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PROGRAM DATA REVIEW

A COMPILATION OF
RATES OF PREVALENCE
OF THE
DEVELOPMENTAL DISABILITIES

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Under HEW, Office of Human Development
Grant of National Significance
#54-P-71220/2-01

The opinions expressed herein do not necessarily
reflect the official position of the Developmental Disabilities
Office.

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- Under "Substantial Rates", a number of states are listed as considering 100% DD to be substantially handicapped. Two types of states are actually in this group: those who do consider all DD persons to be substantially handicapped; and those who consider some lesser portion of the population to be substantially handicapped but dealt with only the substantially handicapped in the state plan. The latter are distinguished by the legend, "SUBSTANTIAL ONLY" in the Rationale columns for Overall Rates.

RATES OF PREVALENCE OF THE DEVELOPMENTAL DISABILITIES
AND THE SUBSTANTIALLY HANDICAPPED

Rates of prevalence and their rationales or sources are given in Table 1 as used in fifty-three (53) FY 1978 DD state plans. The rates are given by state and disability (mental retardation, cerebral palsy, epilepsy and autism). The states are organized by DHEW Region; within each Region, overall rates by disability are listed for all states, followed by the substantial handicap rates by disability for all states.

In estimating the total or overall DD population, states tended to use the "standard" or "nationally accepted" rates promulgated by the national consumer organizations and related sources: Twenty-six (26) states used .03 for mental retardation; nineteen (19) states gave .0035 or .0055 for cerebral palsy; eighteen (18) states used .02 for epilepsy, and twenty (20) states used an autistic rate of .0004.

With the exception of autism, which most states agreed is a substantial disability, few states were in agreement on the rates to be used for substantial handicaps. This wide variation in substantial rates used by states occurs mainly because the substantial rates within a given state are usually dependent on two factors: (1) the policy of definition used by the state DD council to determine who in the DD population is substantially handicapped; (2) the overall prevalence rate by disability used by the state DD council, since the substantially disabled are usually described as some proportion of the total DD population. Substantial rates used in the plans did, however, tend to fall into narrow ranges: .01 to .019 for mental retardation was used by fifteen (15) states; seventeen (17) states used .002 to .0034 for cerebral palsy; nineteen (19) states gave rates between .001 and .0049 for epilepsy; and as was noted above, twenty-one (21) states, most of which stated that all autistic are substantially handicapped, cited the "standard" rate of .0004 for autism.

ABBREVIATIONS USED IN THIS PAPER

MR = Mental Retardation
CP = Cerebral Palsy
E = Epilepsy
A = Autism
LD = Learning Disabilities (dyslexia)

TABLE 1

REGION I
OVERALL RATES

STATE	MR	MR RATIONALE	CP	CP RATIONALE	E	E RATIONALE	A	A RATIONALE
CONN.	.015	Connecticut Dept. of Mental Retardation; PCMR ¹ cited a 1% to 3% range.	.0005	Consultations with UCPA of Connecticut, and a review of numerous state plans.	.020	EFA estimate, used by the majority of other state plans.	.0001	Suggested by authorities in the field of autism; based on review of a 1976 survey of a portion of Conn.; rate includes only Kanner's syndrome.
MAINE	.03	"national incidence" rate	.002	"national incidence"	.009	"national incidence" rate; adjusted to exclude multiple handicaps, based on Conley ² . (10% of epileptics)	.0004	NSAC
MASS.	.03	Blatt ³	.005	UCPA, 1975	.02	EFA, 1975	.0004	NSAC
N.H.	.0058	State survey of the DD population	.00034	State survey of the DD population.	.000087	State survey of the DD population.	.000059	State survey of the DD population.
RHODE IS.	.03	AAMD	.002 .001	Less than 21 years } UCPA ⁴ 21+ years }	.02	EFA	.0004	No Info. Approximately 1/3 have some other handicap affecting the brain or central nervous system.
VERMONT	.0251 .0011 .0014	Mild Moderate Severe/profound } NARC	.0005 .0010 .0005	Mild Moderate Severe/profound } UCPA		EFA, as used in 1975 Hawaii State Plan 0-6 years: .0025 mild .0017 mod. .0008 s/p 7-21 years: .0073 mild .0051 mod. .0022 s/p 22+ years: .0093 mild .0064 mod. .0017 s/p	.0004	EMC Institute

SUBSTANTIAL HANDICAPS

CONN.	8% MR	Severely & profoundly disabled; based on state MR records.	20% CP	Consultations with UCP of Connecticut and review of numerous other state plans	20% E	Uncontrollable seizures; rate recognized by the majority of state plans.	100% A	Rate used by 12-13 other state plans.
MAINE	100% MR		100% CP		100% E		100% A	

REGION I

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SUBSTANTIAL HANDICAPS (CONT'D)

MASS.	.01	Blatt ³ continuous need of spec. services.	.0017	UCPA: 1/3 are substantially disabled.	.004	EFA ⁵ , Karan ⁶ ; uncontrolled seizures	100% A	NSAC
N.H.	100% MR		100%CP		100%E		100% A	
RHODE IS.	11% MR	Mental Retardation due to biomedical, rather than socio-environmental causes.	.002		.002	Henderson ⁷	100% A	
VERMONT	100% MR		100%CP		100%E		100%A	

REGION II

OVERALL RATES

N.J.	.0125	All persons in 0-49 IQ range, plus $\frac{1}{2}$ of those in 49-69 IQ range. This rate is a combination of age-specific rates from Imre ⁸ and other sources: 0-4 yrs = .0119 5-9 = .0102 10-14 = .0101 15-19 = .0207 20-34 = .0126 35-59 = .0116 60+ = .0116	.001	UCPA of New York; those CP persons who can be expected to require special services over an extended period of time.	.0031	Persons with uncontrolled or partially controlled seizures.	.004	NSAC
N.Y.	.001	1) experts believe rate is closer to 1% 2) results of "California Studies" 3) AAMD has dropped the 'borderline' category; most persons in this group can adapt to social living; this group constituted most of the 3% prevalence 4) number of school age MR's identified in NY public schools (95% of school age MR children).	.0035	UCPA	.005	Preliminary estimate of the National Commission for Control of Epilepsy and its Consequences.	.00033	Average of reported rates.

REGION II

OVERALL RATES

STATE	MR	MR RATIONALE	CP	CP RATIONALE	E	E RATIONALE	A	A RATIONALE
P.R.	.0193	Average of age-specific rates from Muestra Básica del Departamento de Salud Fecha, 7/75: 0-6 yrs = .0313 7-13 = .0840 14-24 = .0564 25-44 = .0099 45-64 = .0042 65+ = .0058	.0055	Commonwealth of Puerto Rico, Governor's statewide Commission for Rehabilitation Services: Final Report, Survey of the Mentally Retarded Population, 12/69.		Average of age-specific rates from Muestra Básica del Departamento de Salud Fecha, 7/75: 0-6 yrs = .0104 7-14 = .0164 15-24 = .0098 25-44 = .0070 45-64 = .0042 65+ = .0014	.0004	NSAC ¹⁰
V.I.	.025	Based on record review, services rendered, reports, and judgement of a council committee which met in a training session provided by EMCI consultants and the regional office.	.005	See MR	.005	See MR	.0002	See MR

REGION II

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SUBSTANTIAL HANDICAPS

STATE	MR	MR RATIONALE	CP	CP RATIONALE	E	E RATIONALE	A	A RATIONALE
N.J.	100%MR		100%CP		100%E		100%A	
N.Y.	25%MR	Moderate & severe MR (20%) plus profoundly retarded (5%MR)	80%CP	Persons who cannot be self sustaining	25%E	Persons with seizures which are difficult to control.	100%A	
ALL DISABILITIES: prevents individual from participating in or benefiting from social, economic, educational, recreational or other opportunities available in the community.								
P.R.	5%MR	Severe (3.5%) and profound (1.5%)MR; NARC.	20%CP	Persons with motor involvement and IQ of 45 or less; UCPA ¹²	20%E	Persons with seizures which are not controlled (In Puerto Rico, 95% of known epileptics have control over seizures); EFA consensus of professionals.	100%A	Too little substantiated information to determine if some can live an independent life; NSAC. ¹⁰
V.I.	.0063	Approximately 25% of MR; see rationale for overall MR rate.	.0025	Approximately 50% of CP; see rationale for overall MR rate	.0013	Approximately 25% E; See rationale for overall MR rate	.0002	100% A; see rationale for overall MR rate.

REGION III

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OVERALL RATES

STATE	MR	MR RATIONALE	CP	CP RATIONALE	E	E RATIONALE	A	A RATIONALE
DEL.	.03	NARC	.001	UCP	.02	Delaware Epilepsy Association	.00047	NSAC, Delaware Chapter
MD.	.021	"general incidence" rate (as accepted by the Maryland DD Council & presently used by the state MR Administration); based on age-specific rates quoted by MR Administration Annual Report, based on "recent epidemiological studies,"	.005	UCP of Central Maryland	.01	EFA consensus (.05 to 1.0 per 1000)	.0005	Wing ¹³
PA.	.028	NARC	.007	UCP of Pennsylvania	.01	EFA (range = 1% to 2%)	.0003	NSAC (midpoint of .01% to .05% range).
W. VA.	.03 (.0081)	Lindberg ¹⁴	.004 (.0009)	Lindberg ¹⁴	.02 (.0035)	Lindberg ¹⁴	.0004 (.008)	Based on Lindberg, ¹⁴ actual prevalence may be closer to .008.
VA.	.03	NARC, ¹¹ rounded off from the 2.82% cited	.003	UCP of Washington, D.C.	.02	EFA	.0003	NSAC
D.C.	.03	AAMD	.003	UCP	.01	EFA	.0004	NSAC

SUBSTANTIAL HANDICAPS

DEL.	100% require services to obtain and sustain maximum functioning potential.							
MD.	6%MR	MR Administration of Maryland (4% severe plus 2% profound MR)	20%CP	UCP of Central Maryland (10% to 20% range)	40%E	1) Director of Pediatric Seizure clinic of Kennedy Institute: 30-40% need substantial medical assistance; 2-3% need living assistance; 40% need learning assistance 2) EFA consensus (Majority professional view):	50%A	Rutter ¹⁵ : 1/2 of autistics have a very severe disability.

REGION III

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SUBSTANTIAL HANDICAPS (CON'T)

STATE	MR	MR RATIONALE	CP	CP RATIONALE	E	E RATIONALE	A	A RATIONALE
MD.						15-20% have uncontrollable seizures; an additional number have seizures which will interfere with education, work, etc.		
PA.	.018	Arthur Bolton Assoc. ¹⁶	.0018	Estimate: 25% of CP population.	.002	EFA: uncontrolled seizures	.0003	
VA.	.015	Moderate, severe & profound MR(VDDPC)	.0015	Moderate or low adaptive behavior (VDDPC).	.004	EPA: partially controlled or uncontrolled	.0003	(VDDPC)
D.C.	.01	1/3 MR; based on EMCI analysis of FY 1977 plans	.0015	½ CP; see MR	.005	½E; see MR	.0004	100%A; See MR

REGION IV
OVERALL RATES

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STATE	MR	MR RATIONALE	CP	CP RATIONALE	E	E RATIONALE	A	A RATIONALE
ALABAMA	.03	Hollingsworth ¹⁷ , also age-specific rates.		Hollingsworth ¹⁷ ; overall & age-specific rates: .00071				
FLORIDA	.03 .009 .026 .180	Base rate; national prevalence studies 0-4yrs } California Study 5-19 } Commission on 20+ } Mental Retardation (used in Hawaii State Plan) overall rate=.0193 these are rates for unduplicated counts.	.004 .0024	Base rate; national prevalence (UCP) UCP, adjusted to provide unduplicated count. About 40% of CP persons have MR.	.0163 .0029 .0063 .0067	Base rate; national prevalence (EFA) 0-4yrs } adjusted to 5-19 } eliminate 20+ } duplicated counts and epileptics with onset after age 18 (about 1/2 E); about 10% of epileptics have MR.	.0003	Base rate & adjusted to provide unduplicated count. NSAC midpoint of .01% to .05% range.
GEORGIA	.0193/ .0190	age, degree, and poverty & non-poverty-specific rates; this rate is the average of all county estimates (overlapping counts) for 1978/1980. Details in Weber, 3/77, available at small charge from Georgia DDC.	.005		.01		.0004	
KENTUCKY	.03	Baroff ¹⁸	.0035	UCP of Kentucky	.02	EFA of Kentucky	.0002	Baroff ¹⁸
MISS.	.03 ¹⁹		.0035	See MR	.0062	See MR	.0004	NSAC
N.C.	.03	Routh ²⁰	.0035	UCP, quoted by Routh ²⁰	.005	EFA, quoted by Routh ²⁰	.0004	NSAC, quoted by Routh ²⁰ .
S.C.	.068	S.C. Department of Health & Social Development ²¹ (Due to risk, poverty, other factors in S.C., may be up to 10% NARC, other professionals and/or studies.	.0075	National health organization data.	.01	EFA	.0002	NSAC

OVERALL RATES

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REGION VI OVERALL RATES								
STATE	MR	MR RATIONALE	CP	CP RATIONALE	E	E RATIONALE	A	A RATIONALE
ARK	.03	Stedman ²⁵	.004	UCPA ²⁶	.02	EFA ²⁷	.0004	NSAC
LOUISIANA	.03	General rate	.004	General rate	.02	General rate	.0005	Consistant with that used by other states
NEW MEX.	.03	NARC	.004	UCP of Albuquerque & DHI.	.02	EFA	.0004	NSAC
TEXAS	.03	Average, based on Stedman ²⁵ . .07 of poverty population are MR; .02 of non-poverty population are MR. SUBSTANTIAL ONLY	.0012	Unduplicated count (excludes MR); based on general .0035 prevalence (the 1/3 who are not retarded). SUBSTANTIAL ONLY	.0105	Unduplicated count (excludes MR); based on general .02 prevalence, adjusted to reflect only those who need specialized services (75% of the 70% who are not retarded). SUBSTANTIAL ONLY	.0004	(note: possible duplicated count, since up to 2/3 manifest intellectual deficits severe enough to class them as MR). General prevalence. SUBSTANTIAL ONLY.
SUBSTANTIAL HANDICAPS								
ARK.	100%MR		100%CP		100%CP		100%CP	
LOUISIANA	.0023	Unclear	.0024	Cruickshank ²⁸ : 91% of all CP's need extensive services= .0036 substantially handicapped; .0036 minus the 1/3 (.0012) who are also retarded. Unduplicated count.	.004	30% of all E's are severely impaired by convulsive disorders =.006 substantially handicapped; .006 minus the 1/3 (.002) who are also retarded. Unduplicated count.	.0005	LDC
NEW MEX.	11%MR	All moderate (0.6%), severe (3.5%) and profound (1.5%) MR. National percentages	60%CP	High end of 20% - 60% range quoted by other states; UCPA; J.Paul ²⁹	40%E	Need substantial medical & learning assistance; EFA & Kennedy Institute (See Maryland)	100%A	
TEXAS	100%DD	Only persons needing specialized services were included in overall rates.						

OVERALL RATES								
STATE	MR	MR RATIONALE	CP	CP RATIONALE	E	E RATIONALE	A	A RATIONALE
IOWA	.03	Discussions with state & national organizations	.0035	See MR	.02	See MR	.00005	See MR
KANSAS	.03	Nationally accepted rates	.0035	See MR	.005	See MR	.0004	See MR
MISSOURI	.02	<p>SUBSTANTIAL ONLY</p> <p>Formula prepared for MDDPC by Arthur Bolton Associates, based upon Bolton research in Mo. & throughout the nation:</p> $NO(X+Y) = (NX)X + (NY)Y,$ <p>X = percent of county pop. below poverty level</p> <p>Y = percent of county pop. above poverty level</p> <p>NX = prevalence rate for those below poverty level</p> <p>NY = prevalence rate for those above poverty level</p> <p>NO = prevalence rate for whole county pop.</p>	.01	See MR; also UCP. SUBSTANTIAL ONLY	.005	See MR; Also EFA; SUBSTANTIAL ONLY	.00005	See MR. SUBSTANTIAL ONLY
NEBRASKA	<p>Overall rates not given; state surveys used to count population: <u>Nebraska Investment in Services for the Developmentally Disabled; a Statewide Survey</u>, Wergin, 4/73, using national prevalence rates and state demographic data; data collection from state Information & Referral Projects, 4/75; and questionnaire distributed by Nebraska Council and Nebraska NSAC.</p>							
SUBSTANTIAL HANDICAPS								
IOWA	.01	All severely & profoundly retarded based on professional observations by consumer group representatives.	.0016	Multiply handicapped; See MR	.005	Multiply handicapped; See MR	.00005	Multiply handicapped; See MR (100% A)
KANSAS	100% of DD: All are liable to experience social, legal or economic constraints to some degree at some point in time, thus requiring provision of specialized services.							
MISSOURI	100% DD, by definition; only substantial population is considered in the plan.							
NEBRASKA	13.6% DD: all multiply handicapped identified in state surveys (see Nebraska Overall Rates); 2 disabilities occurring together would seriously impair an individual's life functions; also, few resources exist to provide appropriate services to the multiply handicapped.							

OVERALL RATES								
STATE	MR	MR RATIONALE	CP	CP RATIONALE	E	E RATIONALE	A	A RATIONALE
COLORADO	.01	Tarjan ³⁰ ; assumption of 3% is not supported by clinical experience. Average of age and level-specific rates.	.0006	Kurtzke & Kurland ³¹	.02	EFA of Colorado	.00045	Wing, et.al ³² ; median of 3 rates which resulted from the most comprehensive identification techniques in the study.
MONTANA	.03	National rate	.005	National rate	.02	National rate	.0005	National rate
N.D.	.03	National rate	.005	National rate	.02	National rate	.0005	National rate
S.D.	.03	NARC	.0056	UCPA	.004	EFA	.0004	NSAC
UTAH	.03	"National incidence" rate	.005	"National incidence" rate	.02	"National incidence" rate	.0005	"National incidence" rate.
WYOMING	.03	National rate - PCMR	.005	National rate - UCPA	.02	National rate - EFA	.00005	National rate - NSAC
SUBSTANTIAL HANDICAPS								
COLORADO	.00724	All persons diagnosed as MR based on an assessment of both their intellectual ability and their level of adaptive behavior. Adjusted to exclude multiple handicaps of CP or E.	.00683		.01	All persons with no or partial seizure control.	.00045	100%A
MONTANA	22.5% DD: rationale unclear							
N.D. UTAH	.0081	Lindberg ¹⁴	.0009	Lindberg ¹⁴	.0035	Lindberg ¹⁴	.00033	Edward Rizzo, 1971 NSAC annual meeting: 1/3 will always require special living assistance
S.D.	.0077	Based on a state survey of service needs for the handicapped in Brookings & Codington Co's, and Sioux Falls, 1972, using a Calif. Identification of Need for Service study.	.0056	See MR	.004	See MR	.0004	See MR
WYOMING	1.7% of the general population over 5 years old; 100% DD under 5 years old. Adapted from Lindberg. ¹⁴							

REGION IX
OVERALL RATES

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STATE	MR	MR RATIONALE	CP	CP RATIONALE	E	E RATIONALE	A	A RATIONALE
ARIZONA	.042 .036 .032	0-5 yrs } Floyd O'Brian: a 6-18 } comprehensive review 19+ } and analysis of nation- al and state publications and studies, for ADDPAC	.002 .002 .002	0-5 yrs } 6-18 } See MR 19+ }	.006 .005 .004	0-5 yrs } 6-18 } See MR 19+ }	.002 .002 .002	0-5 yrs } 6-18 } See MR 19+ }
CALIF.	.03	Developed through research, field experience and analysis of relevant information by EMC Institute and DD/TAS: selected as most appropriate in the judgement of the planning staff.	.0055	See MR	.02	See MR	.0002	See MR
GUAM	.02			.003 combined; no source or rationale given.				
HAWAII	.009 .026 .004	0-4 yrs } 5-19 } derived from Tarjan, 20+ } et. al ¹⁸	.002 .002 .001	0-4 yrs 5-19 20+	.003 .0042 .0038	0-4 yrs 5-19 20+	.0004	All ages
NEVADA	.028	mean rate of all FY 1977 state plans	.0035	See MR	.0124	See MR	.00037	See MR

SUBSTANTIAL HANDICAP

ARIZONA	.0428 of total population; based on O'Brian (See MR overall rates).							
CALIF.	.018	See overall MR rate.	.0013	See overall MR rate	.004	See overall MR rate	.0001	See overall MR rate
GUAM	.003 of total population.							
HAWAII	Not calculated; used service target populations calculated from total DD population							
NEVADA	.0131	Mean rate of all FY 1977 state plans.	.0016	See MR	.0058	See MR	.0017	See MR

REGION X
OVERALL RATES

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STATE	MR	MR RATIONALE	CP	CP RATIONALE	E	E RATIONALE	A	A RATIONALE
ALASKA	.009 .026 .026 .018	0-2 yrs FY 1976 <u>Hawaii State Plan</u> 3-5 yrs } 6-20 } Calif. Study Commission 21+ } on MR Validated by literature review.	.002 .001	0-20 yrs } UCPA 21+ }	.0034 .0068 .0142 .026	0-2 yrs } EFA rates, showing 3-5 } variable of age of 6-20 } onset. 21+ }	.00045	Lotter ³³
IDAHO	.0229	Shrang ³⁴ , plus assumption that adult and preschool rates are the same as school age rate.	.002 .001 .0014	0-19 yrs } 20+ } UCPA all ages }	.0032 .0142 .0251 .0197	0-4 yrs } EFA rates, with 5-19 } variable age of on- 20+ } set all ages }	.0004	NSAC
OREGON	(.0168)	(calculated from state plan)	(0.0009 total; calculated from state plan)					
WASH.	.03	Generally used rate	.002	UCPA	.01	WDDPC (note that .02, Commission for the Control of Epilepsy & Its Consequences ³⁵ may be more accurate).	.0004	Average rate from 13 different state studies; accepted by NSAC.

SUBSTANTIAL HANDICAPS

ALASKA	35% MR	All moderate, severe & profound MR plus 25% of mild MR; Council's best estimate A handicap is substantial if a person with that handicap needs assistance in obtaining those services that the population as a whole accepts as being necessary and desirable.	100%CP	Council's best estimate	40%E	EFA & Good Samaritan Hospital Portland, Oregon	100%A	Council's best estimate
IDAHO		100% DD are tentatively substantially handicapped						
OREGON		(.0038 of general population; calculated from state plan)						
WASH.	1/3MR		1/2CP		1/2E		100%A	

LEVELS OF DISABILITY

Nineteen (19) FY 1978 DD state plans contained definitions and/or prevalence rates for levels of the disabilities as shown in Table 2. All of these states gave at least some definition of levels of mental retardation; seven (7) described levels of cerebral palsy; five (5) gave levels for epilepsy, and one (1) state gave levels for autism. One (1) state also described levels of dyslexia.

Six(6) states used approximately the same proportions of the DD population, based on different definitions, to describe levels of disability for mental retardation:

<u>LEVELS OF DISABILITY</u>	<u>PROPORTION</u>
Mild MR	88.0% to 89.0% of the MR population
Moderate MR	6.0%
Severe MR	3.5% to 4.0%
Profound MR	1.5% to 2.0%

Two other states used similar proportions, with Mild MR being 85% and 83.4% of the MR population in these two states.

Of the seven (7) states which described levels of cerebral palsy, five (5) states assumed that more than half of this population were moderately disabled; in four (4) of these states the moderate proportion was cited as either 54.6% or rounded to 55.0% CP, from a University of Minnesota study⁴¹ which defined moderate CP as "verbal and non-ambulatory."

Four of the five (5) states which gave levels of disability for epilepsy listed the following from various sources:

<u>LEVEL</u>	<u>PROPORTION</u>	<u>"DEFINITION"</u>
Mild E	50% to 52% of E population	Seizures are controllable from 90% to 100% of the time, with medication.
Moderate E	30% to 40% E	Partial seizure control.
Severe/Profound E	10% to 20% E	Seizures are controllable less than 20% of the time or are not controlled at all.

Note that six of the states on Table 2 definitely used their rates and/or definitions by level of disability to determine the prevalence of substantial handicaps, for at least some of the four primary disabilities.

Most of the rates given in Table 2 are couched in terms of a proportion of the total population by disability, rather than a rate of the general population. Displaying these proportions is more meaningful than displaying the rates which result by applying these proportions to state overall prevalence rates (as with substantial handicaps, that rate depends on the definition and proportion of each level as well as the overall rate used by the state). Because states tended to use similar proportions of each disability in describing levels of disability, displaying these proportions allows the user to make comparisons.

TABLE 2

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LEVELS OF DISABILITY

*Used to determine substantial rate

State	Dis-ability	Rate	Mild Rationale/Definition	Rate	Moderate Rationale/Definition	Rate	Severe Rationale/Definition	Rate	Profound Rationale/Definition
REGION I									
CONN.	MR*		Combines borderline (IQ 68-83) and mild (IQ 52-67); DD/TAS ³⁷		IQ 35-51 ³⁷		IQ 0-34 ³⁷		
Region II									
P.R.	MR*					3.5%MR	NARC ¹¹	1.5%MR	NARC ¹¹
Region III									
DEL.	MR		IQ 55-70		IQ 35-55		IQ 20-35		IQ 0-20
MD.	MR*	88%MR	Md. MR Administration; IQ 53-68 (S-B). With Ed. & Training, the majority can be self-sufficient, if not self-maintaining, in adult life; Terman ³⁸	6%MR	MRA; IQ 36-52 (S-B). Many attend public school, can benefit from simple work training, & work well in a sheltered environment; are able to use public transportation; Terman ³⁸	4%MR	MRA; IQ 20-35 (S-B). Can learn self-care to a large extent; unless physical involvements interfere, can engage in useful activity; Terman ³⁸	2%MR	MRA; IQ 0-20. Dependent on 24-hour care; many respond to minimal training; Terman ³⁸
PA.	MR CP* LD*	25%CP 25%LD	IQ 53-85; NARC ¹¹ , HEW-SRS ³⁹ UCP, Washington, D.C. Penna. Assoc. for Children with LD	25%CP 25%LD	IQ 36-52 ^{11,39} UCP PACLD	25%CP 25%LD	IQ 21-35 ^{11,39} UCP PACLD	25%CP 25%LD	IQ 0-20 ^{11,39} UCP PACLD
Region IV									
ALA.	MR CP E	89%MR 31.7% CP 52%E	Dybwad ⁴⁰ University of Minn; ⁴¹ ambulatory & verbal EFA; seizures are 90% controllable	6%MR 54.6% CP 36%E	Dybwad ⁴⁰ U. of Minn ⁴¹ ; non-ambulatory & verbal EFA	3.5%MR 13.7%CP 12%E	Dybwad ⁴⁰ U. of Minn ⁴¹ ; non-ambulatory & nonverbal EFA; seizures are controllable less than 20% of the time.	1.5%MR	Dybwad ⁴⁰

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State	Dis-ability	Rate	Mild Rationale/Definition	Rate	Moderate Rationale/Definition	Rate	Severe Rationale/Definition	Rate	Profound Rationale/Definition	
GA	MR	.0045 .0245 .018 .01	0-4 } Based on overall 5-19 } 3% rate in school 20-24 } years, and with 25+ } other adjustments based on critique of Stedman ⁸	.00035 .004 .0035	0-4 years } 5-24 } See Mild 25+ }	.00109 .00105 .00101 .00004	0-4 years } 5-19 } See Mild 20-24 } 25+ }	.0005 .00045 .0004 .00001	0-4 years } 5-19 } See Mild 20-24 } 25+ }	
	MR: Poverty Counties	.00765 .04165 .0306 .017	0-4 years } 5-19 } See Mild 20-24 } above 25+ }	.0035 .00425 .004 .035	0-4 years } 5-19 } See Mild 20-24 } 35+ }	.00297 .00287 .00277 .00012	0-4 years } 5-19 } See Mild 20-24 } 25+ }	.00136 .00123 .00110 .0002	0-4 years } 5-19 } See Mild 20-24 } 25+ }	
	CP E	20%CP 90%E		20%CP		60%CP 10%E				
Region V										
ILL.	MR, CP E	85%		10%		5%				
MICH.	MR		MR not readily apparent at early age, often only detected during school age. Given appropriate skills, can be absorbed into community life and labor market.		Shows developmental delay before school age. With appropriate support & services in developmental years, can function in community.		Pronounced developmental delay, often concurrent with physical, emotional and behavioral conditions. Provision of systematic training to teach basic skills may sometimes allow adults to live semi-independently and work in sheltered employment.			
MINN.	MR	89%MR	IQ 60-75; PCMR	6%MR	IQ 40-60; PCMR	3.5%MR	IQ 20-40; PCMR	1.5%MR	IQ 0-20; PCMR	
Region VI										
ARK.	MR	.02503	IQ 50-70; Stedman ²⁵ (83.4% MR) Keats ⁴²	.00399	IQ 35-50; Stedman ²⁵ (16.6%MR) Keats ⁴² ; can be re- stored to some degree of a happy & useful life.	.00098	IQ 0-35; Stedman ²⁵ (3.3%MR) Keats ⁴²			
	CP	10%CP		80%CP		10%CP				
	E	50%E	Sands & Seaver ⁴³ ; seizures completely controlled by medica- tion	35%E	Sands & Seaver ⁴³ ; seizures markedly decreased by medication	15%E	Sand & Seaver ⁴³			
	A	17%A	Rutter ¹⁵ ; good adjust- ment	17%A	Rutter ¹⁵ ; fair adjust- ment, with some degree of independence.	66%A	Rutter ¹⁵ , this group remains severely handicapped			

State	Dis-ability	Rate	Mild Rationale/Definition	Rate	Moderate Rationale/Definition	Rate	Severe Rationale/Definition	Rate	Profound Rationale/Definition
N.M.	MR*	89%MR	NARC	6%MR	NARC	3.5%MR	NARC	1.5%MR	NARC
Region VII									
MO.	MR	89%MR	Capable of effective social & economic functioning in a low demand competitive environment; need some support and supervision I.Q. 50-67; AAMD	6%MR	Capable of social & economic functioning in a partially competitive environment, to limited functioning in a sheltered environment; need partial or continuing support & supervision in management of their affairs. May need sheltered living. IQ 35-49; AAMD.	3.5%MR	Respond to limited environmental stimuli & interpersonal relationships; dependent upon supervision for daily maintenance & routines; IQ 34-21; AAMD.	1.5%MR	Have gross physical handicaps or function like the grossly physically handicapped; need continuous medical nursing care for survival; IQ 0-20; AAMD.
Region VIII									
COL.	MR	.02083 .61417 .11500	0-4 years 5-21 22+ } Tarjan, et.al. ¹² percent of MR	.01 0.084 0.086	0-4 years 5-21 22+ } Tarjan, et.al. ¹² percent of MR			.00667 .02093 .0224	0-4 years 5-21 22+ } Tarjan, et.al. ¹² percent of MR
	CP*	31.7%CP	Ambulatory & verbal	54.6%CP	Non-ambulatory & verbal	13.7%CP	Non-ambulatory & Non-verbal		
MONT.	MR*	45.5%MR	IQ more than 50; modified NARC	33%MR	IQ 25-50; modified NARC			22.5%MR	IQ less than 25; modified NARC
WYO.	MR	65.4%MR	Kansas/EMCI survey 1972	25.3%MR		6.3%MR			
Region IX									
NEV.	MR CP* E*						Can perform simple self-help tasks; may need total life support. Results in major communication or mobility handicap. Seizures not controlled.		
Region X									
ALA.	MR*	88%MR	IQ 68-52 (S-B) or 69-55 (w)	6%MR	IQ 51-36 (S-B) or 54-40 (w)	4%MR	IQ 35-20 (S-B) or 39-25 (w)	2%MR	IQ 19 or less (S-B) or 24 less (w)
	CP	32%CP	Ambulatory & verbal	55%CP	Non-ambulatory & verbal	13%CP	Non-ambulatory & Non-verbal		
	E	50%E	Complete Seizure control	40%E	Partial seizure control	10%	No seizure control		

State	Dis-ability	Rate	Mild Rationale/Definition	Rate	Moderate Rationale/Definition	Rate	Severe Rationale/Definition	Rate	Profound Rationale/Definition
IDAHO	MR	78%MR	Learns at $\frac{1}{2}$ to $\frac{3}{4}$ normal rate; eventually can attain academic skills equivalent to 4th or 5th grade. Difficulty in dealing with tasks involving abstract reasoning. Independent or semi-independent adults.	20%MR	Learn at $\frac{1}{4}$ to $\frac{1}{2}$ normal rate. Can learn self-help, socialization, oral language and simple occupational skills, but only limited academic or vocational skills.		Learn at less than $\frac{1}{4}$ normal rate. Need self-help and simple work task supervision.		May be able to perform simple self-help tasks; or may need total life support.
	CP	32%CP	Ambulatory & verbal	55%CP	Non-ambulatory & verbal	13%CP	Non-ambulatory & non-verbal		
	E	50%E	Complete seizure control	30%E	Partial seizure control	20%E	No seizure control		

MULTIPLE HANDICAPS

Determination of the prevalence of multiple handicaps in the DD population is an extremely important step for DD planners and councils for several reasons. First, persons with multiple handicaps, most states agree, are substantially handicapped due to the complexity of the problems which arise from multiple disabilities. This population may require specially designed services, such as the Special Education Multiply Handicapped Program, to deal with these complex needs. The West Virginia Survey found that 24.2% of the substantial population (Moderately & severely/profoundly disabled) had multiple disabilities; other estimates are even higher. Therefore, the multiply handicapped must receive strong attention from DD Councils, as part of the target population.

Second, as the West Virginia Survey pointed out, ignoring the multiply handicapped leads to inflated estimates of the size of the DD population, while playing down the severity of the handicaps that result from multiple disabilities. Prevalence estimates used by each of the four national associations tend to encompass all persons in the target groups, and therefore these estimates overlap to some extent due to the presence of multiple handicaps in each of the target groups. The West Virginia study provides a graphic example of this problem, by counting the overall prevalence of each disability in its sample as follows:

RELATIVE PREVALENCE OF THE DEVELOPMENTAL DISABILITIES - LINDBERG¹⁴

Mental Retardation	73.0% of <u>all</u> developmentally disabled persons, regardless of severity of handicap
Down's Syndrome	8.7%
Epilepsy	28.7%
Cerebral Palsy	9.5%
Autism	0.8%
Multiple Handicaps	8.4%

The above list obviously contains double counts; if the general population prevalence rate for each of the above disabilities was calculated separately, without adjusting each rate for multiple handicaps, the resulting overall rate summed over all disabilities would be almost 1/3 greater than the actual overall rate found by the survey. In practical terms, this may cause DD planners and councils to over-estimate some service needs and gaps while under-estimating others, while also making wrong assumptions about service needs and appropriate corrective activities.

TABLE 3-1

PREVALENCE RATES & FORMULAS FOR MULTIPLE
HANDICAPS CITED IN FY 1978 STATE DD PLANS BUT NOT USED

<u>STATE</u>	<u>MENTAL RETARDATION</u>	<u>CEREBRAL PALSY</u>	<u>EPILEPSY</u>	<u>AUTISM</u>	<u>OTHER</u>
MAINE		50%CP=MR (Georgia State Plan)	10%E=MR (Conley ²)		
MASS.	30% MR have physical disabilities; 40% MR have psychiatric problems (Conley ²).	2/3 CP=MR (Conley ²)	10%E=MR (Conley ²)		
PENNA.					22%DD=Multiple handicapped (Boggs ³⁶)
ALASKA		MR+CP=.00072 (50% CP) (middle literature review range)	MR+E=.002 (10%, or Severe E)	MR+A=.00029 (Literature review)	
IOWA	CP+other handicap=.0016 E+other handicap=.005 (no rationale given; while not discounted, multiple handicaps are included in the substantially handicapped.)				

TABLE 3-2

PREVALENCE RATES & FORMULAS FOR MULTIPLE
HANDICAPS USED TO REDUCE DOUBLE COUNTS IN FY 1978
DD STATE PLANS

<u>STATE</u>	<u>MENTAL RETARDATION</u>	<u>CEREBRAL PALSY</u>	<u>EPILEPSY</u>
TEXAS		2/3 CP=MR (Conley ²); discounted from CP estimate	30% E=MR; discounted from E estimate
COLORADO	14% MR=E } (Boggs ³⁶); 13.6% MR=CP } discounted from MR estimate		
IDAHO		2/3 CP=MR (Conley ²); discounted from CP estimate	15% E=MR (Epilepsy League of Idaho); discounted from E estimate.

TABLE 3-3

PREVALENCE RATES & FORMULAS FOR MULTIPLE
HANDICAPS USED TO ELIMINATE DOUBLE COUNTS IN FY 1978
DD STATE PLANS

Note: (with the exception of Nebraska and West Virginia, which used other parameters based on survey results, discounting does not need to be done as it was in Table 2-2: the overall rates for these states, given in Table 1, excluded multiple handicaps of any kind).

<u>STATE</u>	<u>RATIONALES</u>
New Hampshire	Multiple handicaps = .0008 (results of a state survey of DD); calculated separately from MR, CP, E, A.
Nebraska	Multiple handicaps = 13.6% of DD population = the substantially handicapped (results of a state survey of DD).
Georgia	$\left. \begin{array}{l} \text{MR+E} = .0007 \\ \text{MR+CP} = .00215 \\ \text{MR+CP+E} = .0003 \\ \text{CP+E} = .00017 \end{array} \right\} \begin{array}{l} \text{results of review of} \\ \text{existing studies} \end{array}$
Minnesota, Indiana	$\left. \begin{array}{l} \text{MR+E} = .00265 \\ \text{MR+CP} = .00257 \end{array} \right\} \begin{array}{l} \text{(Wisconsin 22)} \end{array}$
Louisiana	$\left. \begin{array}{l} \text{MR+E} \\ \text{MR+CP} \end{array} \right\} .00224$
West Virginia	Lindberg ¹⁴ statistics on the percentage of each disability which involves a second disability.

PREFACE

This paper is one of a series prepared under HEW, Office of Human Development, Grant of National Significance #54-P-71220/2-01, on pertinent issues on planning, administration, monitoring and evaluation in the developmental disabilities formula grant program (DDFGP) of Public Law 94-103.

Issues to be addressed in the series are:

- Prevalence Rates of the Developmental Disabilities.
- Characteristics of the Developmentally Disabled.
- Service Needs of the Developmentally Disabled.
- Roles and Responsibilities of Developmental Disabilities State Planning Councils.
- Status of Comprehensive Planning in the Developmental Disabilities Program.
- Gaps and Barriers to Service for the Developmentally Disabled.
- Goals and Objectives of the State Developmental Disabilities Program.
- Monitoring and Evaluation Activities in the Developmental Disabilities Program.
- Generic Service Program Access and Coordination for the Developmentally Disabled.

The analysis presented in each of the issue papers is based on information in Fiscal year 1978 developmental disabilities state plans. As a result, what is presented in each paper is defined, to varying degrees, by the data recorded in the state plans. The nature and effect of limitations on specific analyses due to source data problems are described in each paper.

The preparation of developmental disabilities state plans for fiscal year 1978 was a monumental effort as well as nation-wide at all jurisdictional levels. The state plans themselves attest to the diligence and care of the investment: over 75% of the 54 states plans contain 50% or more of the information requested in the State Plan Guideline and over 30% of the plans provide 70% or more of the information.

In the Developmental Disabilities Program the "who" is equal in importance to the achievements themselves. Many national, regional, and state constituents of the program have contributed to the overall excellence of the developmental disabilities state plans by their direct support, assistance and spirited debate of planning issues. Frankly, it would be difficult to acclaim each of the over 150 persons at national, regional, and state levels who were instrumental in development of the state plans.

It should be recognized that state level planners and council members who participated in developmental disabilities state plan development have gathered a substantial information base for the Developmental Disabilities Program. In many instances situational and resource difficulties had to be overcome by the councils to produce this meaningful and important document in their states. The Developmental Disabilities Program councils and staff are the principal contributors to the content of these papers.

The staff of each regional developmental disabilities office have contributed guidance as well as many hours of assistance to both the states and BDCI technical assistance staff. Regional officers of the Developmental Disabilities Program shared in the primary development of the developmental disabilities state plans.

At the national level there has been continued direction, awareness of the importance of the comprehensive planning mandate and support for the operational effort to enhance state and regional offices capability to implement the planning guidelines. The Developmental Disabilities Office Director, executive staff and those in the Program Operations and Research and Evaluation Divisions were key contributors to the momentum of the FY 1978 developmental disabilities state plan development effort.

Final compilation and analysis of the information in developmental disabilities state plans is the result of effort by the BDCI Institute staff. Data compilation and paper development were conducted by:

Irwin Schpok, Project Director
Joan Geller, Task Leader.

Rosemary Davis	Lee Koenigsberg
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RATES OF PREVALENCE OF THE DEVELOPMENTAL DISABILITIES

INTRODUCTION

This document contains rates of prevalence and rationales or sources used by fifty-three(53) FY 1978 DD state plans. This information is intended to be used as a resource by state DD councils and planners in determining and validating DD prevalence in individual states.

The material in this document was collected to facilitate an analysis of trends in state DD council perceptions of DD prevalence. The results of that analysis are presented in a separate issue paper in this series, "Prevalence of the Developmental Disabilities." Rates and formulas are given here for four types of DD characteristics:

- (1) the overall DD population by disability;
- (2) the substantially handicapped DD population, by disability;
- (3) level of disability by type of disability;
- (4) multiple handicaps and other disabilities.

Cautions and limitations on state use of this information are given below, followed by a display of the prevalence rates by states. A bibliography of sources cited in the state plans are at the end of this paper.

Unless otherwise indicated, all rates are given as a decimal fraction of the general population; that is, 3% appears as .03, the form that is used in the calculation of DD population data.

USES OF DATA

This document can be used in the following ways:

1. To facilitate state Developmental Disabilities council choice of prevalence rates of the developmental disabilities, as the basis for estimating the size of the Developmental Disabilities population.
2. To provide additional documentation to support a prior choice of prevalence rates.
3. As a developmental disabilities resource guide, the bibliography for this paper contains numerous references which can be used as council and staff orientation materials.

4. As a technical guide to means of calculating multiple handicaps and levels of disability. Used in conjunction with the EMC Institute paper, "A Compilation of Approaches to Service Needs Assessment," it provides a method for calculating the service needs of DD people according to the DDO state DD Plan Guidelines.

LIMITATIONS ON USES OF THE DATA

While this information is presented as a potential planning resource, the user should exercise caution in adopting any of the rates contained herein:

- Most of the rates reviewed in this paper are based on slightly different methodologies, assumptions and definitions, some of which are not even cited in the state plans. The resulting prevalence rates of each state thus depend to a certain extent on a unique combination of methodology, policy, research, assumptions, and definitions. Therefore, individual rates from different state plans (for example, the MR rate from State A and the CP, E, and A rates from State B) should not be used together without intensive review of the actual study reports and other sources cited in the plans.
- Close attention should be given to factors - geographic, socio-economic, demographic, etc. - which might affect prevalence within a state or within geographic regions of a state. The results of a study in one state may not be applicable to all or even most states due to interstate differences in these factors; thus the rates stated in survey results or state plans may or may not be justifiably used by another state.

Additional limitations are imposed by the circumstances surrounding the compilation of this information. The original purpose of these lists of prevalence rates was to provide a national profile of state DD council perceptions and policies on the prevalence of DD, as expressed in the FY 1978 DD state plans. Therefore, the quoted rates do not form an exhaustive list, and no judgments are made or implied on the validity of these rates. They merely illustrate state DD council choices. Because of the literal nature of this compilation, several other cautions should be kept in mind:

- Sources or rationales are given as cited by the state plans and some of these citations may be unclear or incomplete; attempt has been made to clarify citations referenced in the bibliography, but this has not been possible in all cases. A few state plans cite "national incidence" rates, when they are actually referring to national prevalence rates. Some rates on the charts are not accompanied by rationales or sources because this information was not given in the state plans.

OTHER DISABILITIES

Only five (5) states included disabilities other than mental retardation, cerebral palsy, epilepsy and autism in their estimates of the DD population: three states used dyslexia, one used muscular dystrophy and one used "other disabilities" as given by Boggs³⁶. One of these states also made a point of the multiply handicapped by giving separate calculations for this group as though they possessed a separate disability (while other states which calculated multiple handicaps included such handicaps in their estimates of the four primary disabilities).

TABLE 3-4

OTHER DISABILITIES INCLUDED IN DEVELOPMENTAL DISABILITIES IN FY 1978 DD STATE PLANS

<u>DISABILITY</u>	<u>STATE</u>	<u>RATE</u>	<u>RATIONALE</u>
Dyslexia (Learning disabilities)	N.H.	.0001	Results of a state survey of DD. Pa. Bureau of Special & Compensatory Education
	PA.	.02	
		.005	Substantial dyslexia; PDDC estimate
	MD.	.02	No rationale
Muscular dystrophy	COL.	.00004	Danieli, et.al. ⁴⁴ , review of seven studies: three of the studies, with larger sample sizes, gave this rate.
All other mental disorders	MINN. INDIANA	.00049	Wisconsin ²² /Boggs ³⁶
All other nervous/sensory disorders	MINN. INDIANA	.00093	Wisconsin ²² /Boggs ³⁶
All physical (muscular) disorders	MINN. INDIANA	.00224	Wisconsin ²² /Boggs ³⁶
(Multiple handicaps)	N.H.		Results of a state survey of DD. Since these are all grouped together and are calculated separately from the four (4) primary disabilities, for estimation purposes they may be considered an "other disability"

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