 Vol. 36, No. 5, 360–371, October 1998

Mortality of Adults With Developmental Disabilities Living in California Institutions and Community Care, 1985–1994

David Strauss, Theodore A. Kastner, and Robert Shavelle

Abstract: We compared risk factor-adjusted mortality for California adults with developmental disabilities based on 22,576 adults receiving services in California, 1985–1994. Mortality rates were adjusted for factors such as age and level of functioning. Risk factor-adjusted mortality was 72% higher in community care than in institutions. The mortality pattern over the years 1993–1994, which had not previously been studied, was comparable to that of 1985–1992. The substantially increased risk in community care suggests that community settings may be less effective in preventing mortality in this population.

There is a continuous line of research over the past quarter century on the mortality of people with mental retardation and other developmental disabilities, much of it carried out at the University of California, Riverside (Ashwal, Eyman, & Call, 1994; Carter & Jancar, 1983; Eyman, Borthwick, Call, & White, 1988; Eyman, Borthwick, & Tarjan, 1984; Eyman, Grossman, Chaney, & Call, 1990, 1993a, 1993b; Thase, 1982). Most of the literature has been focused on institutionalized populations (Carter & Jancar, 1983; Eyman et al., 1990, 1993a; Thase, 1982); far fewer investigators have directly compared mortality in institutional populations with that in community populations (McCurley, McKay, & Scally, 1972; Miller & Eyman, 1979; Silverman, Zigman, & Silver, 1992). Furthermore, these comparisons include little if any correction for the heterogeneity of populations, partly because until recently institutional and community-based populations had similar risk profiles.

The substantial movement of people with developmental disabilities into community care has significantly altered the demographic composition of institutional and community-based groups. In 1967, some 195,000 people with developmental disabilities lived in state-operated facilities. This fell to 63,000 in 1995 (Lakin, Prouty, Smith, & Braddock, 1996). As a result, large residential facilities now are primarily the home of individuals with the most severe disabilities. Recently, investigators have begun to recognize the important effect of individuals' risk-characteristics on mortality (Eyman et al., 1990, 1993a; Strauss, Eyman, & Grossman, 1996). Strauss and Kastner (1996) were the first researchers to apply risk factor adjustment to compare mortality in different care settings for people with developmental disabilities. After controlling for risk factors, they found a 72% higher relative risk of mortality in the community for people age 40 and above.

The present study builds upon the previous work (Strauss & Kastner, 1996), with some important differences. First, we have used a simplified and more inclusive definition of person-years that yields 26% more data, thereby improving precision. Second, we have used simple contingency tables for the statistical analysis rather than the somewhat complex modeling used previously (Strauss & Kastner, 1996). Third, stratification of the data on the basis of simple functional variables resulted in risk groups that are clinically meaningful. Finally, we extended the study for 2 additional years, through the end of 1994 and, further, considered the 1993–1994 interval in isolation.

The goals were (a) to quantify mortality rates and relative risk of mortality for risk-adjusted subgroups, (b) to highlight differences between community and institutional mortality rates for this population, and (c) to determine whether the mortality pattern over the 10-year period held true for the final 2 years.

Method

Instrument

The source of the study data is the Client Development Evaluation Report (California Department of Developmental Services, 1978). This report is completed annually for all persons receiving services from the California Department of Developmental Services as well as when an individual moves to a different placement. The evaluation is conducted by the primary caregiver or the person most familiar with the client. Services provided by the Department of Developmental Services include board and care, nursing, job training, and a wide range of therapies. The Client Development Evaluation Report includes a 66-item Evaluation Element grouped into six domains of adaptive skills and behavior: motor and self-care skills and social, emotional, cognitive, and communication domains. The reliability of this instrument has been reported elsewhere and is considered to be satisfactory (Arias, Ito, & Takagi, 1993; Harris, Eyman, & Mayeda, 1982; Widaman, 1984; Widaman, Stacy, & Borthwick, 1985).

Sample

The sample consisted of all adults with mental retardation or other developmental disabilities, age 40 or over, who received services from the Department of Developmental Services any time between January 1985 and December 1994. The 40+ age group corresponds to one subgroup of interest, namely "older adults"; other subgroups, not considered here, include high-risk children (Strauss et al., 1996) and younger adults. All persons in the study had been referred to 1 of the 21 regional centers that contract with the state of California to provide services to individuals in their area.

Approximately 5.3% of persons were categorized as having Down syndrome, according to the *International Classification of Diseases* etiology (Context Software Systems, 1995). Age-specific mortality in Down syndrome, relative to that for most other etiologies of mental retardation, accelerates rapidly after age 40 (Strauss & Zigman, 1996). To avoid confounding this "natural" mortality with possible placement effects, we excluded persons with Down syndrome from the main part of the study. For completeness, however, we also summarize the effect of including persons with Down syndrome.

Information on deaths was obtained from annual computer tapes supplied by the California Department of Health Services. In California, death certificates are legally required to be completed and filed with the state, and the resulting computer tapes represent the state's official record of deaths. The matching was updated annually, on the basis of name, date of birth, and social security number when available. We assessed questionable cases (such as matches on name and date of birth with social security number unavailable) by direct inspection, without knowledge of the individual's type of residence.

As in previous work (Strauss et al., 1996; Strauss & Kastner, 1996), the unit of analysis we used here was not an individual person but rather a *person-year*, which represents calendar years (January through December) rather than years between birthdays. A person-year was included only if there was evidence that the individual was in the Department of Developmental Services system at the beginning of the year and either died or was in the system at the end of the year. Specifically, the subject contributed the consecutive person-years that began with year X and ended with year Y, where

(i) X is the first (post-1984) calendar year that followed the subject's first Client Development Evaluation Report evaluation, and

(ii) Y is the earliest of the years of (a) the last Client Development Evaluation Report date plus 2 years; (b) the date of death, if within 2 years of the last report date; and (c) 1994.

(The date of last Client Development Evaluation Report was used in order to deal with the problem of censoring: if a client leaves the system for any reason other than death, the only record of this in the Client Development Evaluation Report data is a hiatus in the evaluations. To avoid bias, we considered subjects in the system and at risk [and counted deaths] only for the 2-year interval after their last evaluation. There was one exception to the procedure: If the interval between two consecutive reports exceeded 3 years, the earlier and later series were treated as those of two distinct persons. This was done to avoid counting long periods of time when a person was not in the system as time at risk.)

This definition of *person-year* is simpler and more inclusive than that used previously (Strauss & Kastner, 1996) and yielded 26% more person-years. In all, there were 131,152 person-years, drawn from 22,576 persons. Total deaths were 1,926, for an overall mortality rate of 14.7 per thousand person-years. Each person contributed between 1 and 10 person-years, with an average of 5.8.

The variables (age, residence, etc.) for each person-year were identified from a Client Development Evaluation Report associated with that year. In most cases there was only one report in a given year, and this was the one that we used. If there were more than one Client Development Evaluation Report, one was used. If none, the first subsequent Client Development Evaluation Report was used if available; otherwise, the most recent prior report was used.

Variables

Our primary objective was to study the relationship of mortality and residence type, controlling for covariates: age, gender, and motor and self-care skills as determined from the Client Development Evaluation Report. Age was stratified into four groups: 40 to 49, 50 to 59, 60 to 69, and 70+. The five motor skill variables and five self-care variables are shown in Table 1. Each of the original Client Development Evaluation Report items had between four and nine levels but were collapsed here to a 3-point scale: the highest level of the item (score = 2), all intermediate levels (score = 1), and the lowest level (score = 0). We knew that mortality rates (computed as the ratio of number of deaths to number of person-years) are generally similar among the intermediate levels, and the grouping substantially improved the discrimination when different variables from

Table 1
Proportions of Person-Years Classified by Skill Variables and Corresponding Crude Mortality Rates and Relative Risks

Skill type/Classification	Person years (%)	Mortality rate	Relative risk[a]
Motor skills			
Ambulation			
Low: does not walk	8.3	28	2.43
Intermediate: walks with support/walks steadily alone at least 3.05 m	13.8	24	2.10
High: walks well alone at least 6.2 m, balances well	77.9	12	1.00
Rolling and sitting			
Low: does not lift head when lying on stomach	1.1	40	2.96
Intermediate: lifts head when lying on stomach/ rolls from side to side or front to back/maintains sitting with minimal support for at least 5 minutes	7.0	27	2.04
High: assumes and maintains sitting position independently	91.9	13	1.00
Crawling and standing			
Low: does not crawl, creep, or scoot	4.9	32	2.63
Intermediate: crawls, creeps, or scoots/ pulls to standing/stands with support at least 1 minute/ or unsteadily alone for 1 minute	14.1	23	1.87
High: stands well alone, balances well for at least 5 minutes	81.0	12	1.00
Arm use			
Low: no functional use of arm	1.0	42	3.10
Intermediate: moves arm, but does not extend/or partially extends	9.3	23	1.72
High: fully extends arm	89.8	14	1.00
Hand use			
Low: no functional use of hand	1.5	39	2.97
Intermediate: raking motion or grasps/uses thumb and fingers in opposition	14.6	21	1.63
High: uses fingers independently of each other	83.9	13	1.00

(continued on next page)

Table 1 *(continued)*

Skill type/Classification	Person years (%)	Mortality rate	Relative risk[a]
Self-care skills			
Eating			
Low: does not feed self, must be fed completely	3.7	37	3.34
Intermediate: attempts to finger feed/finger feeds/ feeds self with spoon and fork with spillage	37.1	18	1.66
High: uses eating utensils with no spillage	59.3	11	1.00
Toileting			
Low: not toilet trained or habit trained	6.4	30	2.61
Intermediate: habit trained/ indicates need/ goes by self, needs help	24.6	20	1.74
High: goes to toilet by self, completes by self	69.0	11	1.00
Bladder control			
Low: no control	5.9	34	2.90
Intermediate: some control/ control during day only	16.9	22	1.87
High: complete control	77.2	12	1.00
Bowel control			
Low: no control	5.5	31	2.59
Intermediate: some control/ control during day only	10.7	26	2.17
High: complete control	83.9	12	1.00
Dressing			
Low: does not put on any clothes by self	5.0	34	3.33
Intermediate: cooperates in putting clothes on/ puts some on self/ puts on clothes but does not do details	40.3	18	1.82
High: dresses self completely, including all fasteners and other details	54.7	10	1.00
Mental retardation level			
Mild	35.8	12	1.00
Moderate	24.1	15	1.25
Severe	15.9	17	1.42
Profound	17.7	17	1.42
Suspected/other	6.5	18	1.50
Placement			
Own home	25.2	12	1.00
Community care	53.0	15	1.20
ICF	7.8	20	1.61
Institutions	14.0	16	1.23

Note. Data are based on the full set of 131,152 person-years. The overall mortality rate (number of deaths per 1,000 person-years) was 14.7.
[a]Crude relative risks are the ratios of the mortality rate for the given level to that of the lowest level.

the same domain were additively combined (Strauss & Kastner, 1996). In addition, the simple 3-point scale is more interpretable and usable by those working with other instruments.

The five motor-skill variables were of roughly comparable predictive value and showed substantial intercorrelation. They were summed, resulting in a 10-point Motor Skills scale. This is analogous to the construction of the Apgar scale (Apgar, 1953; Vaughn, McKay, & Behrman, 1979), which also codes five variables as high/intermediate/low and combines them into a 10-point scale. The mortality rates suggested a grouping into four categories (0, 1 to 4, 5 to 9, and 10) rather than a linear scale, a pattern confirmed by subsequent modeling. The four levels can be interpreted as follows. *None* (sum = 0): lowest scores on all five items; *Poor* (sum = 1 to 4): more lows than highs; *Fair* (sum = 5 to 9): at least as many highs as lows; and *Good* (sum = 10): highest scores on all five items.

The five self-care variables (see Table 1) were also transformed to a 10-point scale, which was grouped into the same four homogeneous categories. The motor skills were all positively associated with the self-care skills, with correlations ranging from .38 to .58. The correlation between the summary motor and self-care 4-point scales was .61, not so large as to raise serious concerns over multicollinearity in the subsequent modeling.

Not shown in Table 1 are the variables from the social, emotional, cognitive, and communication domains. Nearly all were associated with mortality but more weakly than the motor and self-care items. Preliminary multivariate modeling indicated that these domains provided little additional predictive information. Severity of mental retardation (Eyman et al., 1990; Eyman et al., 1993a, 1993b) is shown in Table 1, but the variable proved not to be an important predictor in the presence of the other variables and was excluded from the subsequent analysis. Person-years for which the person was tube fed were also excluded. Although the need for tube feeding is known to be a powerful predictor of mortality (Eyman et al., 1993a; Strauss, Kastner, Ashwal, & White, 1997), subjects were tube fed in only 990 of the person-years (.7% of the total), and this seemed too few to justify an additional stratification. Again, however, we shall summarize the effect of including this group in the main analysis.

Residential placements were grouped into four categories: own home, group homes, intermediate care facilities (ICFs/MR), and institutions. Parent/relative homes were counted as own home. In California, group homes, which are generally privately owned, are predominantly 6 beds or less, though some are larger board and care facilities serving 7 or more people. The ICFs are required to meet more stringent requirements for medical care than are group homes. The institutions, now called "Developmental Centers" in California, are state-operated.

Statistical Methods

Stratification by gender, age, motor skills, and self-care skills resulted in $2 \times 4 \times 4 \times 4 = 128$ cells. For every pair of placement types (e.g., institutions and small group homes), a 2×2 table was constructed for each of the 128 cells. Each 2×2 table cross-classifies the person-years in a cell according to placement and to whether the client survived or died in that year. As in previous work (Strauss & Kastner, 1996), risks for own home and ICFs did not differ significantly from that of group homes (Mantel-Haenszel test [Kahn & Sempos, 1989], $p > .10$ in each case). However, all three risks were significantly higher than those for institutions, $p < .001$ in all cases. We, therefore, simplified some of the analyses by contrasting institutions with a combined group of the other three placement types.

For each of the 4×4 combinations of motor skills and self-care skills, we obtained the 2×2 table of placement and mortality. We used the Mantel-Haenszel estimator (Breslow & Day, 1980) of the mortality odds ratio. This adjusted for the effects of age and gender, which was necessary because the "collapsibility condition" (Feinberg, 1977) did not hold, $p < .01$, based on the Mantel-Haenszel test for non-zero association (Breslow & Day, 1980). In each cell we computed the odds ratio and its 95% confidence interval (Fleiss, 1981), together with the mortality rate (deaths per 1,000 person-years) for the two types of residence. The Breslow and Day test (1980) was used to test whether the odds ratio was homogeneous (constant) across strata. When homogeneity was accepted, we summarized the overall comparative mortality in the two placements with the Mantel-Haenszel estimator.

Because a single individual often contributes several person-years, the complete set of 131,152 person-years is not independent. We note, however, that it is not necessary to assume independence. The contribution to the likelihood function from an individual may be factored into the conditional probabilities of the outcomes in each year, given that the person was alive at the beginning of the year (Cupples, D'Agostino, Anderson, & Kannel, 1988).

This contingency table analysis was sufficient for our primary comparisons. A more complex methodology was needed, however, to test some of the secondary hypotheses. For example, it was not feasible to test for a time trend in baseline mortality rates using contingency table methods. For this we modeled the binary lived/died outcome in terms of the covariates using logistic regression (Hosmer & Lemeshow, 1989). This approach, which we have employed previously (Strauss et al., 1996; Strauss & Kastner, 1996; Strauss et al., 1997), is a standard procedure that has been used in the Framingham Heart Study and elsewhere (Cupples et al., 1988; Singer & Willett, 1991).

Readers more familiar with longitudinal survival analysis may note that these cross-sectional analyses are approximately equivalent to the longitudinal approach. For example, the Cox proportional hazards survival model (with a piece-wise constant hazard function) is mathematically equivalent to the (cross-sectional) Poisson regression model (Laird & Olivier, 1981), and a Poisson regression analysis can be approximated to any desired degree of precision by a logistic regression analysis (SAS, 1990).

Using the logistic model we tested for a number of assumptions, as is recommended when the logistic regression method is employed on repeated-measures data (Cupples et al., 1988; Strauss & Kastner, 1996). Tests were based on Wald chi-square and the deviance statistics. Goodness-of-fit of all the logistic regression models considered appeared adequate according to the Hosmer and Lemeshow (1989) test, with p values associated with the chi-squared statistic all greater than .25.

Finally, we comment on the use of inferential statistics (tests and confidence intervals) in a study of a population rather than a sample. Because we worked with *all* eligible persons in California, one could argue that inferential statistics are inappropriate here. The procedures may be justified, however, by reference to a "superpopulation" from which the present data are a sample, a viewpoint that statisticians commonly adopt (Andrews & Godfrey, 1979; Herson, 1976; Holt, Smith, & Tomberlin, 1979; Moses, 1992). Readers who prefer not to adopt this view point may disregard the inferential results given here.

Results

Table 1 shows the distributions of the primary study variables and their associated mortality rates. The first variable, ambulation, shows a typical pattern: a substantial majority (77.9%) of the person-years are at the highest level (walks well alone at least 6.2 m, balances well), and mortality rises sharply as the level of skill decreases. The relative risk for persons at the highest and lowest levels is 2.43 (= 28.0/11.5), suggesting that ambulatory skill is an important predictor. Note, however, that this is a "crude" relative risk, unadjusted for the effect of other variables. The next variable, rolling and sitting, refers to a lower level of skill. Only 1.1% of the cases are in the lowest category ("does not lift head when lying on stomach"), and these persons have a high mortality rate (40 per thousand person-years). Again the relative risk is large. Also shown in Table 1 are the three other motor skill variables—crawling ability, arm use, and hand use—followed by the five predictors from the self-care domain.

Table 2 stratifies the person-years into four age groups. For each age group, the table shows how the person-years break down according to gender, ambulation, and other selected variables. Also shown are the corresponding mortality rates. The first row shows the decline in the proportions by age and the increasing annual mortality rates.

Table 3 is stratified according to the four residence types. As expected, levels of skill were, on average, much lower in ICFs and institutions than in own home and small group homes. Note that at the low level of function-

Table 2
Person-Years and Crude Mortality Rates by Age Group and Selected Characteristcs

	Age group							
	40–49		50–59		60–69		70+	
Characteristic	%[a]	Rate[b]	%	Rate	%	Rate	%	Rate
Gender								
Male	55.1	9	53.4	16	52.6	31	43.7	63
Female	44.9	9	46.6	14	47.4	23	56.3	49
Ambulation								
High	79.3	7	77.8	13	74.7	22	63.6	44
Intermediate	12.0	13	14.0	21	17.6	41	27.3	70
Low	8.7	21	8.2	24	7.6	49	9.1	87
Eating								
High	60.9	7	58.9	11	55.3	21	46.1	50
Intermediate	34.9	10	38.0	9	2.1	32	50.8	57
Low	4.3	27	3.1	37	2.6	84	3.1	100
Rolling and sitting								
High	91.7	8	91.8	14	92.8	25	89.6	52
Intermediate	7.1	18	7.1	23	6.4	51	9.4	94
Low	1.2	32	1.1	54	0.9	63	0.9	18
Toileting								
High	69.3	7	69.8	12	67.7	21	59.5	50
Intermediate	23.7	11	24.4	20	27.2	37	34.5	59
Low	7.1	21	5.9	32	5.4	57	6.0	90

Note. N = 131,152 person-years. Crude mortality rates = deaths per thousand person-years. See Table 1 for full description of characteristics.
[a]Breakdown of person years. [b]Number of deaths per 1,000 person years.

Table 3
Person-Years and Crude Mortality Rates by Residence Type and Selected Characteristics

	Age group							
	Own home		Community		ICF		Institution	
Characteristic	%[a]	Rate[b]	%	Rate	%	Rate	%	Rate
Gender								
Male	53.2	12	53.4	16	52.0	20	57.5	17
Female	46.8	12	46.6	14	48.0	20	42.5	15
Ambulation								
High	84.7	9	84.3	13	45.3	17	58.2	10
Intermediate	10.7	23	12.6	28	26.9	20	17.1	19
Low	4.6	46	3.1	21	27.8	24	24.7	28
Eating								
High	80.2	9	65.8	12	24.2	18	14.7	9
Intermediate	17.8	22	33.4	20	66.3	19	70.4	14
Low	2.0	71	0.8	33	9.5	30	14.9	32
Rolling and sitting								
High	95.1	11	96.9	14	74.1	18	76.5	12
Intermediate	4.4	39	3.0	23	23.5	24	18.2	27
Low	0.5	80	0.1	32	2.9	51	5.3	31
Toileting								
High	86.2	9	79.2	12	30.4	18	19.2	11
Intermediate	12.0	27	19.5	23	54.3	19	51.0	13
Low	1.8	74	1.3	42	15.4	26	29.8	24

Note. N = 131,152 person years. Crude mortality rates = per thousand person-years. See Table 1 for full description of characteristics.
[a]Breakdown of person-years. [b]Number of deaths per 1,000 person-years.

ing, mortality rates were typically twice as high in own home as in other settings. We shall return to this point.

As noted, the analysis was simplified by the use of a single "community" group comprising own home, small group homes, and ICFs, and, further, by collapsing the data over gender and age group. This resulted in a 4 x 4 stratification by levels of motor skills and self-care skills. Table 4 shows, for each of the 16 strata, the mortality rates for the institution group and the community group, together with the numbers of person-years at risk. In either group the mortality rates were much higher among individuals with poor mobility and self-care skills. For example, mortality rates for people at the bottom of the motor and self-care scales were 106 and 42 deaths per thousand in community and institutional settings, respectively, compared to 9 and 8 per thousand for people with the highest skill levels.

Some cells in Table 4 contained insufficient data to justify the computation of an odds ratio and confidence interval. For example, there were no individuals with self-care skills who lacked all motor skills. Odds ratios were computed only for cells with at least 3 deaths in each of the two residence groups. The odds-ratios exceeded 1.0 in all 10 such cells, indicating consistently higher mortality in the community group than in the institutions. In several cases the data in a single cell were sufficient to show a significant difference.

We tested the null hypothesis that the odds ratios across the cells were constant. For each of the 16 self-care–motor skills categories, odds ratios were constant across age and gender groups (Breslow-Day χ^2 test, p > .10 in all 16 cases); further, the null hypothesis of constant odds ratios across the 16 categories could not be rejected, χ^2 test, p = .05. Consequently, the Mantel-Haenszel estimate of the common odds ratio, 1.72, could be computed (95% confidence interval: 1.50 to 1.99). This means that the mortality odds were 72% higher in the community than in the institutions (Table 5).(When the person-years for individuals with Down syndrome and for those fed by gastrostomy tube were included in the analysis, there was no longer a common odds ratio, Breslow-Day test for homogeneity of the odds ratios, p = .02. If the odds ratios *were* treated as homogeneous, the common estimate would be 1.59 [95% confidence interval: 1.39 to 1.81]. Within the Down syndrome group itself, the odds ratio was 1.18 [95% confidence interval: .69, 2.00].)

Because Strauss and Kastner (1996) had only considered data up to 1992, we also strati-

Table 4
Adjusted Odds Ratios and Crude Mortality Rates Comparing Community Groups With Institutions

	Self-care skill level			
Motor skill	None	Poor	Fair	Good
None	**2.48[a],***	—[g]	—	—
	(1.06, 5.82)[b]	—	—	—
	106[c], 113[d]	29, 34	56, 18	0, 0
	42[e], 333[f]	48, 21	0, 0	0, 0
Poor	**1.41**	**2.15****	**1.03**	—
	(0.87, 2.29)	**(1.49, 3.09)**	**(0.41, 2.57)**	—
	43, 588	39, 2133	16, 2282	0, 34
	31, 1603	24, 1859	31, 291	0, 1
Fair	**1.59**	**2.04****	**1.61****	—
	(0.41, 6.18)	**(1.50, 2.78)**	**(1.13, 2.28)**	—
	61, 66	39, 3743	22, 15223	13, 5696
	50, 121	18, 3344	15, 2469	9, 114
Good	—	**1.68***	**1.65****	**1.19**
	—	**(1.00, 2.81)**	**(1.21, 2.26)**	**(0.61, 2.31)**
	0, 13	22, 2140	14, 30863	9, 49802
	0, 6	12, 1860	8, 5236	8, 1146

Note. Stratified for motor and self-care skills. N = 131,152 person-years. Boldface used to emphasize the more important data.
[a]Odds ratio, community relative to institutions. As explained in the *Method*, odds ratios were computed with stratification by age and gender groups. For this reason, the odds ratios cannot be computed simply from the table mortality rates.* = significantly different from 1.0 at $p < .05$, **$p < .01$. [b]95% confidence interval for odds ratio. [c]Mortality rate per 1,000 person-years in the community group (comprised of own home, small group homes, and intermediate care facilities). [d]Number of person-years at risk in the community group. [e]Mortality rates per 1,000 person-years in institutions. [f]Number of person-years at risk in institutions. [g]Odds ratios and confidence intervals are not computed unless there are at least 3 deaths in both groups, because otherwise the results would be highly unstable.

Table 5
Odds Ratios for 1985–1994 and in Two Subintervals

Interval	No. of person-years	Odds ratio[a]	95% confidence interval
1985–1994	131,152	1.72	(1.50, 1.99)
1985–1992	98,436	1.74	(1.48, 2.04)
1993–1994	32,716	1.71	(1.26, 2.32)

Note. Odds ratios were for community relative to institutions after controlling for age, gender, motor, and self-care skills.
[a]Community to institution.

fied the data into the time periods 1985–1992 and 1993–1994 (Table 5). Data for 1985–1992 demonstrated an odds ratio in the community of 1.74. For 1993–1994, the relative risk in the community was 1.71. Note that the both of these odds ratios were significantly larger than 1, $p < .01$. This was the case despite the brevity of the 1993–1994 time period, which resulted in a reduced sample size.

Although the three odds ratios for own home, group homes, and ICF versus institution were not significantly different, and the groups were combined as previously described for simplicity, there were some suggestive differences. The odds ratio for own home was somewhat larger than the others, especially for persons with the most severe disabilities. This is illustrated by the stratification into can/cannot walk (Table 6). Among persons unable to walk, mortality odds in own home were more than triple those in the institutions. We must note, however, that the sample size for this comparison was small and the confidence interval correspondingly large.

We tested a number of auxiliary hypotheses using the logistic regression procedures described previously. We found that the following hypotheses could not be rejected:

Time homogeneity: This can be expressed as the absence of a secular trend or constancy of the baseline mortality rate across the study period. Specifically, no significant time effects in

Table 6
Crude Mortality Odds Ratios by Placement and Ambulation

Ambulation	No. of person-years	Odds ratio	95% confidence interval
Able to walk[a]			
Own home	32,812	1.98	1.64, 2.39
Group home	69,409	1.64	1.39, 1.93
ICF	10,041	1.55	1.27, 1.88
(Institution)	(17,429)		
Not able to walk[b]			
Own home	176	3.53	1.91, 6.52
Group home	94	3.07	0.83, 11.32
ICF	216	2.20	1.05, 4.61
(Institution)	(975)		

Note. Each community placement was compared to an institutionalized placement. Results are based on a total of 131,152 person-years.
[a]129,691 person-years. [b]1,461 person-years.

the logistic regression were observed, whether the time period was broken into two parts, three parts, or modeled with linear, quadratic, or cubic terms. Technically, this is a test for the presence of a main effect of calendar year in the logistic regression.

No trend in the magnitude of placement effect: The relative risk for institutions versus other settings was constant across the study period. Formally, this is a test for interaction of the effects of calendar year and placement.

The Markov assumption (Cupples et al., 1988): Given an individual's current residence and other current covariates, variables from previous *person-years do not need to be taken into account.* We tested this by introducing *lag terms*—values of variables from an individual's previous person-years—into the model. Lag terms for the time-varying covariates (the placement and skills in the previous person-year in addition to the current year) did not significantly improve the fit (deviance statistic = 9.6, not significant as chi-square with 8 degrees of freedom). Further, the addition of lag terms for motor and self-care skills did not affect the estimate of the community–institution odds ratio to two decimal places. These results suggest that it was sufficient to work with the variables for the current person-years rather than to augment them with values from previous years.

Discussion

Overall, the risk ratio for community mortality was 1.72, the same value as obtained previously using different methods (Strauss & Kastner, 1996). Although the exact agreement (to two decimal places) is doubtless an artifact of chance, the consistency of the two results is noteworthy. In both studies the results were obtained after risk factors such as age and level of functioning were controlled simultaneously, a feature absent in earlier studies. In a re-analysis of the data of this study, Strauss and Shavelle (1997) reported that when deaths due to types of cancer considered unavoidable were eliminated, the excess mortality in community care rose to 96%.

Mortality rates were quite high for the lower functioning groups. For example, crude mortality rates for people at the lowest levels of the motor and self-care scales were 106 and 42 deaths per thousand person-years in community and institutions, respectively. This may be contrasted with individuals with good (Level 4) motor skills and fair (Level 3) self-care skills, where the crude rates were 14 and 8, respectively. Although these rates are much lower, the community mortality rate was again substantially larger than the institution rate.

We examined data through 1994 and further considered the 1993–1994 interval in isolation. The pattern of increased community mortality between 1980 and 1992 was also found in the 1993–1994 interval, which is more representative of current conditions. This test of the mortality difference between institutions and the community is based on data that have no overlap at all with those considered in our earlier study (Strauss & Kastner, 1996). As such, the test may be regarded as an independent verification of the mortality difference.

In this study own home, group homes, and ICFs were combined for some purposes to simplify the analysis. Although we did not find statistically significant differences between their mortality risks, relative to institutions, we recognize the great differences in patterns of care across these settings. Risk factor-adjusted mortality appeared to be somewhat higher in own home than in group homes and ICFs, especially among persons with the most severe disabilities. This may merely reflect chance error, but a follow-up analysis of causes of death would be of interest here.

One limitation of the study is its restriction to the state of California. Parallel studies in other states are encouraged in order to facilitate assessment of the generalizability of the results. Further, the study is epidemiological; it would be helpful to supplement it with more in-depth analysis of the circumstances and causes of death. We note that in another epidemiological study, Strauss, Shavelle, Anderson, and Baumeister (1998) analyzed data on external causes of death (e.g., accidents, homicides). They found, for example, that deaths due to medication overdoses were much more likely in group homes than in own homes and that homicides were more common in supported living than in other settings.

Durkin (1996) and others have raised the possibility that the type of residence affects the individual's level of functioning. If community living indeed promotes higher functioning then controlling for functional level would introduce a bias against that type of residence. In some auxiliary analyses based on the Client Development Evaluation Report evaluations (not described in detail here), we found no evidence that Californians with developmental disabilities who moved from institutions to the community tended to improve in functioning. It is, of course, possible that more refined data would demonstrate such an improvement. On the other hand, the reverse may be true. The federal Health Care Finance Agency (1998), for example, stated in its recent report on the California Medicaid program that:

> Coffelt-class consumers (individuals who under a court order were transferred from California's Developmental Centers into the community) showed significant signs of loss of functional ability or health status since being placed in the community. (p. 3)

We recognize that a single epidemiological study is rarely decisive by itself. Confidence in the results and conclusions grows when a number of studies, using different populations, methodologies, and outcomes, are mutually consistent. Together with the present work, our recent California mortality studies may meet this criterion (Strauss & Kastner, 1996; Strauss et al., 1996; Strauss, Shavelle, Anderson, and Baumeister, 1998; Strauss, Shavelle, Baumeister, & Anderson, 1998). Consequently, policy inferences are not drawn here from the present study; rather, the implications of all of these studies are considered in a separate article (Strauss & Shavelle, 1998).

References

Andrews, R. W., & Godfrey, J. T. (1979). Super population models on auditing populations. ASA *proceedings of Business and Economic Statistics Section* (pp. 397–400). Washington, DC: American Statistical Association.

Apgar, V. (1953). A proposal for a new method of evaluation of the newborn infant. *Current Research in Anesthesia and Analgesia*, *32*, 260–265.

Arias, M., Ito, E., & Takagi, N. (1993). Concurrent validity of the client development and evaluation report. In A. B. Silverstein & A. L. Fluharty (Eds.), *Pacific State archives VIII* (pp. 28–33). Pomona: University of California at Los Angeles, Developmental Disabilities Immersion Program.

Ashwal, S., Eyman, R. K., & Call, T. L. (1994). Life expectancy of children in persistent vegetative state. *Pediatric Neurology*, *10*, 27–33.

Breslow, N. E., & Day, N. E. (1980). *Statistical methods in cancer research: I. The analysis of case-control studies*. Lyon, France: International Agency for Research on Cancer.

California Department of Developmental Services. (1978). *Client Development Evaluation Report*. Sacramento, CA: Author.

Carter, G., & Jancar, J. (1983). Mortality in the mentally handicapped: A 50 year survey at the Stoke Park group of hospitals (1930–1980). *Journal of Mental Deficiency Research*, *27*, 143–156.

Context Software Systems, Inc. (1995). *The International classification of diseases* (9th rev.), Clinical modification (4th ed.). New York: McGraw-Hill.

Cupples, L. A., D'Agostino, R. B., Anderson, K., & Kannel, W. B. (1988). Comparison of baseline and repeated measure covariate techniques in the Framingham heart study. *Statistics in Medicine*, *7*, 205–218.

Durkin, M. S. (1996). Beyond mortality—residential placement and quality of life among children with mental retardation. *American Journal of Public Health*, *86*, 1359–1361.

Eyman, R. K., Borthwick, S. A., Call, T. L., & White, J. F. (1988). Prediction of mortality in community and institutional settings. *Journal of Mental Deficiency Research*, *32*, 203–213.

Eyman, R. K., Borthwick, S. A., & Tarjan, G. (1984). Current trends and changes in institutions for the mentally retarded. In N. R. Ellis & N. W. Bray (Eds.), *International review of research in mental retardation* (Vol. 12, 177–203). New York: Academic Press.

Eyman, R. K., Grossman, H. J., Chaney, R. H., & Call, T. L. (1990). The life expectancy of profoundly handicapped people with mental retardation. *New England Journal of Medicine, 323*, 584–589.

Eyman, R. K., Grossman, H. J., Chaney, R. H., & Call, T. L. (1993a). Survival of profoundly disabled people with severe mental retardation. *American Journal of Diseases of Children, 147*, 329–336.

Eyman, R. K., Grossman, H. J., Chaney, R. H., & Call, T. L. (1993b). Mortality and the acquisition of basic skills by children and adults with severe disabilities. *American Journal of Diseases of Children, 147*, 216–222.

Feinberg, S. E. (1977). *The analysis of cross-classified data* (2nd ed). Cambridge: MIT Press.

Fleiss, J. L. (1981). *Statistical methods for rates and proportions* (2nd ed.). New York: Wiley.

Harris, C. W., Eyman, R. K., & Mayeda, T. (1982). *An interrater reliability study of the Client Development Evaluation Report*. Pomona: University of California, Los Angeles, Mental Retardation Research Center, Lanterman State Hospital.

Health Care Finance Agency. (1998). *Compliance review of California's Home and Community-Based Services Waiver Program for the Developmentally Disabled* (Control No. 0129.91). San Francisco: Author.

Herson, J. (1976). An investigation of relative efficiency of least squares prediction to conventional probability sampling plans. *Journal of the American Statistical Association, 71*, 700–703.

Holt, D., Smith, T. M. F., & Tomberlin, T. J. (1979). A model-based approach to estimation for small sub-groups of a population. *Journal of the American Statistical Association, 74*, 405–410.

Hosmer, D. W., & Lemeshow, S. (1989). *Applied logistic regression*. New York: Wiley.

Kahn, A. H., & Sempos, C. T. (1989). *Statistical methods in epidemiology*. Oxford: Oxford University Press.

Laird, N., & Olivier, D. (1981). Covariance analysis of censored survival data using log-linear analysis techniques. *Journal of the American Statistical Association, 76*, 231–240.

Lakin, K. C., Prouty, B., Smith, G., & Braddock, D. (1996). Nixon goal surpassed-two fold. *Mental Retardation, 34*, 67.

McCurley, R., McKay, D., & Scally, B. (1972). The life expectancy of the mentally subnormal under hospital and community care. *Journal of Mental Deficiency Research, 16*, 57–66.

Miller, C., & Eyman, R. K. (1979). Hospital and community mortality rates among the retarded. *Journal of Mental Deficiency Research, 22*, 137–145.

Moses, L. C. (1992). Some uses of statistical thinking. In J. C. Bailar & F. Mosteller (Eds.), *Medical uses of statistics* (pp. 5–26). Boston: New England Journal of Medicine Books.

SAS Institute. (1990). SAS/STAT users' manual, version 6. Cary, NC: Author.

Silverman, W. P., Zigman, W. B., & Silver, E. J. (1992). Adults with profound mental retardation and multiple handicaps: Factors associated with mortality. In J. W. Jacobs, S. N. Burchard, & P. J. Carling (Eds.), *Community living for people with developmental and psychiatric disabilities* (pp. 82–93). Baltimore: Johns Hopkins University Press.

Singer, J. D., & Willett, J. B. (1991). Modeling the days of our lives: Using survival analysis when designing and analyzing longitudinal studies of duration and the timing of events. *Psychology Bulletin, 110*, 268–290.

Strauss, D. J., Eyman, R. K., & Grossman, H. J. (1996). The prediction of mortality in children with severe mental retardation: The effect of placement. *American Journal of Public Health, 86*, 1422–1429.

Strauss, D. J., & Kastner, T. (1996). Comparative mortality of people with mental retardation in institutions and the community. *American Journal on Mental Retardation, 101*, 26–40.

Strauss, D. J., Kastner, T., Ashwal, S., & White, J. F. (1997). Tubefeeding and mortality in children with severe developmental disabilities and mental retardation. *Pediatrics, 99*, 358–362.

Strauss, D. J., & Shavelle, R. M. (1997). Comparative mortality in institutions and the community: Avoidable and unavoidable deaths. *American Journal of Public Health, 87*, 1870–1871.

Strauss, D., & Shavelle, R. (1998). What can we learn from the California mortality studies? *Mental Retardation, 36*, 406–408.

Strauss, D. J., Shavelle, R. M., Anderson, T. W., & Baumeister, A. A. (1998). External causes of death of persons with developmental disabilities: The effect of residential placement. *American Journal of Epidemiology, 147*, 855–862.

Strauss, D. J., Shavelle, R. M., Baumeister, A. A., & Anderson, T. W. (1998). Mortality of persons with developmental disability after transfer into community care. *American Journal on Mental Retardation, 102*, 569–581.

Strauss, D. J., & Zigman, W. B. (1996). Behavior capabilities and mortality risk in adults with and without Down syndrome. *American Journal on Mental Retardation, 101*, 269–281.

Thase, M. E. (1982). Longevity and mortality in Down's syndrome. *Journal of Mental Deficiency Research, 26*, 177–192.

Vaughn, V., McKay, R. J., & Behrman, R. E. (1979). The fetus and the neonatal infant. In V. Vaughn, R. J. McKay, & R. E. Behrman (Eds.), *Nelson textbook of pediatrics*. Philadelphia: Saunders.

Widaman, K. F. (1984, August). *Interrater reliability of adaptive behavior assessments: Item and factor levels*. Paper presented at the annual meeting of the American Psychological Association, Toronto.

Widaman, K. F., Stacy, A. W., & Borthwick, S. A. (1985, May). *Multitrait-multimethod of evaluating adaptive and maladaptive behavior of mentally retarded people*. Paper presented at the annual meeting of the American Association on Mental Deficiency, Philadelphia.