATA

As has been pointed out elsewhere, the SIE was not designed to obtain information about the developmentally disabled population. As a result, there are no items that explicitly ascertain the extent to which an individual meets the various criteria in the definition. In order to arrive at an estimate of the developmentally disabled population it was, therefore, necessary to operationalize the definition of developmental disabilities in terms of the data that were actually gathered. In this section the method used to operationalize each of the criteria in the definition is presented.

The definition of developmental disabilities has five components, each of which represents a criterion for a developmental disability:

1. Physical and/or Mental Impairment

   Only people who were asked about limiting health conditions were considered to be potentially developmentally disabled.

2. Lasting Indefinitely

   The SIE does not report chronicity for ages 26 and over. The assumption was made that anyone who met the other criteria used, particularly in terms of number and extent of life activity limitations were also chronically disabled.

3. Manifests Prior to Age 22

   Age of manifestation information was obtained and used for the 25 and under population.

   For the over 25 population the information in the SIE that indicated a person's work history was used as a surrogate indicator of the extent to which the person was likely to have been disabled prior to age 25. (See Chart I)

4. Substantial Limitation in 3 Out of the 7 Life Activity Areas

   Each of the seven life activity areas was operationally defined using the existing information. The definitions were varied according to the age of the individual. For the specific definitions used see Chart II in this section.

   Because of the fact that limited data were gathered on young children and because concepts such as "economic self sufficiency" are difficult to define for children, the decision was made to relax the criterion that a person be substantially limited in three out of seven life activity areas. Similarly, little information was obtained on the economic self-sufficiency of people over age 65. Therefore:

- children aged 3 and 4 were assumed to be developmentally disabled with only one functional limit (ability to play)
- children aged 5 to 17 were assumed to be developmentally disabled with only two substantial functional limits
- adults over age 65 were assumed to be developmentally disabled with only two substantial functional limits.

5. Need for Services

No information was obtained on service need and no effort was made to operationalize this criterion. It was assumed that having the life activity limits just described would be sufficient indicators of service needs.

6. Additional Assumptions Based on Limiting Health Conditions

Because the total size of the mentally retarded population was so small it was assumed that virtually everyone counted was at least moderataly retarded. It was further assumed that all such people would have been retarded from childhood and were chronically disabled. Therefore, all people listed as mentally retarded in the SIE were considered to be developmentally disabled.

It was also assumed that being retarded would automatically result in a substantial limitation in certain of the life activity limitations such as self direction. Similiar assumptions were made regarding other specific limiting health conditions in terms of their likelihood of resulting in specific life activity limitations. For example, deafness was assumed to result in a substantial limitation in learning. Table C - 2 of this section describes the operational definitions for each of the life activity limitations.

CHART II

LIFE ACTIVITY LIMITATIONS - SIE OPERATIONAL DEFINITIONS

1. SELF-CARE

age group	question	response
5-13	Q 91 (personal needs)	Usually/Frequently Needs Help
14+	Q 68 (personal needs)	Usually/Frequently Needs Help

2. RECEPTIVE AND EXPRESSIVE LANGUAGE

age group	question	response
5-13	Q 93 Limiting Health Condition	Mental Retardation Hard of Hearing Deaf Speech Impairment Serious Difficulty Seeing or Blind
14+	Q 70 Limiting Health Condition	

PLUS ONE OF

age group	question	response
5-13	Q 88 (regular school work)	Yes, Having Difficulty
14-17	Q 60 (regular school work)	Yes, Having Difficulty
18-25	Q 63A (regular school work)	Yes, Having Difficulty
18+	Q 24 (highest grade attended)	3 (Third)

3. LEARNING

age group	question	response
5-13	Q 93 Limiting Health Condition	Mental Retardation Deaf Serious Difficulty Seeing or Blind Seriously Emotionally Disturbed 2+ Other Limiting Health Conditions
14+	Q 70 Limiting Health Condition	

4. MOBILITY

age group	question	response
3-4	Q 87 (play)	Yes, Limited in Ability

CHART II (continued)

age group	question	response
5-13	Q 92 (get around out-side)	Usually/Frequently Needs Help
14+	Q 69 (get around out-side)	Usually/Frequently Needs Help

5. SELF-DIRECTION

age group	question	response
5-13	Q 93 } Limiting Health Condition	Mental Retardation Seriously Emotionally Disturbed
14+	Q 70	

6. CAPACITY FOR INDEPENDENT LIVING

Serious Difficulty in Self-Direction

OR

age group	question	response
5-13	Q 88A (school attendance)	Cannot Attend or Frequently Absent
	PLUS EITHER	
	Q 91 (personal needs)	Usually/Frequently Needs Help
	Q 92 (get around out-side)	Usually/Frequently Needs Help
14-17	Q 60A (school attendance)	Cannot Attend or Frequently Absent
	PLUS EITHER	
	Q 68 (personal needs)	Usually/Frequently Needs Help
	Q 69 (get around out-side)	Usually/Frequently Needs Help
18-25	Q 63B (school attendance)	Cannot Attend or Frequently Absent

CHART II (continued)

age group	question	response
	OR	
	Q 66 (work)	Cannot Work At All
	OR	
	Q 66A (work)	Can Work Only Occasionally/ Irregularly
	PLUS ONE OF	
	Q 67 (work around house)	Limited in Amount or Kind
	Q 68 (personal needs)	Usually/Frequently Needs Help
	Q 69 (get around outside)	Usually/Frequently Needs Help
24-64	Q 66 (work)	Cannot Work At All
	OR	
	Q 66A (work)	Can Work Only Occasionally/ Irregularly
	PLUS ONE OF	
	Q 67 (work around house)	Limited In Amount Or Kind
	Q 68 (personal needs)	Usually/Frequently Needs Help
	Q 69 (get around outside)	Usually/Frequently Needs Help
65+	Q 67 (work around house)	Limited in Amount or Kind
	PLUS EITHER	
	Q 68 (personal needs)	Usually/Frequently Needs Help
	Q 69 (get around outside)	Usually/Frequently Needs Help

7. ECONOMIC SELF-SUFFICIENCY

age group	question	response
13-64	Q 66 (work)	Cannot Work At All
	----------	----------
	Q 58 (school enrollment)	Not Enrolled
	AND	
	Q 66A (work)	Limited In Amount Or Kind, But Can Work Occasionally/ Irregularly Or Regularly
	PLUS EITHER	
	Q 14F (work history)	Never Worked Fulltime 2+ Weeks Or Never Worked At All
	Q 16 (work history)	Never Worked At Regular Job For Pay
	----------	----------
	Q 66A (work)	Limited In Amount Or Kind, But Can Work Occasionally/ Irregularly Or Regularly
	PLUS EITHER	
	Q 46A (welfare)	Receives Public Welfare
	Q 46D (public compensation)	Receives Workmen's Compensation
	----------	----------
	Q 58 (school enrollment)	Not Enrolled
	AND	
	Q 66A (work)	Limited In Amount Or Kind, But Can Work Occasionally/ Irregularly Or Regularly
	AND	
	Q 24 (highest grade attended)	7 (Seventh)
	----------	----------
	Q 58 (school enrollment)	Not Enrolled

CHART II (continued)

age group	question	response
	AND	
	Q 66A (work)	Limited In Amount Or Kind, But Can Work Occasionally/ Irregularly Or Regularly
	AND	
	Earned Income (calculated)	$5,000.00
	Q 45B (SSI)	Receives U.S., State or Local

APPENDIX B

Procedure Used to Estimate the Number of Developmentally Disabled (DD) Adults on the SSI or SSDI Rolls by State

An updated census of the number of adults on the SSI or SSDI rolls is available for the end of each calendar quarter. However, these counts are not broken out by disabling condition.

Figures are available on the number of SSDI awards each year by disabling condition in the United States from 1955 through 1973 and from 1975 to date; the Social Security Administration will not release the 1974 data as it is considered to be unreliable. Figures on the number of annual SSI awards are available since the federal program's inception in 1974. Like data is available by state though the disabling conditions are grouped (e.g., mental illness is shown together with mental retardation under the group entitled mental disorders). These data are available for fewer years.

One might estimate the number of adults on the SSI or SSDI rolls by type of disabling condition (i.e., mental retardation) by simply assuming that the proportion of persons on the disability rolls for reason of mental retardation at any given point in time is the same as the proportion of total awards made for reason of mental retardation in years past. This assumption would be valid if persons with different types of disabling conditions remained on the rolls for the same period of time. However, available data indicate otherwise. According to several studies by the Office for Research and Statistics (Social Security Administration) persons awarded SSDI benefits for reason of some disorders such as mental disorders are likely to continue on the rolls for a much longer period of time than are persons awarded benefits for other disorders such as cardiovascular disorders. In view of these findings, it's apparent that the use of such a simplifying assumption would lead to under-estimates of the size of the mentally disordered population and over-estimates of persons with other disorders on the rolls.

Accordingly, in lieu of this assumption HSRI estimates the numbers of persons on the SSI and SSDI rolls for each categories of disabling conditions factoring in the expected time on the rolls for each category. More specifically, the estimates are derived for the U.S. and for each state by factoring counts of the number of SSI and SSDI awardees within each of the disability categories by their expected duration on the rolls.[1] Data on the average duration of SSI and SSDI cases by type of disabling condition were obtained from the Office for Research and Statistics (ORS), Social Security Administration. These data are compiled from regularly scheduled disability reviews and continuing disability investigations conducted by the Social Security Administration in the years 1981 through 1983, and from special longitudinal unpublished studies of cohorts of SSI awaredees from 1977 through 1981 conducted by ORS staff. The selection criteria for cases to review were not found to be biased in terms of the variables of interest: specifically, duration on the rolls and recipient age within particular

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[1] 1955-1984 for the SSDI awardees, and 1974-1984 for the SSI awardees.

disability groups (Krute, 1985).

Using these data HSRI constructed "life tables" showing the probability of SSDI and SSI awardees in each of the past years remaining on the rolls at the end of the year of award and subsequent years through 1984 by type of disabling condition. Individual tables were constructed for two of the three types of SSDI beneficiaries, namely "workers" and "children" (age 18 and above disabled and dependent on an insured worker since childhood). Tables for disabled widows of SSDI workers were not compiled as these cases were too few in number to derive reasonably reliable estimates and to be of any significance. Tables were also constructed for SSI "adult" and SSI "child" recipients by type of disabling condition.

Using these data, HSRI is able to estimate the numbers of each type of SSI and SSDI awardee in a given state each year (from 1955 through 1984) expected to still be on the rolls as of December 31, 1984 by disability group. The total number in each disability group expected to still be on the rolls as of December 31, 1984 is obtained by summing these estimates across all years (1955 through 1984).

Comparing the grand total of the numbers in each disability group estimated to be on the rolls as of December 31, 1984 according to the Quadrant method against the known counts of all SSDI and all SSI disability cases as of December 31, 1984 serves as a rough check on the relative accuracy of the estimates. The estimated totals by disability group are then reconciled to the known SSI and SSDI totals adjusting them by the percentage difference between the estimated SSI and SSDI totals and known SSI and SSDI totals.

Sources of Error

Logically speaking these estimates of the number of adults on the SSI and SSDI rolls by disability group, because they are sensitive to differences in the length of time SSI payees and SSDI beneficiaries remain on the rolls, should be more accurate than estimates not sensitive to these differences. However, the relative accuracy of these estimates cannot be represented statistically as the estimates are based on assumption as well as hard data. Assumptions were necessary to impute values for missing data. State-by-state figures were missing on the number of awards by disability group:

- for SSDI worker awardees in years 1955 through 1965, and 1984.
- for SSDI childhood awardees* in years 1974 through 1984
- for SSI awardees in years in years 1955-1974 and 1977-1984**

Prior to 1974, disability awards to indigent persons were made as part of the state welfare programs and not as part the federal SSI program. Knowing the total number of persons on the SSI rolls in 1974 and the expected duration of each disability

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* Counted as SSDI childhood awardees are disabled persons age 18 and over whose disability began before age 22 (age 18 before January 1973); these persons were eligible to receive benefits beginning in 1957.

** Within two years the Social Security Administration expects to maintain current estimates of the numbers of persons on the SSI rolls by disability group.

group, it was possible to estimate the number of awards in each of the years prior to 1974 by assuming that the percentage of all awards by disability group was the same as in the known years (1975-1976), and that the number of awards in each of these early years was constant from year to year. What little relevant data is available indicates that this seems to be a reasonable assumption.

The numbers of awardees by disability group were imputed for those years where figures were missing by multiplying the known total number of awardees in the state that year by the average percent of awards made to that disability group in the years for which the data was available. In those cases where the average percent figures were markedly different in years closer to the year for which the data was missing than years distant, the average was taken on the closest years.

Data on the average length of time on the rolls by the different types of beneficiaries (e.g., SSDI workers, SSDI children, and SSI adult disabled) was available at the national level for years one through 26. Data on the average length of time on the rolls for years 27 through 30 were projected using a linear regression technique following a logarithmic transformation of the data. The transformation was necessary in order to capture the curvilinear pattern of the data.

State-specific data was not available on the breakdown of SSDI and SSI awardees within the mental disorders group (e.g., mental retardation as opposed to mental illness) or among the diseases of the nervous system and sensory organs (e.g., deaf, blind, cerebral palsy, epilepsy). Therefore state breakdowns are assumed to mirror the national MR/MD percentage breakdowns.

APPENDIX C

COMMUNITY AGENCY SERVICE PROVIDERS HAVING CONTRACTS WITH DD BUREAU (HED)

1. Adelante Development Center
4906 Jefferson, N.E.
Albuquerque, New Mexico 87109
883-1102
Director: Mike Kivitz

2. Albuquerque Special Preschool
3501 Campus Blvd., N.E.
Albuquerque, New Mexico 87106
268-0213
Director: Gail Beam

3. Association for Retarded Citizens of
Albuquerque (ARCA)
1408 San Pedro, N.E.
Albuquerque, New Mexico 87110
255-5516
Director: Cherie Hymes

4. Bernalillo County Mental
Health/Mental Retardation Center
Programs for Children
Developmental Disabilities Team
2600 Marble, N.E.
Albuquerque, New Mexico 87106-2797
843-5566
Director: Stan Handmaker, M.D.

5. Carlsbad Association for Retarded Citizens, Inc.
(CARC Farm)
Rt. 1, Box 52M
Carlsbad, New Mexico 88220
887-1570
Director: Larry White

6. Citizens for the Developmentally Disabled, Inc.
Colfax County Workshop
P. O. Box 1559-444 Martinez Street
Raton, New Mexico 87740
445-5674
Director: Duane Roy

7. Coyote Canyon Rehabilitation Center, Inc.
P. O. Box 158
Brimhall, New Mexico 87310
735-2261
Director: Bertha Muskett

8. Door of Opportunity
P. O. Box 282-6th and North James St.–Old Lomita Bldg.
Artesia, New Mexico 88210
746-9642
Director: Mike Garcia

9. Eastern New Mexico Rehabilitative Services
for the Handicapped (ENMRSH)
P. O. Drawer 1989-1121 Rencher
Clovis, New Mexico 88101
762-3718
Director: Robert Spencer

10. Esperanza Para Nuestros Ninos, Inc.
P. O. Box 12212-1830 Valdora, S.W.
Albuquerque, New Mexico 87105
873-0600
Director: Pat McMahon

11. Hobbs ARC Rehabilitation Industries
P.O. Box 1607 - 200 E. Park
Hobbs, New Mexico 88240
Director: David Welch
393-8201

12. La Vida De Valencia Preschool
P. O. Box 459-Don Pasqual Road, House No. 4
Los Lunas, New Mexico 87031
865-4651
Director: Pat Thalhammer

13. Las Cumbres Learning Services, Inc.
P. O. Box 663
Los Alamos, New Mexico 87544
662-4323
Director: Pat Tompkins-McGill

14. McKinley Area Services for the Handicapped, Inc. (MASH)
P. O. Box 1332-721 E. Coal
Gallup, New Mexico 87301
722-4383
Director: Jon Hellebust

15. New Horizons Development Center
804 E. Avenue
Carrizozo, New Mexico 88301
648-2379
Director: Jenny Kelly

16. New Vistas, Inc.
P. O. Box 2332-739 Agua Fria Street
Santa Fe, New Mexico 87501
988-3803
Director: Mary Russell

17. Otero County Association for Retarded Citizens, Inc.
900 White Sands Blvd.
Alamogordo, New Mexico 88310
437-0919
Director: Frank Kovacich

18. Peanut Butter and Jelly Preschool, Inc. no
1101 Lopez, S.W.
Albuquerque, New Mexico 87105
877-7060
Director: Angela Vachio

19. Presbyterian Medical Services (PMS)
P. O. Box 2267-820 Paseo de Peralta
Santa Fe, New Mexico 87501
982-5566
Vice-President: John Glass

Shield: Jim Riebsomer - 327-4796
Farmington Site: P.O. Box 3239, Farmington/87499

20. Santa Maria El Mirador
P. O. Box 81-6 Miles N. of Española
Alcalde, New Mexico 87511
852-4244
Director: Mark Johnson

21. Southern Pueblos Agency
Division of Education
P. O. Box 1667-1000 Indian School Road, N.W., Bldg. 233
Albuquerque, New Mexico 87103-1667
766-3034, 3035
Director: Efren Medrano

22. Southwest Communication-PIPE
(Pueblo Infant-Parent Education Project)
P. O. Box 788
Bernalillo, New Mexico 97004
867-3396
Director: Norman Segel

23. Southwestern N.M. Services to Handicapped Children & Adults, Inc.
(SWSH)
309 W. College Avenue
Silver City, New Mexico 88016
388-1976
Director: Bob Hand

24. ~~Special Olympics~~
~~6001 Marble, N.E.-Suite 6~~
~~Albuquerque, New Mexico 87110~~
~~266-8893~~
~~Director: Pat Putnam~~

25. Taos County Association for Retarded Citizens, (Taos ARC)
P. O. Box 112-Armory Street
Taos, New Mexico 87571
758-4274
Director: Jose Rodriguez

26. The Rehabilitation Center, Inc.
1023 Stanford Drive, N.E.
Albuquerque, New Mexico 87106
255-5501
Director: Bob McKeown

27. The Resource Center, Inc.
1500 North 3rd Street
Grants, New Mexico 87020
287-7985
Director: Chris Graham, Ph.D.

28. Tobosa Development and Training Center
336 E. Sixth Street
Roswell, New Mexico 88201
624-1025
Director: Joe Madrid

29. Tresco, Inc.
P. O. Box 2548
Las Cruces, New Mexico 88001
523-5549
Director: Jamie Gerbracht

30. Zia Therapy Center
900 First Street
Alamogordo, New Mexico 88310
437-3040
Director: Richard Barbaras

DD BUREAU
Revised 2/25/85

AGENCY SURVEY FORM

Please fill-in blank spaces and correct any incorrect information provided

____
Name of Agency

1. Number of Clients Served (Unduplicated Count)

a. _______________. Total number of active clients as of March 31, 1985.

b. _______________ Number reported under the Client Oriented Option Profile (COOP) system as of March 31, 1985.

c. _______________ Number not reported under COOP (if any)

d. Please describe the ways in which those persons not reported under COOP differ from those reported (e.g., not HED-funded, time lag, ...)

2. SSI/SSDI Participation

a. _______________ Number of clients receiving Supplemental Security Income (SSI) payments as of March 31, 1985

b. _______________ Number of clients receiving Social Security Disability Insurance (SSDI) benefits as of March 31, 1985

3. _______________ Number of families having sought or received services from your agency and known to have since had to relocate or make arrangements to receive needed MR/DD services in other states over the last three years

WITH DEVELOPMENTAL DISABILITIES IN THE STATE OF NEW MEXICO

Agency Name ______________________________

______________________, ______________________, and
Name Title

______________________________ of person
phone Number

primarily responsible for completing this survey.

Programs Provided by Agency:

Please Check:		Year Agency First Began Providing Program
	HABILITATIVE	
	CHILDREN/ADOLESCENT PROGRAMS	
______	Pre-School	______
______	Special Education	______
______	Day Program	______
	ADULT DEVELOPMENTAL PROGRAMS	
______	General Activities	______
______	Daily Living Training	______
______	Pre-Vocational	______
______	Work Activity*	______
______	Sheltered Workshop*	______
______	Mobile Work Force Teams or Work Stations in Industry*	______
______	Job Placement/Follow up*	______
______	Post-Vocational*	______
	RESIDENTIAL	
______	Skilled Nursing/Extended Care*	______
______	Intermediate Care Facilitie -- MR/DD*	______
______	Residential - High Supervision*	______
______	Residential - Moderate Supervision*	______
______	Residential Minimum Supervision*	______

For each program checked above, please complete one program survey form.

Return this cover sheet, the agency survey form and all program survey forms to Human Services Research Institute, 120 Milk Street, Eighth Floor, Boston, MA 02109.

A postage-paid envelope is enclosed.

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* See definitions. Definitions included for program categories other than those used in the COOP reports.

PROGRAM SURVEY FORM

______________________ Name of program

1. Number of Clients Served

a. __________ Total number of active clients as of March 31, 1985.

b. __________ Number reported under the Client Oriented Option Profile (COOP) system as of March 31, 1985.

c. __________ Number not reported under COOP (if any)

d. Please describe the ways in which those persons not reported under COOP differ from those reported (e.g., not MED-funded, time lag, ...) (please use back of page)

e. __________ Total number of clients the program was capable of serving as of March 31, 1985

2. Client Levels of Functioning (See Instructions)

a. __________ Estimated number of active clients with severe medical/physical problems

b. __________ Estimated number of active clients with moderate medical/physical problems

c. __________ Estimated number of active clients with endangering behavior problems

d. __________ Estimated number of active clients with disruptive behavior problems

e. __________ Estimated number of active clients with minimum adaptive skills

f. __________ Estimated number of active clients with moderate adaptive skills

g. __________ Estimated number of active clients with high adaptive skills

3. Client Movement

a. __________ Number of individuals applying for program or who would have participated in program had space been available in 1984

b. __________ Number of persons that applied in 1984 but whom you could not accept for service. Please outline chief reasons why in order of importance (e.g., behavior problems, medical problems, need for special physical assistance, limited capacity, lack of funding) (please use back of page)

4. Clients Wait Listed (please count all persons awaiting service whether or not they are on a formal waiting list)

a. __________ Total number of individuals on waiting list (If the waiting list is shared with other agencies, name these agencies: ______________________________ ______________________________)

b. Urgency

__________ Number of wait-listed individuals whose circumstances pose an immediate underlying threat to the health or the safety of the individual or others., e.g.: no place to live, an abusive situation, . . .

__________ Number of wait-listed individuals whose current circumstances are not adequate, e.g. inadequate food, shelter, clothing, care and treatment, right to privacy, dignity, respect.

__________ Number of wait-listed individuals whose current circumstances are not appropriate e.g., supportive family situation but not able to meet individuals habilitative training needs

__________ Number of wait-listed individuals whose current circumstances are not the least restrictive feasible alternative, e.g., living in a situation not age appropriate, (i.e., with parents), or a physically handicapped person living in a home not fully accessible

__________ Number of wait-listed individuals for whom alternative circumstances are desired or necessary for any other reason.

c. __________ Longest period of time (months/years) an individual has been on the current waiting list.

d. __________ Average period of time a person must stay on the current waiting list.

5. Staffing

a. __________ Number of full time equivalent (FTE) staff

b. __________ Number of FTE staff whose primary responsibility and largest amount of time is spent working face-to-face with clients

c. __________ Number of additional staff if any required to adequately supervise/manage clients now in the program

6. Cost/Funding

a __________ Total Cost Fiscal Year 1983-1984
b. __________ % State General Funds
c. __________ % Other State Funds (not including Medicaid
d. __________ %Medicaid/Supplemental Security Income (SSI)
e. __________ %Other Federal Funds (not including Medicaid or SSI)
f. __________ %Private (1st or 3rd Party)
__________ 100%

Please fill-in blank spaces and correct any incorrect information provided

SELECTED PROGRAM DEFINITIONS

1. Group_Residences

Group Residences consist of living units (apartments, houses or other dwellings) that are owned or rented to provide food, clothing, shelter and supervision on a long or short-term basis by staff who are paid a wage. These programs may be operated by public or private agencies.

1.1 Group_Residences-High_Supervision

Residential arrangements where extra supervision is required to manage clients with behavior problems or to assist physically handicapped clients in activities of daily living. Includes residents who must be carried, wheeled or led from the building by others in emergency situations.

1.2 Group_Residences_-_Moderate_Supervision

Residential arrangements where 24-hour supervision is provided by staff (live-in or shift); residents are capable of basic self-help skills only under continual supervision. Residents require reminding, verbal instructions or gestures in order to depart from the residence within a reasonable period of time when warned of danger by a signal device. Also includes residents who are deaf, unless the home is equipped with special visual fire warning devices.

1.3 Group_Residences_-_Minimum_Supervision

In semi-independent living programs, residents have their own living quarters (apartments, small homes) with staff nearby and on-call in the same building or building complex. Residents take care of their own housekeeping needs, but some may need intermittent training or supervision in certain areas of domestic activity or community independence (e.g., meal preparation, use of public transportation, banking, etc.). Daytime activities are most likely to be vocational in nature and to be in group-supervised work centers, supervised work placements, or independent job placements.

Residents do not require any reminding, verbal instructions, gestures or physical assistance from staff or other residents to depart from the residence within a reasonable period of time when warned of danger by a signal device (e.g., a fire alarm).

While living quarters should not exceed three persons, minimum supervision (less than 24-hour) programs may include as many as 10-20 living quarters for 30-60 clients.

2. Skilled Nursing, Extended Care, Infirmary Facilities

Establishments with three or more in-patient beds that provide for persons who are not in an acute phase of illness but who require 24-hour supervision and observation services. Services include: (1) Diagnosis and treatment services under the direction of a medical director or medical advisor who is a physician, and (2) continuous nursing care, planned, performed, supervised and/or directed by a registered nurse who is available on an around-the-clock basis.

3. Adult Day Programs

In most states, adults become ineligible for public school services at age 22. But many of these adults still require additional instruction related to community life and vocation. Though the specific nature of these post school services will depend on the characteristics and needs of individual clients, the primary intent of most adult day services is to prepare its clients for gainful employment in some occupation. As such, adult day services can be sorted into four fundamental categories:

- Pre-vocational Programs These programs teach skills pre-requisite to work-oriented instruction. Such instruction spans numerous content areas including self-help, functional academics, motor skills, travel training and social skills, and can involve remediation of inappropriate behavior. As individual clients show improvements in independent functioning, the focus of instruction becomes increasingly vocational.

- Work Activity Programs Using work as a learning medium these programs operate within sheltered environments and provide instruction to help the client attain sufficient vocational, personal, social and independent living skills to progress to higher levels of job training. Specifically these programs:

    Introduce the client to the meaning of work in society, the characteristics of successful employees, the expected demands of an employer, and the responsibilities of wage earners and prepare clients to participate in, and profit from, additional vocational instruction.

    Utilize personal and work adustment training to develop appropriate worker behavior and to help the individual meet the requirements of sheltered employment, occupational training, on-the-job training, industry integrated habilitation programs or competitive placement.

Persons enrolled in work activity centers produce at a rate which is less than 50% of the production standards of a non-handicapped employee based on criteria established by the Federal Wage and Hour Division of the U.S. Department of Labor.

- <u>Sheltered Employment Programs</u>. These programs involve either short-term remunerative employment designed to promote competitive employment, long-term remunerative work in a sheltered environment, or work under specialized conditions in industry. Specific programs include:
  - <u>Sheltered workshops</u> that utilize work experience and related services to promote progress toward a productive vocational status. Clients enrolled in this program produce at a rate which is 50% or more of the production standards of a non-handicapped employee based on the criteria established by the Federal Wage and Hour Division of the U.S. Department of Labor.
  - <u>Mobile work force teams</u> comprised of client/trainees who work away from the rehabilitation agency. The agency contracts with an outside organization or business to perform maintenance, lawn care, janitorial services or similar tasks and the trainees are paid by the agency. A training supervisor from the agency accompanies each work crew.
  - <u>Work stations in industry</u> that provide group-training of client/trainees at the industry site. Training is conducted by a habilitation representative or by company personnel. As training progresses, any of three outcomes may occur. First, as a client demonstrates competence, training is phased out and the client stays on the job as a regular employee of the host industry. Second, competent clients may obtain similar jobs as regular employees elsewhere. Third, clients may remain within a training phase at the industry site or at some alternate site.
  - <u>Job placement and follow-along</u>. Once a client attains competitive employment, these services help the client keep his or her job. A representative of the habilitation agency maintains communication with the employer, periodically monitors client performance and work adjustment, and helps resolve any job-related difficulties that emerge. These services are eventually phased out when the client meets some criterion related to ongoing satisfactory performance.
- <u>Post-vocational Programs</u> These services are designed to meet the needs of senior citizens with developmental disabilities. As such, vocational skill instruction is not emphasized. Instead, instruction revolves around helping these senior citizens maintain previously learned daily living skills and develop new areas of socio-recreational interest. In addition, ample opportunity for leisure activity is provided.

INSTRUCTIONS

Seven level-of-functioning groups are defined below. In deciding in what group clients best fit, consider each group from one -- seven, in that order. In those cases when a client could conceivably fit into two or more groups, s/he should be shown in the lowest-numbered group (i.e., lowest functioning group).

The medical disability category (1) includes those persons whose medical problems are severe enough to demand continued attention from medically trained personnel. The physical disability category (2) includes those persons whose physical impairments demand personal care services above and beyond that required for persons with developmental disabilities but without such physical limitations. The behaviorally-related categories 3) and 4) include those persons whose behavioral problems are severe enough to require supervision, controlled environments and behavior management measures that are above and beyond those required for persons with developmental disabilities but without these behavioral problems. Persons assigned to one of the habilitative categories (5 - 7) have no overriding medical, physical or behavioral problems that demand an extra level of care and that hold their adaptive skills below what they otherwise might be.

1. Persons with Chronic and Serious Medical Problems

   - have serious and chronic medical conditions requiring continual medical attention
   - taking medications that must be administered by medically trained persons and where monitoring is required to monitor side effects and to assure proper administration (e.g., having diabetes and requiring frequent insulin

injections);

- bedridden 24 hours a day (nonambulatory)
- incontinent (no level of bowel or bladder control)
- life threatening condition that requires 24 hour monitoring and rapid access to medical care
- life support equipment required
- uncontrolled seizure activity
- alcohol or drug addiction

2. <u>Persons with Severe and Chronic Physical Impairments</u>

Persons able to perform few or no self-care activities and few or no other activities of daily living unaided due primarily to serious and chronic physical impairments

- severe auditory, visual, or cognitive impairment does not interact or relate to environment
- does not feed self
- must be dressed/undressed completely
- does not tend to own personal hygiene
- needs help using prosthetics or similar devices
- needs special help getting around
- history of seizures requiring continual monitoring

3. <u>Persons with Endangering Behavior Problems</u>

- exhibit behaviors dangerous to themselves (e.g., head banging, pica, copography and self biting) or to others (e.g., physical attacks, forceable sexual advances);
- exhibit behaviors destructive to property (e.g., arson);
- regularly refuse staff requests or are nonattentive to their surroundings in situations where their well being or that of others is seriously jeopoardized (e.g., runs, away, runs in front of cars, . . .).

4. <u>Persons with Disruptive Behavior Problems</u>

- exhibit endangering and destructive behaviors infrequently and with ample warning so that they can be managed without constant monitoring in a controlled environment;

- exhibit less serious behavior problems such as disrupting others activities, and minor damage to property;
- ignore staff requests of minor consequence in terms of client well-being (e.g., use profane or hostile language, public displays, withdrawn and unresponsive, scratches, hits, steals)

5. Persons with Minimal Adaptive Skills

- Able to perform few activities of daily living* and then only with considerable assistance, but have no overriding physical, medical, or behavioral problems limiting their potential to do more for themselves.
- scores on tests of intelligence ranging below 35
- severe auditory, visual, or cognitive impariment, does not interact or relate to environment.
- does not feed self
- must be dressed/undressed completely
- does not tend to personal hygiene

6. Persons with Moderate Adaptive Skills

- able to do most activities of daily living* with supervision and assistance and who have no overriding phsyical, medical, or behavioral problems limiting their potential to do more for themselves.
- scores on tests of intelligence ranging from about 35 to 49

7. Persons with High Adaptive Skills

- able to perform most activities of daily living with intermittent supervision
- scores on tests of intelligence ranging from 50 to 70

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* Activities of daily living include: eating, toileting, personal hygiene, dressing, money handling, shopping, reading and writing, care of personal belongings, interaction with others, participation in group activities, house cleaning, use of tools, sense of responsibility, and various vocational activities.

APPENDIX E

Data Obtained from the Client Oriented Option Profile (COOP) System

- seriously medically/physically disabled -- includes persons who:
  - require life support medication (28h) and need assistance in administering it (28g) or
  - are non mobile (27n) or
  - have a significant hearing impairment (27h) and a significant vision impairment (27i) and a chronic medical condition (27m)
- Moderately medically/physically disabled -- includes persons who:
  - take seizure control medicine (28f) and need assistance administering it (29g), or
  - use an orthopedic brace (28c), a wheelchair (28d), or other walking aid (28e) and need assistance in five or more activities (29a-h), or
  - are blind, (27i) or deaf (27h) and need assistance in five or more activities (29a-h)
- Endangering Behavior
  - includes persons who exhibit extreme maladaptive behavior (27l)
- Disruptive behavior -- includes persons who:
  - are known to have behavioral/emotional problems (27k), or
  - are taking psychotropic medication (28g) and need assistance in administering it (29g)
- Minimally Adaptive
  - includes persons who are rated severe (26d) or profound (26e), or who require assistance in five or more activities (29a-h)
- Moderately Adaptive
  - includes persons who are rated moderate (26c) or who require assistance in two to four activities (29a-h).