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Mortality of People With Mental Retardation in California With and Without Down Syndrome, 1986–1991

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Mortality of people with mental retardation receiving services in California was examined. The large population (N = 118,653) enabled us to work directly with mortality rates at specific ages. Up to about age 35, mortality rates of people with Down syndrome were comparable to those of people with mental retardation due to other causes. Subsequently, the increase was much more rapid in the group with Down syndrome. Mortality rates of individuals with Down syndrome doubled every 6.4 years compared to 9.6 years for people without Down syndrome. Life tables were constructed; the remaining life expectancy of a 1-year-old child with Down syndrome with mild/moderate retardation was 55 years and with profound mental retardation, 43 years.

Mortality studies for the mentally retarded population fall into two major classes. The first is focused on the *predictors* of mortality, with investigators aiming to identify the skills and characteristics that are important for survival and to quantify their effects (Eyman, Call, & White, 1991; Strauss, Eyman, & Grossman, in press; see Eyman & Borthwick-Duffy, 1994, for a recent review). This line of research has shown, for example, that mobility (the abilities to roll, sit, crawl, or walk) and self-care skills (e.g., toileting, feeding) are strongly associated with survival. For these types of studies, regression models in a cross-sectional analysis are usually most convenient (Strauss & Kastner, in press; Strauss, Kastner, & White, in press; see also the studies cited previously).

In the second type of study, investigators focus on the *longevity of various cohorts* rather than on the predictors of mortality. Primary tools used in this kind of study are the life table (Keyfitz, 1985; Schoen, 1988) and the closely related survival function (Cox & Oakes, 1984). The *life table* estimates the fraction of the population remaining alive at each age together with the residual expectation of life. Thus, for example, Eyman, Grossman, Chaney, and Call (1990) showed that certain groups of individuals with severe mental retardation had residual life expectations of less than 10 years, regardless of present age. Other studies of this type include Eyman, Grossman, Chaney, and Call (1993), Baird and Sadovnick (1987), and Wolf and Wright (1987). As will be discussed later, life-table analysis is only appropriate for groups whose defining characteristics are at least approximately time-invariant.

A number of studies of the second type have concentrated on mortality rates for individuals with Down syndrome, partly because Down syndrome is perhaps the most common identifiable etiology of mental retardation. A dramatic increase in

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life expectancy in individuals with Down syndrome over the last few decades has been amply documented (see the reviews in Thase, 1982, and Carter & Jancar, 1983), but the high mortality of older persons with Down syndrome has persisted. Some studies have suggested that females with Down syndrome have higher mortality rates than do males, possibly related to gender differences in immunological functioning (Thase, 1982).

The present study is of this second type. Our focus is on the longevity of individuals with Down syndrome compared to persons with mental retardation due to other causes. There are two major differences between our approach and earlier studies: (a) the emphasis is on *age-specific* mortality rates rather than on survival probabilities and life expectancies, and (b) most of the comparisons of interest are controlled for gender or for severity of mental retardation.

The age-specific mortality rates, or *hazard rates*, correspond to the *incidence* of mortality, whereas the survival probability at a given age determines the *prevalence* (Rothman, 1986). These incidence and prevalence measures reveal different features of the survival and mortality process. For long-range planning purposes, survival chances and life expectancies are helpful summaries. For scientific study of the mortality process, however, hazard rates are generally more revealing (Singer & Willett, 1991). The hazard rates, moreover, depend only on mortality at the age in question, whereas the survival function is strongly affected by mortality in the earliest months of life, when diagnoses of mental retardation or Down syndrome are often unreliable. The disadvantage of the hazard rate is that it can only be estimated reliably when a large population is available because otherwise the number of people at risk in a specific age-group will be too small. Similarly, control for gender or severity of mental retardation is, in principle, desirable but not feasible in small populations. Sample size limitations are probably the main reason why most investigators have avoided hazard rates and used little if any stratification. We were able to use these tools because our population base, which included all persons receiving services from the state of California, was exceptionally large, perhaps the largest of any comparable study.

The present study was designed to determine how mortality rates of individuals with Down syndrome change over the lifespan and how these rates compare with those for people with mental retardation due to other causes. In particular, does the well-documented phenomenon of premature aging in individuals with Down syndrome (Zigman, Seltzer, & Silverman, 1994) cause their hazard rates to increase more rapidly with age? Other questions concern gender differences in adult mortality rates and the age at which rates for people with and without Down syndrome begin to diverge. In the present paper we have introduced a simple but effective summary of changing mortality rates, the *doubling time* (i.e., the time taken for the mortality rate to double). We have also presented life tables and compared the results with earlier research.

Method

Instrument

The data were obtained from the Client Development Evaluation Report (California Department, 1978). This instrument is completed approximately annually for anyone receiving services from the state of California and when an individual moves to a new placement. There are more than 100 categories of services, ranging from payments for room and meals to therapies, transportation, and medical care. The Client Developmental Evaluation Report contains a 100-item Diagnostic Element and a 66-item Evaluation Element that include all the variables used here. (See Eyman et al., 1993, for further information.) Reliability of the items in this

report has been investigated elsewhere and judged to be satisfactory (Arias, Ito, & Takagi, 1983; Harris, Eyman, & Mayeda, 1982; Widaman, Stacy, & Borthwick, 1985). Mortality data were obtained from a regularly updated magnetic tape from the California Bureau of Vital Statistics.

Variables

Some analyses carried out here use stratification according to level of mental retardation. Categories were mild (IQ in the range from 50–55 to 70–75), moderate (35–40 to 50–55), severe (20–25 to 35–40), and profound (< 20–25). This grouping is consistent with the American Psychiatric Association's (1994) *Diagnostic and Statistical Manual.* An additional California category, "Suspected MR," was used primarily for those individuals whose level of mental retardation had not been formally assessed. Mortality rates for this group were strikingly similar to those for the severe group at most ages and in the construction of life tables. We have combined the two groups for economy. We do not mean to imply, however, that the two groups were comparable, except with respect to mortality rates. The mild and moderate groups have been combined throughout the study because the mortality rates for the moderate group were only slightly higher than those for the mild group. As may be seen from Table 1, this was the largest group in the California population.

We used other variables only for demographic description. Chief among these are use of tube feeding and three adaptive skills: rolling and sitting, a 9-point scale whose highest level was "Assumes and maintains sitting position independently"; toileting, with highest level "Goes to toilet by self, completes by self"; and eating, with highest level "Uses eating utensils with no spillage." These four items have been demonstrated to be strongly associated with mortality. Finally, presence of Down syndrome was assessed through clinical examination by

Table 1
Demographics for Clients Ages 1 or Over in the Department of Developmental Services Population for 1986–1991 (N = 118,653)

Variable	%
Gender	
Male	56.2
Female	43.8
Ethnicity	
White	55.5
Hispanic	21.8
Black	10.6
Asian	3.9
Other	8.2
Age (in years)	
1–9	31.0
10–19	20.0
20–29	23.3
30–39	14.5
40–49	6.0
50–59	3.0
60–69	1.6
70–79	0.5
80 and over	0.1
Severity of retardation	
Suspected	23.9
Mild	32.7
Moderate	21.1
Severe	11.5
Profound	10.8
Current residence	
Own home	66.9
Small group home	11.4
Large group home	6.3
State hospital	6.1
Health facility	3.4
Skilled nursing	1.0
Other	4.9
Rolling, sitting	
Cannot roll over	7.5
Rolls over	5.0
Sits unaided	87.5
Ambulation	
Can't walk	18.3
Partial walking	11.2
Walks unaided	70.2
Hand use	
No functional use	5.1
Partial use	20.2
Full use	74.7
Arm use	
No functional use	3.6
Partial use	10.7
Full extension	85.7
Creeping, standing	
Cannot crawl	12.1
Crawls	5.7
Stands	82.1
Toilet training	
Not trained	24.7
Partially trained	21.0
Trained	54.2
Use of feeding tube	
No	97.9
Yes	2.1

regional center physicians and recorded on the Client Developmental Evaluation Report.

Sample

Subjects were people with mental retardation who had received services from the California Department of Developmental Services between January 1986 and December 1991. All had been referred to one of the 21 regional centers contracted by the state to serve clients in their catchment area. In all, 118,653 subjects were available for study. Table 1 provides some overall demographics. Table 2 contains comparisons of individuals with and without Down syndrome at three age groups (5 to 9, 25 to 29, and 55 to 59 years of age). Data were stratified by level of mental retardation, gender, use of tube feeding, and the previously mentioned adaptive skills.

Data Analysis

The central quantity in the study was the age-specific mortality rate, or hazard rate, which may roughly be interpreted as the chance that an individual who has survived to a given age will die within the next 12 months (Schoen, 1988). For a specified population, age stratum, and calendar year, we estimated the mortality rate by the *occurrence/exposure ratio.* As is common in demographic practice, the numerator is the number of deaths to individuals in the specified population and age group during the year, and the denominator is the number "exposed" on July 1 of that year. We defined an individual as *exposed* (i.e., alive and in the system), if he or she had at least one Client Developmental Evaluation Report in the 3 years prior to the July 1 date and either died or had another Client Developmental Evaluation Report during the 3 following years. For this and related reasons, we restricted analysis to the period from 1986 to 1991. This yielded a total of some 500,000 person years of exposure.

Preliminary analysis within several subpopulations indicated that there were no major differences or trends in mortality rates for the 6 years (1986–1991), and the rates were therefore pooled. The resulting 6-year "period" is longer than in most

Table 2
Population Profile by Age Group and Level of Mental Retardation (in %)

	5 to 9 years			25 to 29 years			55 to 59 years		
Characteristic/ Group*	Mild/ Moderate	Severe	Profound	Mild/ Moderate	Severe	Profound	Mild/ Moderate	Severe	Profound
Female									
DS	46	41	45	50	41	38	48	36	38
NDS	39	42	46	45	42	44	53	51	53
Able to sit									
DS	98	92	51	99	98	94	93	92	76
NDS	94	68	20	97	91	67	95	91	78
Full ambulation skill									
DS	95	79	33	98	94	78	77	73	57
NDS	83	47	8	91	80	47	82	70	54
Full toileting skill									
DS	41	26	7	91	67	16	76	56	21
NDS	42	13	1	91	53	9	84	56	17
Full eating skill									
DS	31	18	5	86	43	16	68	39	18
NDS	26	9	1	83	58	9	72	41	9
Tube fed									
DS	0.2	1	8	0	0	0	0.8	0.3	6.4
NDS	1	5	26	0.1	0.3	4	0.3	0.3	2

*DS = Down syndrome, NDS = no Down syndrome.

demographic applications, but we considered this greatly outweighed by the corresponding increase in sample size.

Several plots of hazard functions against age were constructed. It proved convenient to fit the Gompertz Law (Cox & Oakes, 1984), according to which the logarithm of the hazard rate increases linearly with age. This relation has been shown to provide a tolerable fit to hazard rates of a number of human populations, roughly in the age range 35 to 75. It proved adequate to fit straight lines to the logarithms of hazard rates using ordinary (least squares) regression, although a case could be made for more complex procedures. A simple and effective summary statistic is *the time taken for the hazard rate to double.* According to the Gompertz Law, the hazard rate at time t is proportional to $exp(bt)$; from this it can be seen that the time taken to double the hazard rate is $ln(2)/b$. One estimate of b, and its standard error, is obtained from the regression of the log-hazard rate on age.

Life tables were constructed using standard methods. Our computer program, using the "mean age at transfer" method, is based on the method described by Schoen (1988). We worked with the standard "abridged" life table, based on 5-year increments after age 5, with one exception: the age group 0 to 12 months was omitted entirely. Inclusion of this age group would have raised procedural issues concerning admission to the California system in the earliest months, together with the unknown reliability of diagnosis of mental retardation in that period. As constructed, the life tables are to be read as applying to a cohort of children who have already reached their first birthday. This does not affect the estimates of remaining life expectancy after age 1, but it needs to be considered when examining the survival function in the life table. These "period life tables" apply to a synthetic cohort subject to the mortality schedule that obtained in the period 1986 to 1991, this schedule assumed constant in the period.

Results

Age-Specific Comparison of Groups

Figures 1, 2, and 3 plot the hazard rates for individuals with Down syndrome and for those with mental retardation due to other causes. The data have been stratified according to severity of mental retardation. The plots are for ages 35 and older. For people between the ages of 5 and 34, there was only a slight variation in rates with age, and rates for the two groups were fairly comparable. The Down syndrome rates were only plotted up to age 64 because beyond that age the surviving population was rather small.

As discussed previously, mortality rates increased at a roughly exponential rate from about 35 years of age onwards (Figures 1, 2, and 3). For this reason the vertical (rate) scale was plotted logarithmically, and it can be seen that the Down syndrome group and non-Down syndrome group plots were then both reasonably linear.

The slopes of the graphs are an important feature; as noted previously, the slope determines the number of years it takes to double the rate. It can be seen that in each of the three figures the Down syndrome group has the steeper slope. Thus, for individuals with mild or moderate mental retardation (Figure 1), the rate for the Down syndrome group doubled every 6.3 years (standard error [SE] = 0.4), whereas the non-Down syndrome rates doubled only every 9.6 years (SE = 0.3). The effect of this difference in slopes is rather striking; for example, at age 60 individuals with Down syndrome were subject to a 7% annual mortality rate compared to only 2.2% for the non-Down syndrome group. This result may be contrasted with that of Sinex (1986), who did not find a significant difference between the slopes for Down syndrome and the general population. We note for comparison that the doubling time in the general population is approximately 8 years.

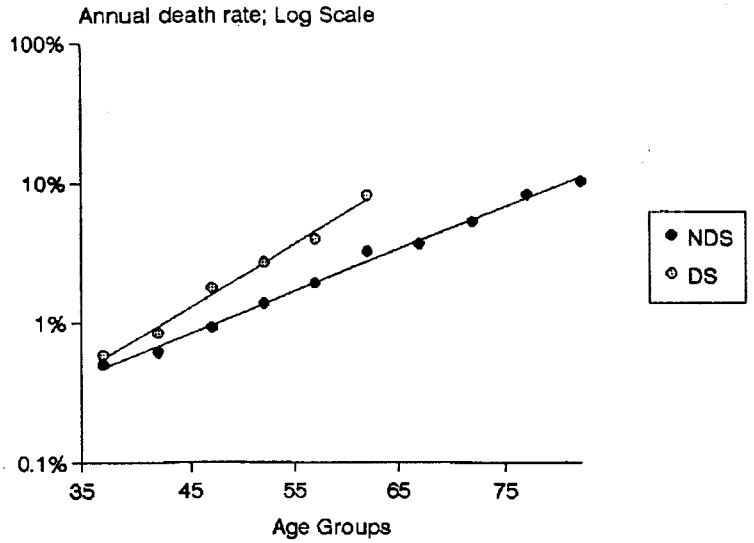

Figure 1. Mortality rates for individuals with (DS) and without (NDS) Down syndrome who had mild/moderate mental retardation and were 35 years of age and older.

Figures 2 and 3 show the corresponding results for the groups of individuals with severe (and suspected) mental retardation and with profound mental retardation. Mortality rates in Figure 2 are consistently higher than in Figure 1, and those in Figure 3 are consistently higher still. Nevertheless, in each case we found a similar pattern: the mortality rate for individuals with Down syndrome grew at a faster (exponential) rate than those without Down syndrome. It is interesting that the onset of divergence between the two groups was around the mid-30s in each case.

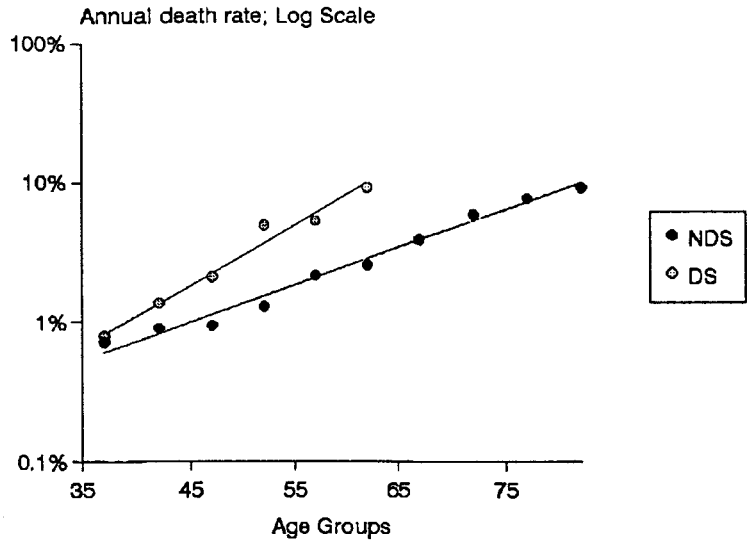

Figure 2. Mortality rates for individuals with (DS) and without (NDS) Down syndrome who had severe mental retardation and were 35 years of age and older.

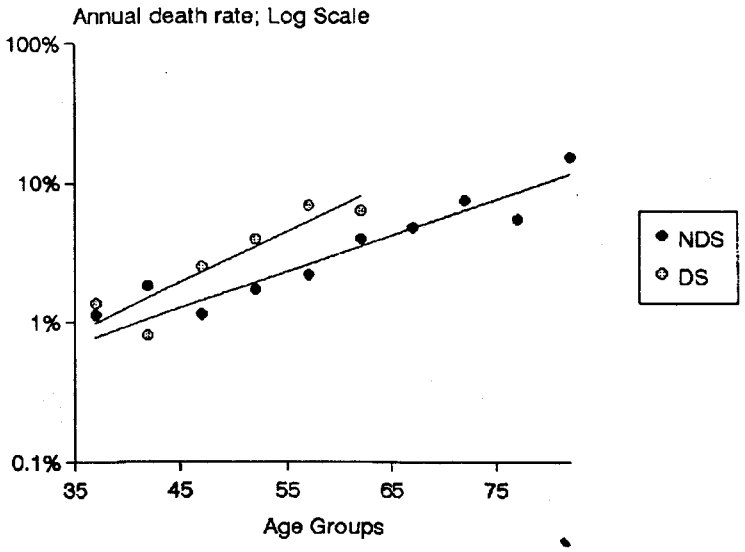

Figure 3. Mortality rates for individuals with (DS) and without (NDS) Down syndrome who had profound mental retardation and were 35 years of age and older.

Gender Comparisons

Among both the Down syndrome and non-Down syndrome groups, there were no systematic gender differences in rates up to about age 35. Beyond that age, in the non-Down syndrome group, the exponential increase was slightly faster for males than for females, resulting in noticeably higher rates for older men than for older women. The difference was marginally significant at the 5% level. Among persons with Down syndrome, there was no suggestion of gender differences, even at the older age groups. Thus, the *relative* mortality risk of females to males was slightly higher for people with Down syndrome than for those without Down syndrome. This finding may be viewed as being consistent with a previously mentioned study (Thase, 1982) on gender differences in Down syndrome.

Life Tables

Table 3 shows the life tables for the non-Down syndrome group, stratified by severity of mental retardation. For brevity, only two of the more important columns of each life table are shown: the survivorship function and the remaining life expectancy. As noted previously, the former is read as applying to a cohort of 100,000 children who all survived to their first birthday. The table clearly shows the decrease in life expectancy with increasing severity of the mental retardation level. In particular, the individuals in the mildly/moderately mentally retarded group have life expectancies only a few years less than the general population. Note that the life expectancies for those in the profoundly mentally retarded group are only about 35 years for young children, but the residual life expectancies decline very slowly over the next few decades. This probably reflects a healthy survivor effect. A similar pattern for a cohort of extremely debilitated children was observed by Eyman et al. (1990).

Table 3 also shows the corresponding results for people with Down syndrome. The same trend is evident with respect to mental retardation level. Life expectancy for individuals with Down syndrome is generally shorter than that for people without Down syndrome, although this is reversed for young children with

Table 3
Life Tables for 1986–1991 California Clients With Mental Retardation (MR) by Severity of Retardation

Group/Age Interval	Mild/moderate MR		Severe MR		Profound MR	
	Of 100,000 born alive	Average remaining lifetime[a]	Of 100,000 born alive	Average remaining lifetime[a]	Of 100,000 born alive	Average remaining lifetime[a]
Non-Down syndrome						
1 to 4	100,000	64.8	100,000	50.7	100,000	35.1
5 to 9	98,104	62.0	88,280	53.2	84,538	37.3
10 to 14	96,771	57.9	83,121	51.3	72,311	38.2
15 to 19	95,728	53.5	78,605	49.2	62,926	38.5
20 to 24	94,490	49.1	75,958	45.8	55,333	38.5
25 to 29	93,030	44.9	73,606	42.2	50,758	26.7
30 to 34	91,626	40.5	71,570	38.3	47,060	24.4
35 to 39	89,823	36.3	69,132	34.6	44,379	31.3
40 to 44	87,613	32.1	66,668	30.7	41,937	28.0
45 to 49	84,613	28.2	64,012	26.9	38,276	25.5
50 to 54	81,402	24.2	60,281	23.4	36,144	21.8
55 to 59	76,872	20.4	55,385	20.3	33,172	18.5
60 to 64	69,739	17.3	49,652	17.3	29,699	15.4
65 to 69	61,458	14.2	41,518	15.2	24,582	13.1
70 to 74	51,043	11.6	34,302	12.8	19,497	10.8
75 to 79	36,753	10.1	26,338	11.0	13,722	9.3
80 to 84	24,138	9.2	17,658	10.2	10,460	6.4
85 & over	13,996	9.1	11,098	9.8	4,743	6.3
Down syndrome						
1 to 4	100,000	55.4	100,000	47.9	100,000	42.0
5 to 9	99,193	51.8	92,923	47.4	93,893	40.6
10 to 14	97,868	47.5	87,413	45.2	84,858	39.6
15 to 19	96,616	43.1	84,100	41.9	79,597	37.1
20 to 24	94,848	38.8	81,250	38.3	75,777	33.9
25 to 29	93,100	34.5	80,042	33.8	71,932	30.5
30 to 34	91,189	30.2	79,288	29.1	68,349	27.0
35 to 39	89, 241	25.8	76,351	25.2	64,476	23.5
40 to 44	87,017	21.4	73,589	21.0	61,397	19.5
45 to 49	83,102	17.2	69,305	17.1	56,827	15.9
50 to 54	76,546	13.4	62,861	13.6	50,288	12.6
55 to 59	62,042	11.0	53,622	10.5	41,448	9.7
60 to 64	48,983	8.2	41,377	7.9	30,517	7.3
65 to 69	32,265	6.2	27,086	5.7	18,769	5.3
70 to 74	16,369	5.0	13,500	3.9	8,631	3.8
75 & over	6,890	3.5	4,199	2.6	2,420	2.7

[a]At beginning of interval.

profound mental retardation. As before, the more severely mentally retarded groups show higher mortality than do the mildly/moderately mentally retarded group in earlier years, but the remaining life expectancy for the survivors who reach middle age is almost as large as for the mildly/moderately retarded group. In previous studies investigators have established that the presence of medical difficulties is more likely in individuals with severe mental retardation than in those with milder levels (Brooke, Eyman, & Geller, 1965; Eyman, Grossman, Tarjan, & Miller, 1987; O'Connor, Justice, & Payne, 1970; Tarjan, Dingman, & Miller, 1960). Our results suggest that those individuals with severe mental retardation who do survive to middle age may be nearly as medically robust as those with much milder disabilities.

A life table (not shown here) was constructed for all persons with Down syndrome, regardless of severity of mental retardation. The results suggest comparison with those of Dupont, Vaeth, and Videbech (1986), who constructed a life table for all persons registered as having Down syndrome in Denmark, 1976–1984. The age-specific residual life expectancies they reported are strikingly similar to ours, agreeing to within about 2 years.

Discussion

We have shown that mortality rates for people with Down syndrome and for people with mental retardation due to other causes are fairly comparable up to about age 35. After age 35 rates for both groups grow approximately exponentially (as they also do in the general population). The rate of increase is substantially higher for people with Down syndrome (doubling every 6.4 ± .4 years) than for the comparison group (doubling every 9.6 ± .3 years). The disparity is probably a reflection of the increased risk in individuals with Down syndrome of early dementia and neuropathology consistent with Alzheimer disease (Zigman et al., 1994).

Our data indicate that the mortality rates in the two groups begin to diverge before age 50. One way to illustrate this is by comparing relative risks (Agresti, 1990). The relative risk was 1.08 for ages 30 to 44, indicating an 8% higher mortality rate for people with Down syndrome than for people with mental retardation due to other causes. By contrast, the relative risk increased to 2.07 for the 44 to 49 age group. The difference was significant at the 1% level (Agresti, 1990). This result may be compared with that of Zigman, Schupf, Sersen, and Silverman (1995), who studied losses of adaptive skills in people with mental retardation with and without Down syndrome and found no substantial differences before age 50.

As we have shown, use of the age-specific mortality rate (hazard rate) can reveal features that are more difficult to observe from a survival analysis or life table. On the other hand it is not feasible to work directly with hazard rates without access to an exceptionally large data source, as was available here.

Our sample was a service population and, thus, not representative of all persons with mental retardation. In particular, the majority of people with mild mental retardation are known not to receive state services (although it is believed that the great majority of those with severe or profound mental retardation are served). On the other hand the population receiving services is a well-defined one that is of considerable practical importance in its own right. It is, for instance, the group of greatest interest for those concerned with fiscal and other planning. (See Widaman, Borthwick-Duffy, and Powers, 1994, for further discussion.)

Like several investigators (e.g., Haveman, Maaskant, & Sturmans, 1989), we compared a group of individuals with Down syndrome to an age-matched group of individuals with undifferentiated etiology. Findings in such studies are more generalizable to the larger population with mental retardation than are studies with no controls (Thase, 1982; Zigman et al., 1994). An even better procedure would be to identify a homogeneous (single-etiology) comparison group for the purpose, but this is generally not feasible.

We note that we made no attempt to study rates or life expectancies for groups of people with specific medical difficulties, such as limited mobility or the need for tube feeding. Instead, we focused only on *fixed* characteristics, such as gender, presence or absence of Down syndrome, and level of mental retardation. The reason is that when group membership depends on time-varying criteria, the period life table no longer describes any (synthetic) cohort of practical interest. There are several statistical approaches to the study of prognosis for groups with time-varying conditions. One of the more promising is the multistate life table (Schoen, 1988), which models the transitions between more than one living state as well as transition to the dead state. A preliminary study using this model has been completed (Strauss, Shavelle, & White, 1995), but much more remains to be done.

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