17. Masana L, Escobar A, Joven J, et al. Treatment of diet-resistant polygenic hypercholesterolaemic patients with a new nicotinate derivative; in vivo and in vitro low density lipoprotein metabolic studies. J Clin Pharmacol 1989; 29:201-6.
18. International Collaborative Study Group. Metabolic epidemiology of plasma cholesterol: mechanisms of variation of plasma cholesterol within populations and between populations. Lancet 1986; 2:991-6.
19. Simo J, Bertran N, Juanpere M, Camps J, Joven J. Evaluación preliminar del analizador automático Monarch 2000. Quim Clin 1989; 8:329-35.
20. Joven J, Vilella E, Costa B, Turner PR, Richart C, Masana L. Concentrations of lipids and apolipoproteins in patients with clinically well-controlled insulin-dependent and non-insulin-dependent diabetes. Clin Chem 1989; 35:813-6.
21. Beaumont JL, Carlson LA, Cooper GR, Fejfar Z, Fredrickson DS, Strasser T. Classification of hyperlipidaemias and hyperlipoproteinaemias. Bull World Health Organ 1970; 43:891-915.
22. Ohta T, Matsuda I. Lipid and apolipoprotein levels in patients with nephrotic syndrome. Clin Chim Acta 1981; 117:133-43.
23. Chopra JS, Mallick NP. Hyperlipoproteinaemia in nephrotic syndrome. Lancet 1971; 1:317-20.
24. Jensen H. Plasma protein and lipid pattern in the nephrotic syndrome. Acta Med Scand 1967; 182:465-73.
25. Alexander JH, Schapel GJ, Edwards KD. Increased incidence of coronary heart disease associated with combined elevation of serum triglyceride and cholesterol concentrations in the nephrotic syndrome in man. Med J Aust 1974; 2:119-22.
26. Appel GB, Blum CB, Chien S, Kunis CL, Appel AS. The hyperlipidemia of the nephrotic syndrome: relation to plasma albumin concentration, oncotic pressure, and viscosity. N Engl J Med 1985; 312:1544-8.
27. Joven J, Rubiés-Prat J, Espinel E, Ras MR, Piera L. High-density lipoproteins in untreated idiopathic nephrotic syndrome without renal failure. Nephrol Dial Transplant 1987; 2:149-53.
28. Kashyap ML, Srivastava LS, Hynd BA, et al. Apolipoprotein CII and lipoprotein lipase in human nephrotic syndrome. Atherosclerosis 1980; 35:29-40.
29. Gitlin D, Cornwell DG, Nakasato D, Oncley JL, Hughes JL Jr, Janeway CA. Studies on the metabolism of plasma proteins in the nephrotic syndrome. II. The lipoproteins. J Clin Invest 1958; 37:172-84.
30. Warwick GL, Caslake MJ, Boulton-Jones JM, Dagen M, Packard CJ, Shepherd J. Low-density lipoprotein metabolism in the nephrotic syndrome. Metabolism 1990; 39:187-92.
31. Allen JC, Baxter JH, Goodman HC. Effects of dextran, polyvinylpyrrolidone and gamma globulin on the hyperlipidemia of experimental nephrosis. J Clin Invest 1961; 40:499-508.

SPECIAL ARTICLE

THE LIFE EXPECTANCY OF PROFOUNDLY HANDICAPPED PEOPLE WITH MENTAL RETARDATION

RICHARD K. EYMAN, PH.D., HERBERT J. GROSSMAN, M.D., ROBERT H. CHANEY, M.D., AND THOMAS L. CALL, M.A.

Abstract *Background.* The life expectancy of people with mental retardation is shorter than that of the general population. Exact estimates of the length of survival for mentally retarded persons at especially high risk are not available, however.

Methods. We collected data on mortality and other factors for 99,543 persons with developmental disabilities, including mental retardation, who received services from the California Department of Developmental Services between March 1984 and October 1987. Three subgroups were selected on the basis of the four characteristics identified in previous studies as the best predictors of mortality among mentally retarded people (deficits in cognitive function, limitations on mobility, incontinence, and inability to eat without assistance). In all three subgroups, the subjects had severe deficits in cognitive function and were incontinent; the subjects in subgroup 1 (n = 1550) were immobile and required tube feeding; those in subgroup 2 (n = 4513) were immobile but could eat with assistance; those in subgroup 3 (n = 997) were mobile (but not ambulatory) and could eat with assistance. Life tables were generated for each of the three subgroups.

Results. Immobile subjects were found to have a much shorter life expectancy than those who could move about. Those who also required tube feeding (subgroup 1) had a very short life expectancy (i.e., four to five additional years). Those who could eat if fed by others (subgroup 2) had an average life expectancy of approximately eight additional years. In contrast, those who were mobile though not ambulatory (subgroup 3) had a life expectancy of about 23 additional years.

Conclusions. Severe mental retardation is associated with a decrease in life expectancy, particularly for those who are immobile. (N Engl J Med 1990; 323:584-9.)

IT has been well established that the life expectancy of children and adults with severe mental retardation is reduced as compared with that of the general population.[1-4] However, no studies have specifically addressed the life expectancy of profoundly handicapped people who are mentally retarded — i.e., those who are unable to care for any of their personal needs.

From the Lanterman Developmental Center, University of California, Riverside (R.K.E., T.L.C.); the Departments of Pediatrics, Neurology, and Psychiatry, University of Michigan Medical School, Ann Arbor (H.J.G.); the School of Medicine, University of California, Los Angeles (R.H.C.); and the School of Medicine, Loma Linda University, Loma Linda, Calif. (R.H.C.). Address reprint requests to Dr. Eyman at the U.C. Riverside Research Group at Lanterman Developmental Center, P.O. Box 100-R, Pomona, CA 91769.

Supported in part by grants (HD22953 and HD21056) from the National Institute of Child Health and Human Development.

The clinical practice of most physicians does not usually include treating mentally retarded persons, yet most handicapped children with mental retardation now survive the first years of life and live with their families in the community, where they will need medical treatment and guidance.

A number of previous studies have addressed the association of handicapping conditions with survival among mentally retarded people.[2,3,5-20] The most common predictors of early death are the severity of retardation and deficits in mobility, toileting skills, and self-feeding. The presence or absence of seizures and of cerebral palsy does not generally add much additional predictive power.[6] The best single predictor of early death is reduced mobility,[3,6,7,10,12,16,20] followed

by poor feeding ability in children and lack of toilet training in older persons.[6]

The purpose of our study was to provide estimates of life expectancy for people who are severely mentally retarded because of brain damage.

METHODS

The persons we studied had all received services from the California Department of Developmental Services between March 1984 and October 1987. All had decreased cognitive function due to prenatal, perinatal, or postnatal insult, the causes of which included infection and intoxication; physical trauma or hypoxia; disorders of metabolism, growth, or nutrition (including cerebral lipidosis, hepatocellular degeneration, hypothyroidism, and phenylketonuria); gross brain disease (including infantile diffuse sclerosis, neurofibromatosis, progressive subcortical encephalopathy, spinal sclerosis, and tuberous sclerosis); unknown prenatal influences; chromosomal abnormalities; prematurity; major psychiatric disorders; environmental deprivations; and unspecified disorders.

The degree of retardation was determined on the basis of the results of psychological evaluation; the categories we used were consistent with the classification systems in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, third edition, revised (DSM-III-R)[21] and the manual *Classification in Mental Retardation* of the American Association on Mental Retardation[22] (profound, intelligence quotient [IQ] less than 20 to 25; severe, IQ between 20 to 25 and 35 to 40; moderate, IQ between 35 to 40 and 50 to 55; mild, IQ between 50 to 55 and 70 to 75). Both the American Psychiatric Association and the American Association on Mental Retardation use IQ ranges to indicate that clinical judgment should be used in determining degrees of mental retardation on the basis of information about intellectual functioning from all available sources. An additional category, "suspected retardation," is used in California (and therefore in this study) to identify persons who are thought to be mentally retarded but for whom a degree of retardation has not yet been determined because they are untestable. The majority of such persons included in this study were young and living with their natural families, and they had other profound handicaps and health problems in addition to mental retardation. Although most would eventually be assigned a mental-retardation level by the state, their immediate need for services precluded prompt psychometric evaluation. Moreover, the state evaluation teams are often uncertain about the degree of retardation in the presence of other profound handicaps.

In addition to assessing their degree of retardation, we also evaluated the subjects in our sample according to the following characteristics:

Ambulation. Those who were totally unable to walk were compared with those with at least some ability to walk.

Mobility. Subjects were designated as immobile if they lacked the ability to crawl, creep, or "scoot" (propel themselves on the stomach). Some subjects classified as immobile could be seated in a wheelchair with support or could roll over. Immobile subjects were compared with those classified as mobile. This category was more restrictive than ambulation, since some nonambulatory persons could still crawl, creep, or scoot.

Toileting skills. Persons who were not toilet trained were compared with those who had some ability to take care of their toileting needs.

Eating skills. Persons who had to be fed completely by others or who attempted only finger feeding were classified as unable to feed themselves.

Tube feeding. Feeding by means of nasogastric or gastrostomy tubes was provided for patients who were unable to swallow or who frequently aspirated food.

Subjects with cerebral palsy were defined as those who had impaired voluntary movement as a result of prenatal or perinatal brain damage. Subjects with epilepsy were classified according to the type and frequency of seizures, as well as the need for medication for epilepsy. For the purpose of this study, subjects were subdivided into two groups: those with a history of seizures and those who had never had seizures.

All these variables have been found in previous studies to predict mortality among retarded people.[3,5-13] The cause of mental retardation, although related to mortality, is often indeterminate[23] and does not predict early death as well as the variables listed above.[3,7]

Sample

The subjects were drawn from among 99,543 persons with developmental disabilities, including documented or suspected mental retardation, who received services from the California Department of Developmental Services between March 1984 and October 1987. Their ages ranged from less than 1 month to 92 years. This group included nearly 100 percent of the children (defined by Public Law 94-142 as persons under 22 years of age) with profound and severe mental retardation listed in a registry established by the state in order to provide mandated educational opportunities for all children regardless of their degree of handicap. The study group also included approximately 50 percent of the children with moderate mental retardation and 10 percent of the children with mild mental retardation known to school districts in California. Mentally retarded adults were identified either because they continued to receive services first provided when they were children or because their aging parents were concerned about the care of their children in future years and requested services for them.[24] The subjects lived in a variety of places — including their own homes (60.3 percent), state and private institutions, health care facilities, and community care homes.

Within the group of 99,543 persons who received services from the department, we examined three mutually exclusive subgroups with different combinations of risk factors. The members of all three subgroups had profound, severe, or suspected mental retardation and were incontinent. Subgroup 1 (n = 1550) consisted of all such persons in the total sample who were immobile and required tube feeding. Subgroup 2 (n = 4513) consisted of persons who were immobile but were able to take food if it was fed to them by others. Subgroup 3 (n = 997) comprised persons who were able to move about voluntarily, though not to walk, and who were able to take food from others. These three subgroups were chosen because they represented the most common combinations of characteristics in persons with profound handicaps and because they included the characteristics that have been found to be the best predictors of early death.

Collection of Data

We obtained information on the characteristics of the retarded persons in this study from the subjects' Client Development Evaluation Reports.[25] Such a report is submitted to the Department of Developmental Services once a year and whenever the retarded person moves to a new placement. Local agencies use the Client Development Evaluation Report to report residential placement and diagnostic and health information to the state. In addition, the report contains a 66-item measure of adaptive behavior. From these reports, we obtained information on sex, race or ethnic group, degree of retardation, age, cause of mental retardation, toileting and eating skills, degree of ambulation and mobility, presence of seizure disorders, and other characteristics. The reliability and validity of the Client Development Evaluation Report have previously been found to be satisfactory.[26-29]

Deaths are reported to the Department of Developmental Services by the 21 regional centers in California. All deaths that occurred between March 1984 and October 1987 were included in our analysis of the data. The population at risk (i.e., the number of persons who received services from the department) was approximately 70,000 each year, and roughly 650 deaths were reported per year. Over the 3½-year study period, the population at risk totaled 99,543. The causes of death for the subjects who resided in the community (over 90 percent of the total sample) were not available.

Statistical Analysis

In calculating life expectancy, we used a "period" or "current" life table, which estimates the average number of additional years

of life remaining once a person has survived to the age of interest.[30] Such a life table is interpreted "as depicting the lifetime mortality experience of a single cohort of newborn babies who are subject to age specific mortality rates on which the table is based."[30] Moreover, the number of persons living (out of the 100,000 assumed initially) at a particular age provides a probability estimate of the number of persons who will survive to the age of interest. The observed death rates were included and represent the number of deaths for a specific age interval divided by the number of people in that age interval. Intermediate calculations produced by the life-table function relating to survivorship and person-years lived have been deleted. The abbreviated tables presented do not provide all the information needed to link the observed death rates to the values in the columns designated as "Number Dying during Interval" in Tables 3, 4, and 5. The advantage of the period life table is that it does not require an extended period to estimate the age by which 50 percent of a given birth cohort will have died. An abridged life table provides life-table functions for 5-year or 10-year age intervals rather than for every year. The specific life-table algorithm used in this paper was based on the work of Schoen.[31]

We were able to check the accuracy of the life expectancy estimated for subgroups 1 and 2 on the basis of the period life table by applying proportional-hazards functions[32,33] to additional longitudinal data available over a 10-year period (1980 to 1990) for 2217 persons identical to and including those in subgroup 1 and 5053 identical to and including those in subgroup 2. A proportional-hazards function can be used to estimate survival curves (a curve depicting the proportion of a group that survives during the follow-up period) with use of such longitudinal data. This analysis was undertaken to investigate the reliability of the period-life-table results.

Results

Tables 1 and 2 show the total group of 99,543 persons and the three subgroups according to sex, age, degree of retardation, presence or absence of seizures, presence or absence of cerebral palsy, race or ethnic group, and cause of mental retardation. The three subgroups include all the subjects who met the criteria for inclusion (see Methods). Subgroup 1, composed of the most seriously handicapped persons, had the highest crude mortality rate during the 3½-year period. The ages of the persons in this subgroup ranged from less than 1 month to 61 years, with most clustered in the younger age groups. The subjects in subgroup 2 were also severely handicapped, although they did not require tube feeding. The ages in this subgroup ranged from less than 1 month to 73 years, with most of the subjects being children. The subjects in subgroup 3 were the least handicapped of the subgroups studied. Most of these subjects were young children, but some were older — as reflected by the age range from less than 1 month to 80 years. The causes of mental retardation among persons admitted to institutions in California suggest that the greatest number of older profoundly handicapped persons had severe brain damage due to automobile accidents, near-drowning, or other types of accidents as adults. The three subgroups were mutually exclusive and accounted for 7060 of the entire group of 99,543 persons with developmental disabilities who were receiving services in California.

As Table 1 shows, there were large differences between the group as a whole and the three subgroups in terms of the degree of retardation and age. Specifically, the subgroups comprised a greater number of younger and more severely retarded persons in whom the prevalence of seizures and cerebral palsy was higher than in the total sample. The differences between the subgroups with regard to sex and race or ethnic group were small. The average age of the subjects in the group as a whole was higher than in the subgroups, largely because of the higher mortality rates among the high-risk persons in the subgroups.

Table 1. Selected Characteristics of Developmentally Disabled Persons Receiving Services in California and Subgroups with Severe Brain Damage.*

Characteristic	Total Group	Subgroup 1	Subgroup 2	Subgroup 3
No.	99,543	1550	4513	997
Sex (%)				
Male	56.1	51.8	51.2	56.4
Female	43.9	48.2	48.8	43.6
Mental-retardation level (%)				
Unknown	0.3	0.0	0.0	0.0
Mild-to-moderate	66.7	0.0	0.0	0.0
Severe	13.0	10.3	16.1	20.1
Profound	13.1	70.8	55.1	41.8
Suspected	6.9	18.9	28.8	38.1
Age (%)				
0–4 years	14.2	35.6	37.1	43.2
5–9	11.9	18.9	15.2	19.0
10–14	8.8	10.1	9.8	9.5
15–19	10.5	12.0	7.4	6.3
20–24	13.4	8.6	6.9	4.9
25–29	12.1	5.3	7.1	5.2
30–34	9.5	4.0	6.1	5.2
35–39	6.9	1.9	4.7	3.6
40–49	6.8	2.0	3.4	2.1
≥50	5.9	1.6	2.3	1.0
Race or ethnic group (%)				
White	59.3	56.0	52.2	50.6
Black	10.4	8.6	7.2	10.2
Hispanic	20.0	24.6	27.6	25.3
Asian	3.3	3.1	3.9	4.0
Mixed	2.8	3.2	4.1	4.9
Other	4.2	4.5	5.0	5.0
Seizures (%)				
No	77.1	37.0	47.3	56.0
Yes	13.4	43.6	35.2	27.7
Suspected	9.5	19.4	17.5	16.3
Cerebral palsy (%)				
No	78.5	35.8	36.6	40.0
Yes	21.5	64.2	63.4	60.0
Type of residence (%)				
Own home	60.3	34.5	53.0	65.6
Small-group home	13.5	5.2	7.0	9.8
Community board and care	7.5	1.2	2.0	1.7
Skilled nursing facility	1.0	4.6	3.3	1.8
Intermediate health care facility	4.4	5.3	12.7	8.8
State institution	7.7	45.0	20.8	10.8
Other†	5.6	4.2	1.2	1.5
Serious medical condition (%)‡				
None	64.1	25.4	47.0	53.5
One or more	35.9	74.6	53.0	46.5
Crude death rate (per 1000)	29	245	113	35

*Subgroup 1 was made up of persons with profound, severe, or suspected mental retardation who were immobile and incontinent and required tube feeding; subgroup 2, of persons with profound, severe, or suspected mental retardation who were immobile and incontinent and who could be fed by others; and subgroup 3, of persons with profound, severe, or suspected mental retardation who were mobile, though not ambulatory, and incontinent and who could be fed by others.

†"Other" includes private institutions, rehabilitation facilities, and independent or semi-independent living situations.

‡Diabetes, heart disease, chronic respiratory infection, or hepatitis.

Table 2. Diagnostic Categories of Persons in the Total Sample and Three Subgroups.

Diagnostic Category*	Total Group	Subgroup 1	Subgroup 2	Subgroup 3
No.	99,543	1550	4513	997
		percent		
Following infections and intoxications	13.3	14.3	14.8	11.5
Following trauma or physical agents	7.3	27.8	16.2	13.2
With disorders of metabolism, growth, or nutrition	1.4	2.6	2.5	1.8
Associated with gross brain disease (postnatal)	2.6	10.3	5.6	4.9
Associated with diseases and conditions due to (unknown) prenatal influence	7.3	20.1	19.5	14.5
With chromosomal abnormalities	13.0	4.7	10.0	10.8
Associated with prematurity	2.2	4.1	3.3	3.9
Following major psychiatric disorder	1.0	0.1	0.2	0.2
With psychosocial (environmental) deprivation	1.4	0.1	0.2	0.3
Other and unspecified	39.2	11.6	21.1	25.9
Unknown	11.3	4.3	6.6	13.0

*Categories are the *International Classification of Diseases* categories for mental retardation.[34]

Table 1 also shows that the type of residence and the prevalence of serious medical conditions varied in a predictable way with the handicaps of these persons. The state of California provides residential and other services for most medically fragile people (subgroup 1). More people in subgroup 1 than in the other two subgroups had serious medical conditions.

Table 2 shows the causes of mental retardation in the group as a whole and in the subgroups. The proportion of subjects in the three subgroups who had mental retardation caused by trauma or physical agents, gross brain disease, or diseases and conditions due to unknown prenatal influences was greater than that in the total sample. "Other and unspecified" causes were the most common among the group as a whole and accounted for 12 to 26 percent of the subjects in the three subgroups.

Table 3 is a life-expectancy table for subgroup 1 (1550 subjects), the most medically fragile group. As the table shows, children or adults with profound, severe, or suspected retardation who were immobile, not toilet-trained, and tube-fed had a very low life expectancy and usually died within four years. Close to 80 percent of the original hypothetical cohort of 100,000 children with the stated problems would be expected to have died by 10 years of age. However, if a child did survive to 15 years of age, his or her life expectancy would still be about 4.5 more years. After 35 years of age, the estimates of survival are based on very few survivors. On the basis of a subset of 975 subjects, the life expectancy of those with seizures or suspected seizures was similar to that of the subgroup as a whole.

Table 4 shows the life expectancy of the subgroup of people who could take food if fed by others but who, like those in subgroup 1, were profoundly or severely retarded, immobile, and not toilet trained (subgroup 2). The estimates in Table 4 are based on a larger number of persons (n = 4513) and show a longer life expectancy than that for subgroup 1. For example, a four-year-old child would be expected to live about eight more years, on the average. Still, over 90 percent of these people would be expected to have died by 20 years of age. Although these life-expectancy estimates are higher than those for similar children who require tube feeding, the overall outlook for survival is nevertheless poor. About 2400 persons in this subgroup also had or were suspected to have seizures. For subjects with seizures, the survival estimates were about ½ year shorter up to the age of 20; thereafter, the estimates were nearly identical.

Another combination of characteristics that is moderately common among persons with profound handicaps should be considered. Persons with this profile have most of the handicaps mentioned previously but can move about somewhat (crawl, creep, or scoot), although they are still not ambulatory. Table 5 shows the life-expectancy estimates for such persons (subgroup 3). The survival estimates are much better than those for persons who are completely immobile. For example, a four-year-old child with the above characteristics would have an average of 23 additional years of life. Moreover, about half of such persons would be expected to survive to at least 20 years of age. Thus, the ability to move about somewhat has a considerable influence on survival.

Sixty to 64 percent of the children in the three sub-

Table 3. Life Table for 1550 Persons Receiving Services from the California Department of Developmental Services from 1984 through 1987 Who Had Profound, Severe, or Suspected Mental Retardation, Were Immobile, Were Not Toilet Trained, and Required Tube Feeding (Subgroup 1).

Age Interval	Observed Death Rate	No. Living at Beginning of Interval (per 100,000)*	No. Dying during Interval (per 100,000)*	Average No. of Years of Life Remaining†
yr				
<1	0.45	100,000	41,354	3.3
1–4	0.27	58,646	37,623	4.1
5–9	0.21	21,022	13,755	4.8
10–14	0.20	7,268	4,734	4.8
15–19	0.22	2,534	1,737	4.5
20–24	0.25	797	583	4.4
25–29	0.22	214	144	5.4
30–34	0.18	70	41	7.0
35–39	0.07	29	8	8.9
40–44	0.19	20	13	6.4
45–49	0.14	8	4	8.1
50–54	0.00	4	0	9.2
55–59	0.20	4	3	4.2
≥60	0.39	1	1	2.6

*Of a hypothetical cohort of 100,000 children born alive. Values have been rounded.

†The average number of years of life remaining for a person who survives to the beginning of the age interval.

Table 4. Life Table for 4513 Persons Receiving Services from the California Department of Developmental Services from 1984 through 1987 Who Had Profound, Severe, or Suspected Mental Retardation, Were Immobile, Were Not Toilet Trained, and Were Able to Be Fed by Others (Subgroup 2).

Age Interval	Observed Death Rate	No. Living at Beginning of Interval (per 100,000)*	No. Dying during Interval (per 100,000)*	Average No. of Years of Life Remaining†
yr				
<1	0.07	100,000	7,014	8.5
1–4	0.13	92,986	35,891	8.1
5–9	0.13	57,096	26,945	8.3
10–14	0.11	30,150	13,057	8.7
15–19	0.13	17,093	8,090	8.5
20–24	0.14	9,003	4,455	9.1
25–29	0.11	4,548	1,849	10.8
30–34	0.05	2,699	644	11.6
35–39	0.07	2,055	588	9.5
40–44	0.13	1,467	687	7.3
45–49	0.12	780	356	6.7
50–54	0.17	424	249	5.3
55–59	0.20	175	113	4.6
60–64	0.26	62	47	3.9
≥65	0.25	15	15	4.0

*Of a hypothetical cohort of 100,000 children born alive. Values have been rounded.

†The average number of years of life remaining for a person who survives to the beginning of the age interval.

groups had cerebral palsy. In each case, the life expectancy of those with cerebral palsy was similar to that of the subgroup as a whole.

Discussion

We estimated life expectancy for the subgroups of persons with the most common combinations of profound handicaps. These estimates demonstrate a shortened life expectancy.

The reliability of the data on individual characteristics, deaths, and other variables and the life-table estimates were investigated separately. The reliability and validity of the data on individual characteristics have been found to be satisfactory, as reported elsewhere.[25-29] Moreover, the California Department of Developmental Services periodically verifies the accuracy of this information, since it is used to reimburse service providers. The life-table estimates of life expectancy (shown in Tables 3 through 5) were verified independently by checking against data on persons being served by the department and records of deaths between 1980 to 1990. Proportional-hazards functions were computed for groups that included those in subgroups 1 and 2. Since these subgroups were found to have a life expectancy of less than 10 years, it was possible to determine when 50 percent of a particular age group had died and compare that age with the average estimated survival times. The median survival ages defined by the proportional-hazards functions for the period from 1980 to 1990 were within one year of the life-table estimates shown in Tables 3 and 4. Hence, a longitudinal analysis of survival over a 10-year period verified the relatively short life expectancies we estimated (Tables 3 and 4). The subjects in subgroup 3 (Table 5) had a life expectancy that extended beyond our 10-year follow-up period. Thus, their survival could not be verified with this technique.

Several studies have shown the importance of mobility to survival,[6,8,10,12,13] and others have shown the importance of toileting skills, feeding skills, and the presence or absence of seizures.[3,6] The results of our study verified the importance of these variables to survival. Once mobility, toileting skills, and feeding skills were included with the degree of retardation in the estimates of life expectancy, however, additional variables such as the presence or absence of seizures and cerebral palsy did not alter the prediction of survival times. This finding is consistent with those of studies that were primarily concerned with predicting mortality.[6,7]

The association with life expectancy of any degree of mobility, such as the ability to crawl, is pronounced. Of all of the variables we studied, mobility was the best predictor of survival — a finding that is consistent with those of previous studies.[6,12] Roboz[12] noted that the retarded people with the highest mortality were those with extensive brain damage who were almost completely bedridden or needed wheelchairs. Our findings confirmed that the need for tube feeding is also a strong predictor of mortality.

Although we were unable to determine the cause of death for most of the persons included in our study, the causes of death for similar persons are well documented in the literature.[1,13,14-19] The most common cause of death among mentally retarded people has

Table 5. Life Table for 997 Persons Receiving Services from the California Department of Developmental Services from 1984 through 1987 Who Had Profound, Severe, or Suspected Mental Retardation, Were Ambulatory, Were Not Toilet Trained, and Were Able to Be Fed by Others (Subgroup 3).

Age Interval	Observed Death Rate	No. Living at Beginning of Interval (per 100,000)*	No. Dying during Interval (per 100,000)*	Average No. of Years of Life Remaining†
yr				
<1	0.03	100,000	2,446	23.8
1–4	0.02	97,554	8,280	23.4
5–9	0.06	89,274	22,691	21.4
10–14	0.03	66,583	9,802	22.9
15–19	0.03	56,781	8,479	21.5
20–24	0.04	48,302	9,088	19.8
25–29	0.04	39,214	6,918	18.8
30–34	0.00	32,297	0	17.4
35–39	0.03	32,297	4,329	12.4
40–44	0.15	27,968	14,835	8.7
≥45	0.09	13,133	13,133	11.0

*Of a hypothetical cohort of 100,000 children born alive. Values have been rounded.

†The average number of years of life remaining for a person who survives to the beginning of the age interval.

consistently been found to be respiratory disease in general and pneumonia in particular. Roboz[12] was emphatic about the contribution of immobility to death from respiratory infections. Higashi et al.[20] followed patients in a persistent vegetative state for five years and found that 50 percent died within two years, the majority of them from pulmonary infection. The more severe the degree of retardation and the associated handicaps, the more likely it was that death would be due to respiratory infections.[13,16] Finally, Eyman et al. found that "severe deficits of the central nervous system are usually associated with (1) swallowing difficulties; (2) disturbances in coughing and gagging; and (3) shallow respiration. The latter problem is associated with decreased vital capacity of the lung. All of these problems are frequently encountered in profoundly retarded individuals who are nonambulatory."[3] The present study adds further evidence that the prognosis for persons with such severe handicaps is poor.

References

1. Baird PA, Sadovnick AD. Life expectancy in Down syndrome. J Pediatr 1987; 110:849-54.
2. Balakrishnan TR, Wolf LC. Life expectancy of mentally retarded persons in Canadian institutions. Am J Ment Defic 1976; 80:650-62
3. Eyman RK, Grossman HJ, Tarjan G, Miller CR. Life expectancy and mental retardation: a longitudinal study in a state residential facility. Monographs of the American Association on Mental Deficiency, 7. Washington, D.C.: American Association on Mental Deficiency, 1987.
4. Dayton NA, Doering CR, Hilferty MM, Maher HC, Dolan HH. Mortality and expectation of life in mental deficiency in Massachusetts: analysis of the fourteen-year period 1917-1930. N Engl J Med 1932; 206:555-70, 616-31.
5. Chaney RH, Eyman RK, Miller CR. The relationship of congenital heart disease and respiratory infection mortality in patients with Down's syndrome. J Ment Defic Res 1985; 29:23-7.
6. Eyman RK, Borthwick-Duffy SA, Call TL, White JF. Prediction of mortality in community and institutional settings. J Ment Defic Res 1988; 32:203-13.
7. Eyman RK, Call TL, White JF. Mortality of elderly mentally retarded persons in California. J Appl Gerontol 1989; 8:203-15.
8. Eyman RK, Chaney RH, Givens CA, Lopez EG, Lee CK. Medical conditions underlying increasing mortality in institutionalized persons with mental retardation. Ment Retard 1986; 24:301-6.
9. Heaton-Ward WA. The life expectation of mentally subnormal patients in hospital. Br J Psychiatry 1968; 114:1591-2.
10. Miller C, Eyman R. Hospital and community mortality rates among the retarded. J Ment Defic Res 1978; 22:137-45.
11. Miller CR, Sabagh G, Dingman HF. Latent class analysis and differential mortality. J Am Stat Assoc 1962; 57:430-8.
12. Roboz P. Mortality rate in institutionalized mentally retarded children. Med J Aust 1972; 1:218-21.
13. Tarjan G, Brooke CE, Eyman RK, Suyeyasu A, Miller CR. Mortality and cause of death in a hospital for the mentally retarded. Am J Public Health 1968; 58:1891-900.
14. Carter G, Jancar J. Mortality in the mentally handicapped: a 50 year survey at the Stoke Park group of hospitals (1930–1980). J Ment Defic Res 1983; 27:143-56.
15. Chaney RH, Eyman RK, Givens CA, Broderick J, Watkins G. Current mortality among institutionalized mentally retarded individuals: a comparison with an earlier study. J Calif Assoc Postsecondary Educ Disabled 1984; 1:27-33.
16. Chaney RH, Eyman RK, Miller CR. Comparison of respiratory mortality in the profoundly mentally retarded and in the less retarded. J Ment Defic Res 1979; 23:1-7.
17. Blisard KS, Martin C, Brown GW, Smialek JE, Davis LE, McFeeley PJ. Causes of death of patients in an institution for the developmentally disabled. J Forensic Sci 1988; 33:1457-62.
18. Øster J, Mikkelsen M, Nielsen A. The mortality and causes of death in patients with Down's Syndrome (mongolism). In: Øster J, ed. International Copenhagen Congress on the Scientific Study of Mental Retardation, Copenhagen, Denmark, August 8–14, 1964: proceedings. Vol. 1. Copenhagen: Det Berlingske Bogtrykkeri, 1964:231-5.
19. Richards BW, Sylvester PE. Mortality trends in mental deficiency institutions. J Ment Defic Res 1969; 13:276-92.
20. Higashi K, Hatano M, Abiko S, et al. Five-year follow-up study of patients with persistent vegetative state. J Neurol Neurosurg Psychiatry 1981; 44:552-4.
21. Diagnostic and statistical manual of mental disorders: DSM-III-R. 3rd ed. rev. Washington, D.C.: American Psychiatric Association, 1987.
22. Grossman HJ, ed. Classification in mental retardation. Washington, D.C.: American Association on Mental Deficiency, 1983:11-26.
23. Chaney RH, Eyman RK. Etiology of mental retardation: clinical vs. neuroanatomic diagnosis. Ment Retard 1982; 20:123-7.
24. Seligman M, ed. The family with a handicapped child: understanding and treatment. Orlando, Fla.: Grune & Stratton, 1983.
25. Client development evaluation report (CDER). Sacramento: California Department of Developmental Services, 1978.
26. Arias M, Ito E, Takagi N. Validation of the client development evaluation record. In: Ford T, Silverstein AB, Fluharty AL, eds. Pacific state archives VII. Pomona: University of California at Los Angeles Developmental Disabilities Immersion Program, 1983.
27. Harris CW, Eyman RK, Mayeda T. An interrater reliability study of the client development evaluation report. Final report to the California Department of Developmental Services, 1982.
28. Widaman KF. Interrater reliability of adaptive behavior assessments: item and factor levels. Presented at the Annual Meeting of the American Psychological Association, Toronto, August 24–28, 1984.
29. Widaman KF, Stacy AW, Borthwick SA. Multitrait-multimethod of evaluating adaptive and maladaptive behavior of mentally retarded people. Presented at the Annual Meeting of the American Association on Mental Deficiency, Philadelphia, May 27–31, 1985.
30. Shryock HS, Siegel JS, et al. The methods and materials of demography. New York: Academic Press, 1976.
31. Schoen R. Modeling multigroup populations. New York: Plenum Press, 1988.
32. BMDP statistical software manual. Vol. 2. Los Angeles: BMDP Statistical Software, 1988.
33. Cox DR. Regression models and life-tables. J R Stat Soc [B] 1972; 34:187-220.
34. ICD-8, International Classification of Diseases, 8th rev. Geneva: World Health Organization, 1968.