

Comparative Mortality in Mentally Retarded Patients in California, with and without Down's Syndrome, 1986-1991

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Background: The large database of the California Department of Developmental Services provides a data source for mortality rates in persons with mental retardation by age, sex, severity, cause and associated conditions.

Results: Data for 1986-1991 were used to determine age-related mortality rates in cases with and without Down's Syndrome, in three severity levels of mental retardation. Distribution data for the database population are also given.

Conclusion: In both Down's and non-Down's patient groups excess mortality increased with severity of mental retardation at all ages. In both groups excess mortality tended to decrease with advancing age to age 35-39 years, and to increase at the older ages. The age increase in excess death rate at age 40 years and up was steeper in the patients with Down's Syndrome.

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References

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2. Strauss D, unpublished life table data, 1996.

Objective of This Abstract

To present comparative annual mortality rates of patients in the registry of the California Department of Developmental Services, 1986-1991, by age, level of mental retardation and presence or absence of Down's Syndrome.

Subjects Studied

The database managed by the State of California's Department of Developmental Services utilizes at least annual CDER reports (Client Development Evaluation Reports). These reports are prepared by local centers throughout the state, and include reports on entry, change in status, and death, in addition

to the regular annual report. The authors of the published article¹ also obtained additional deaths by matching names and other data with death data on a regularly updated magnetic tape of all deaths in the state, prepared by the California Bureau of Vital Statistics. Data for both sexes combined have been analyzed by the following attained age groups: 1-4 years, 85 years and up, and by intermediate quinquennial age groups. Infants 0-1 year of age were thus excluded. At the older age groups it was often necessary to combine quinquennial age groups because of the small numbers of exposures and deaths. Both exposures and deaths were counted over the entire 6-year period of observation, 1986-1991 (see under Follow-up).

Patients were also classified by clinical characteristics from the CDER data on the database. The level of mental retardation was characterized as mild/moderate, severe or profound. (see below). In addition, those patients with Down's Syndrome were identified and ana-

lyzed separately from all other patients with mental retardation. Mild mental retardation was defined by an IQ estimated to be in the range from 50-55 to 70-75, moderate from 35-40 to 50-55, severe from 20-25 to 35-40, profound under 20-25, and "suspect", if no formal IQ test was reported. After analysis of the mortality in each of these groups, the authors combined data of the mild and moderate groups, and the severe and suspect groups, because there was little age-specific difference in mortality between the members of each of these pairs. Registrants with borderline or no mental retardation (IQ at 75-80 or above) were excluded. Thus final results are shown by presence or absence of Down's Syndrome for three mental retardation groups, after this combination of mild and moderately retarded groups, and the severely retarded and suspect groups.

Demographic and other characteristics are summarized in Table 1 for the 118,653 individuals in the registry during the 1986-1991 observation period. These are in terms of percentage distribution of the total. Males predominated over females, 56.2% to 43.8%. Over half of the registrants were under age 20 years, and only 5.2% were age 50 years or over. With respect to the severity of mental retardation, the size of the group decreased progressively as the severity increased. Based on exposure data, patients with Down's Syndrome made up 11.6% of the total, and all others, 88.4%.

Associated physical or functional disability was common in these mentally retarded patients, especially in those with severe or profound retardation. The overall prevalence of various methods of measuring disability is also shown in Table 1. Fully 18.2% of the patients were unable to walk at all, and only 70.2% were able to walk unaided. Nearly one half of these patients were not toilet-trained, or only partially trained, and 2.1% required tube-feeding. Associated severe disability results in high excess mortality, as shown in previous studies of patients in this California registry,

one of which was summarized in Mortality Abstract 048M-216M1 (see *J Ins Med* 26:348, in 1994). Disability was not a variable used in the study reported here.

As shown in Table 2, the six major groups of patients differed widely in age distribution and mean age. The widest variation in mean age was found in the patients with Down's Syndrome, ranging from 19.1 years in those with mild to moderate retardation to 31.8 years in those with profound retardation. Young patients predominated in all groups, with few patients age 55 years and older (only 1.3% to 4.7%). The largest group, patients with mild to moderate retardation and no Down's Syndrome had an intermediate mean age of 26.0 years; this group had an intermediate 25% of children age 1-14 years, with the largest percentage of those age 55 years and older. In contrast, the patients with Down's Syndrome and profound retardation had only 7.8% of children age 1 to 14 years, but the highest percentage of young adults, age 15 to 34 years.

Follow-up

Enumeration of the registry was carried out on July 1 of each observation year, 1986 through 1991. A registrant with a CDER in a particular year was considered to be at risk if he or she had at least one CDER in the three years prior to the observation year, and either died or had another CDER in the following three years. This method of counting yielded a total exposure (E) of 488,324 person-years (53,574 in patients with Down's Syndrome, and 434,750 in all others). This gives an average of 81,387 eligible subjects counted on July 1 over the observation period. Of the 4,113 deaths enumerated 422 were in the group with Down's Syndrome, and 3,691 in the group without a diagnosis of Down's Syndrome. All CDER death reports were counted in each of the 6 calendar years. As noted previously, the authors obtained additional death records not on the database, by searching the records of the California Bureau of Vital Statistics for the period 1986-1991.

Expected Mortality

The 1986 U.S. Abridged Life Table was used to derive age-specific expected mortality rates (q') for the total population. A matching q' rate was found for the central age of each quinquennial age group, with its corresponding observed mortality rate, q (Tables 3 - 7). When age groups were combined, expected deaths (d') were calculated as the product of exposure and expected mortality rate: $d' = (q')(E)$. The d' values were then added and the total divided by the total exposure of the groups to obtain an aggregate mean annual q' , all ages combined.

The variations in age distribution exert a major effect on the overall mean expected rate, q' . At the bottom of Table 2 we have added the tabular age corresponding to the mean q' , calculated as $\Sigma d' / \Sigma E$ in Tables 3 through 7. Because q' increases geometrically from age 35 to about 85 years at a nearly constant 10% annual rate, mean q' derived from d' in the actual distribution of age subgroups is always higher than the tabular q' derived from the actual mean age, x . The tabular age matched to the actual mean q' is correspondingly higher than the mean age. The impact, on the mean q' , of the q' values for cases above the mean age is always relatively greater than the opposite impact of the q' values of cases below the mean age. This phenomenon is discussed in the article by Singer and Kita, reprinted as Chapter 4 in *Medical Risks - 1991 Compend of Mortality and Morbidity* (Praeger Publishers, 1994). The difference between tabular age and mean age has been found to vary rather widely according to the pattern of age distribution in various series of patients with coronary heart disease or cancer. But the differences are even wider in these groups with young mean ages, as evident in Table 2. The range of the age difference varies from 5 to as much as 18 years. As discussed in Chapter 4, cited above, this re-emphasizes the uncertainty of attempting to derive mean q' by adjusting the mean age upward by some constant number of years. For the preparation of comparative mortality tables it is important to have the

age/sex distribution specified in the published follow-up study.

Results

The reader is referred to Table 2 of the original article¹ for a profile of the prevalence of various disability factors in the groups with and without Down's Syndrome, in three age groups, 5-9, 25-29, and 55-59 years. The prevalence of disability increased with the severity of mental retardation in both groups, but overall was slightly lower in these with Down's Syndrome. At age 25-29 years 98% of patients with mild or moderate mental retardation due to Down's Syndrome were able to walk without assistance; in the non-Down's group the prevalence was 91%. If the mental retardation was profound at age 25-29 years, the ability to walk unaided fell to 78% and 47%, respectively. The skill of walking was less well preserved at age 55-59 years, as compared with the equivalent subgroup at the younger adult age. These prevalence rates serve as an example of the data given in the cited Table 2 of the original article.

Comparative mortality results for the six major groups of patients with and without Down's Syndrome are shown in Tables 3 - 7. The group with the largest experience, 273,135 patient-years of exposure and 1,259 deaths, is that for patients with mild or moderate mental retardation, exclusive of those with Down's Syndrome, in Table 3. There are 17 age subgroups in this table, ranging from age 1-4 years (infants under 12 months were excluded from all major groups) to age 80 years or higher. Mortality ratios were very high under age 15, then fell to about 275% between ages 15-44, then decreased progressively with advancing age. In terms of the excess death rate (EDR), excess mortality decreased from an initial 4.3 extra deaths per 1,000 per year to below 2.0 in the age range 15 through 29 years, then increased with advancing age to a maximum of 32 per 1,000 at age 75-79 years.

The experience is much smaller in the group of patients with mild to moderate mental retar-

dation due to Down's Syndrome (Table 4). Because of the death total of only 169, older age groups have been combined with age group 65-69 years. There were differences in the age trend in mortality. The youngest Down's Syndrome patients had the lowest annual EDR, only 1.5 per 1,000, in contrast to the EDR of 4.3 per 1,000 in Table 3. The EDR was fairly constant, about 2.8 per 1,000 per year, from ages 5 through 29 years, then increased with advancing age, but more rapidly and to higher EDR levels, which reached 128 per 1,000 in the oldest age group. There was also an unusual pattern for the mortality ratio, which increased with advancing age from age group 35-39 to 50-54 years, and remained at a very high level, about 500% or more over age 55 years. The progression of the annual mortality rate, q , to very high levels in Down's Syndrome patients is emphasized by the authors of the source article¹ in a series of graphs relating q on a log scale to age on a linear scale from age 35 years up. The relation is linear for both patients with and without Down's Syndrome, but the slope is higher for the patients with Down's Syndrome, consistent with the life table patterns seen in Tables 3 and 4 and described above. This reflects the early onset of Alzheimer's Disease in Down's Syndrome. The slope for patients with Down's Syndrome was such that the annual mortality rate doubled every 6.3 years, in contrast to a doubling time of 9.6 years for all other patients with mild to moderate mental retardation. To see the actual graphs the reader is referred to Figures 1 - 3 in the source article.¹

Observed mortality and excess mortality were generally higher in patients with severe or profound mental retardation, both in non-Down's patients (Tables 5 and 6) and in those with Down's Syndrome (Table 7). The age pattern for all groups may be divided into three differing phases, but with some similarities from one major group to another. In childhood (age 1-14 years), excess mortality was higher in patients without than with Down's Syndrome. Annual EDR ranged downward

from 31 to 11 per 1,000 in severe, and from 42 to 28 per 1,000 in profound retardation in the main bulk of the patients, but in those with Down's Syndrome, the excess rates were 12 down to 7 in the severe subgroup, and 13 per 1,000 in the profound subgroup age 1-19 years (no age breakdown with only 10 deaths age 1-19 years). Observed and excess mortality were higher in children than in adolescents and younger adult patients, tended to decrease with advancing age, and were lower in patients with Down's Syndrome.

During the age period from adolescence to mid-adulthood (about age 15-44 years), minimum EDR values, under 10 per 1,000 per year, prevailed or were attained in all of the major groups, but there was little difference in mortality between those with and without Down's syndrome. Increase in EDR with advancing age commenced at age 45-49 years in the non-Down's patients, and age 40-49 years in those with Down's Syndrome, in whom quinquennial age groups were combined because of their small size. Annual EDR in both severe and profound retardation increased with advancing age at these older ages, and again the increase was at a faster pace and to higher EDR levels in patients with Down's Syndrome. The maximum annual EDR was 84 per 1,000 in the severely retarded, and 66 per 1,000 in the profoundly retarded patients age 60 years and up. In the four age groups age 60 and up in patients without Down's Syndrome annual EDR ranged between 15 and 36 per 1,000, and was somewhat higher in the profoundly than in the severely retarded.

Overall mortality, all ages combined, is summarized for all major groups in Table 8. Mean age has been added in the last column to the right of the life table data. Age-specific differences in excess mortality between patients with and without Down's Syndrome, as described above, are blurred in these results for all ages combined. Differences in EDR are small, and mortality ratios are difficult to interpret because of the difference in age distribution and in mean q' in the patients with

Down's Syndrome. EDR values were almost identical at 6.3 and 6.5 per 1,000 per year, when all degrees of mental retardation were combined. The higher mortality ratio in patients with Down's Syndrome in the mild/moderate and severe retardation groups is mostly due to the lower mean age and lower mean q' values (see Table 8).

Comment

In this study¹ and in previous ones on the same database Strauss and Eyman have emphasized the "snapshot" nature of utilizing observations over a limited period of years to derive a life table by age, without attempting to complete a follow-up study by duration as well as age. In the decennial U.S. Life Tables deaths are counted for three years to increase the accuracy of this count when it is combined with the census data for July 1 of the decennial year.[†] Only two columns of life table data were given in Table 3 of the source article¹: the number of survivors out of 100,000 alive at age 1 year, and the average remaining lifetime (life expectancy), for each of the three classes of mental retardation. Like the Abridged U.S. Life Tables, these derived data are given at 5-year intervals, corresponding to the quinquennial age groups, not for individual years of age. The observed data, E and d , were not published, but are given in Tables 3 - 8, with d' , mortality rates, and the indices of comparative mortality, in the customary Abstract format. Collection of death (and exposure) data over the 6-year observation period from 1985 through 1991 did provide a more accurate estimate of the annual mortality rates for the large number of age groups reported, especially in the smaller series of patients with Down's Syndrome. Examination of the results in Tables 3 - 7 will reveal the differences in mortality patterns with age in the six major groups studied. These are briefly described in the text. For life expectancy data the reader is referred to Table 3 of the source article.¹

Values of EDR similar in magnitude and age pattern were reported in Abstract #1234 of

Volume 2 of the 1990 *Medical Risks* monograph. This was a series of 1,045 patients with Down's Syndrome in England, but only 37 deaths were observed in six complete years of follow-up. There was no differentiation by severity of mental retardation. Annual EDR was about 3 per 1,000 in age groups <15 and 15-34 years, 8.5 per 1,000 in age group 35-54 years, and 122 per 1,000 in patients >55 years (based on 8 deaths in only 57 person-years of exposure). As noted in the text, Down's Syndrome causes an accelerated increase in EDR after age 35 years.

Another feature of Down's Syndrome not examined in the California experience reported here is the common occurrence of congenital heart disease in association with the other characteristics of the Syndrome. In 1970 Fabia and Drolette published a report, "Life Tables up to Age 10 for Mongols with and without Congenital Heart Disease"[^]. Observed annual mortality was much higher in children who also had congenital heart disease, and also much higher in the first year of life than from 1 - 10 years of age. Distribution by sex was nearly equal, but the girls had somewhat higher mortality rates than the boys did. The experience in this Article includes all patients with Down's Syndrome, regardless of any congenital heart disease.

Acknowledgment: Data in Table 1 are reproduced with permission of the authors of Reference 1, and permission of the publishers of the American Journal of Mental Retardation.

Reference

[^] *J Memn Def Res*, 14:235-242, 1997

Table 1

**Demographic, Mental Retardation and Disability Characteristics of
118,653 Clients in the 1986-1991 Registry of the California Department of
Developmental Services**

Demographic		Mental Retardation and Disability	
Category	Distribution	Category	Distribution
Male Sex	56.2%	Mental Retardation	
Female Sex	43.8	None (IQ 70-75% up)	7.6%
		Mild (IQ 50-55% to 70-75%)	32.7
		Moderate (IQ 35-40% to 50-55%)	21.1
White	55.5	Severe (IQ 20-25% to 35-40%)	11.5
Hispanic	21.8	Profound (IQ under 20-25%)	10.8
Black	10.6	Suspect (No IQ test result)	16.3
Asian	3.9		
Other Race	8.2	Disability - Ambulation	
		Cannot walk	18.3
		Walks with assistance	11.2
Age 1-9 years	31.0	Walks unaided	70.2
10-19	20.0	Crawling, standing	
20-29	23.3	Cannot crawl	12.1
30-39	14.5	Crawls	5.7
40-49	6.0	Stands	82.1
50-59	3.0	Rolling, sitting	
60-69	1.6	Cannot roll over	7.5
70-79	0.5	Rolls over	5.0
80 years up	0.1	Sits unaided	87.5
		Hand use	
		No functional use	3.6
Residence		Partial use	20.7
Individual home	66.9	Full use	74.7
Small group home	11.4	Toilet training	
Large group home	6.3	Not trained	24.7
State hospital	6.1	Partially trained	21.0
Health facility	3.4	Fully trained	54.2
Skilled nursing facility	1.0	Feeding tube used	
Other residence	4.9	Yes	2.1
		No	97.9

Adapted from data of Table 1 in Reference 1, with permission of the authors and the publisher.

Table 2

**Attained Age Distribution of Clients in the Registry of the California Department
of Developmental Services, 1986-1991 by Severity of Mental Retardation
and Presence or Absence of Down's Syndrome**

Age	Mild/Mod. Retard.		Severe Retardation		Profound Retardation	
	No Down's	With Down's	No Down's	With Down's	No Down's	With Down's
1- 4 yrs	0.059	0.156	0.245	0.211	0.046	0.011
5- 9	0.108	0.177	0.141	0.088	0.081	0.026
10-14	0.087	0.112	0.090	0.059	0.092	0.041
1-14	0.254	0.445	0.476	0.359	0.219	0.078
15-19	0.107	0.101	0.080	0.067	0.119	0.053
20-24	0.144	0.124	0.091	0.102	0.137	0.117
25-29	0.139	0.111	0.088	0.122	0.140	0.187
30-34	0.112	0.087	0.075	0.112	0.113	0.193
15-34	0.502	0.423	0.334	0.403	0.509	0.550
35-39	0.083	0.057	0.059	0.089	0.076	0.159
40-44	0.056	0.034	0.041	0.065	0.041	0.085
45-49	0.035	0.021	0.024	0.036	0.025	0.047
50-54	0.023	0.012	0.019	0.021	0.017	0.032
35-54	0.197	0.124	0.143	0.211	0.159	0.323
55-59	0.017	0.007	0.014	0.017	0.013	0.024
60-64	0.013	0.004	0.013	(60 up)	0.009	0.019
65-69	0.009	0.001	0.009	0.012	0.006	(65 up)
70-74	0.005	0.0003	0.005	—	0.002	0.007
75-79	0.002	(75 up)	0.003	—	0.001	—
80-84	0.001	0.0002	0.001	—	0.001	—
85 up	0.0004	—	0.001	—	0.0004	—
55 up	0.047	0.013	0.046	0.029	0.032	0.050
Exposure	273,135	39,725	96,296	13,056	68,919	5,766
Mean age	26.0 yrs	19.1	20.8	22.6	27.5	31.8
Tab. age*	40 yrs	24	39	34	40	41.5

*Tabular age in the 1986 U.S. Life Table, total population, matched to the actual mean q' (see text).

Table 3

**Comparative Mortality by Age, Patients with Mild to Moderate
Mental Retardation (IQ from 35-40% to 70-75%), Observed 1986-1991,
Cases of Down's Syndrome Excluded - Data from California State Registry**

Attained Age (years)	Exposure Patient-Yrs.	No. of Deaths		Mortality Ratio	Mean Annual Mortality Rate per 1000		
		Observed	Expected*		Observed	Expected	Excess
	E	d	d'	100d/d'	q	q'	(q - q')
1 - 4	16,049	77	8.32	925%	4.8	0.5	4.3
5 - 9	29,599	81	8.88	910	2.7	0.3	2.4
10 -14	23,986	52	4.40	1,180	2.2	0.2	2.0
15 - 19	29,198	76	26.28	290	2.6	0.9	1.7
20 - 24	39,197	122	41.04	260	3.1	1.2	1.9
25 - 29	37,811	115	45.37	255	3.0	1.2	1.8
30 - 34	30,457	121	45.69	265	4.0	1.5	2.5
35 - 39	22,700	113	40.86	275	5.0	1.8	3.2
40 - 44	15,359	107	39.23	270	7.0	2.6	4.4
45 - 49	9,496	73	35.89	205	7.7	3.8	3.9
50 - 54	6,305	72	39.72	181	11.4	6.3	5.1
55 - 59	4,735	92	45.46	200	19.4	9.6	9.8
60 - 64	3,653	92	56.26	164	25	15.4	10
65 - 69	2,499	92	54.98	167	37	22	15
70 - 74	1,273	83	43.28	192	65	34	31
75 - 79	564	47	28.76	163	83	51	32
80 up	294	32	28.52	133	109	97	18

*Basis of expected deaths: 1986 Abridged U.S. Life Table, total population.

Table 4

**Comparative Mortality by Age, Patients with Down's Syndrome and
Mild to Moderate Mental Retardation (IQ from 35-40% to 70-75%),
Observed 1986-1991 - Data from California State Registry**

Attained Age (years)	Exposure Patient-Yrs. E	No. of Deaths		Mortality Ratio 100d/d'	Mean Annual Mortality Rate per 1000		
		Observed d	Expected* d'		Observed q	Expected q'	Excess (q - q')
1 - 4	5,426	11	2.11	405%	2.0	0.5	1.5
5 - 9	5,950	16	1.78	900	2.7	0.3	2.4
10 - 14	3,844	10	0.78	1,280	2.6	0.2	2.4
15 - 19	3,519	13	3.17	410	3.7	0.9	2.8
20 - 24	4,302	16	5.16	310	3.7	1.2	2.5
25 - 29	3,856	16	4.62	345	4.1	1.2	2.9
30 - 34	3,020	13	4.53	285	4.3	1.5	2.8
35 - 39	1,984	10	3.57	280	5.0	1.8	3.2
40 - 44	1,198	11	3.11	375	9.2	2.6	6.6
45 - 49	736	12	2.80	430	16.3	3.8	12
50 - 54	430	18	2.71	665	42	6.3	36
55 - 59	235	11	2.26	535	47	9.6	37
60 - 64	146	12	2.25	490	82	15.4	67
65 up	64	10	1.78	560	156	28	128

*Basis of expected deaths: 1986 Abridged U.S. Life Table, total population.

Table 5

**Comparative Mortality by Age, Patients with Severe Mental Retardation
(IQ from 20-25% to 35-40%), Observed 1986-1991, Cases of Down's
Syndrome Excluded - Data from California State Registry**

Attained Age (years)	Exposure Patient-Yrs. E	No. of Deaths		Mortality Ratio 100d/d'	Mean Annual Mortality Rate per 1000		
		Observed d	Expected* d'		Observed q	Expected q'	Excess (q - q')
1 - 4	12,683	402	6.34	6,300%	31.6	0.5	31
5 - 9	13,092	158	3.93	4,000	12.1	0.3	12
10 - 14	8,313	93	1.67	5,600	11.3	0.2	11
15 - 19	7,459	51	6.70	760	6.9	0.9	6.0
20 - 24	8,424	53	10.18	520	6.3	1.2	5.1
25 - 29	8,202	46	9.84	465	5.6	1.2	4.4
30 - 34	6,925	48	10.39	460	5.9	1.5	5.4
35 - 39	5,524	40	9.34	405	7.3	1.8	5.5
40 - 44	3,817	31	9.92	310	8.1	2.6	5.5
45 - 49	2,252	27	8.56	315	12.0	3.8	8.2
50 - 54	1,715	29	10.80	270	16.9	6.3	11
55 - 59	1,383	29	12.80	225	22	9.6	12
60 - 64	1,176	42	18.11	230	36	15.4	21
65 - 69	868	33	19.10	173	38	22	16
70 - 74	458	24	15.57	154	52	34	18
75 up	485	42	24.67	121	87	72	15

*Basis of expected deaths: 1986 Abridged U.S. Life Table, total population.

Table 6

**Comparative Mortality by Age, Patients with Profound Mental Retardation
(IQ under 20-25%), Observed 1986-1991, Cases of Down's Syndrome Excluded -
Data from California State Registry**

Attained Age (years)	Exposure Patient-Yrs.	No. of Deaths		Mortality Ratio	Mean Annual Mortality Rate per 1000		
		Observed	Expected*		Observed	Expected	Excess
	E	d	d'	100d/d'	q	q'	(q - q')
1 - 4	3,155	135	1.58	8,500%	43	0.5	42
5 - 9	5,591	175	1.67	10,500	31	0.3	31
10 - 14	5,822	162	1.16	14,000	28	0.2	28
15 - 19	6,322	163	5.69	2,900	26	0.9	25
20 - 24	8,217	142	9.86	1,440	17.3	1.2	16
25 - 29	9,439	143	11.93	1,200	15.2	1.2	14
30 - 34	9,629	113	14.44	785	11.4	1.5	10
35 - 39	7,791	80	14.02	570	11.3	1.8	9.5
40 - 44	5,029	32	13.08	245	6.4	2.6	3.8
45 - 49	2,794	32	10.62	300	11.5	3.8	7.7
50 - 54	1,762	30	11.10	270	17.1	6.3	11
55 - 59	1,161	26	11.15	235	22	9.6	12
60 - 64	929	35	14.31	245	38	15.4	23
65 - 69	652	30	14.34	210	46	22	24
70 - 74	384	27	13.06	205	70	34	36
75 up	234	21	15.59	135	90	67	23

*Basis of expected deaths: 1986 Abridged U.S. Life Table, total population.

Table 7

Comparative Mortality by Age, Patients with Down's Syndrome and Severe or Profound Mental Retardation (IQ under 35-40%), Observed 1986-1991 - Data from California State Registry

Attained Age (years)	Exposure Patient-Yrs. E	No. of Deaths		Mortality Ratio 100d/d'	Mean Annual Mortality Rate per 1000		
		Observed d	Expected* d'		Observed q	Expected q'	Excess (q - q')
Severe Retardation (IQ from 20-25% to 35-40%)							
1 - 4	2,755	51	1.38	3,700%	18.4	0.5	12
5 - 9	1,145	14	0.34	4,100	12.2	0.3	12
10 - 19	1,645	12	0.99	1,200	7.3	0.6	6.7
20 - 29	2,922	7	3.51	200	2.4	1.2	1.2
30 - 39	2,619	20	4.19	475	7.6	1.6	6.0
40 - 49	1,316	19	3.95	480	14.4	3.0	11
50 - 59	501	19	3.91	455	38	7.8	30
60 up	135	14	2.70	520	104	20	84
Profound Retardation (IQ under 20-25%)							
1 - 19	750	10	0.45	2,200%	13.3	0.6	13
20 - 29	1,749	18	2.10	855	10.3	1.2	9.1
30 - 39	2,025	26	3.24	800	12.8	1.6	11
40 - 49	765	11	2.37	465	14.4	3.7	11
50 - 59	425	19	3.32	575	45	7.8	37
60 up	152	13	3.04	430	86	20	66

*Basis of expected deaths: 1986 Abridged U.S. Life Table, total population.

Table 8

**Comparative Mortality and Mean Age, Patients in the Registry of
the California Department of Developmental Services, 1986-1991,
Classified by Down's Syndrome and Severity of Mental Retardation
(Infants under 1 Year Excluded)**

Severity of Retardation	Exposure Patient-Yrs.	No. of Deaths		Mortality Ratio	Mean Annual Mort. Rate per 1000			Mean Age (Yrs.)
		Observed	Expected*		Observed	Expected	Excess	
	E	d	d'	100d/d'	q	q'	(q - q')	x
Without Down's Syndrome								
Mild/Mod.	273,135	1,259	599.6	210%	4.6	2.2	2.4	26.0
Severe	92,696	1,147	188.4	610	12.4	2.0	10	20.8
Profound	68,919	1,285	150.6	855	18.7	2.2	16	27.5
Total	434,750	3,691	938.6	395	8.5	2.2	6.3	25.1
With Down's Syndrome								
Mild/Mod.	34,752	169	41.3	410%	4.9	1.2	3.7	19.1
Severe	13,056	156	21.2	735	11.9	1.6	10	22.6
Profound	5,766	97	14.3	675	16.8	2.5	14	31.8
Total	53,574	422	76.7	550	7.9	1.4	6.5	21.3

*Basis of expected deaths: 1986 Abridged U.S. Life Table, total population.