Comparative Mortality of People With Mental Retardation in Institutions and the Community

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The role of institutions has come into question in recent decades, and the size of the institutionalized population has been drastically reduced. Risk-adjusted mortality rates in institutions and the community in California from 1980 through 1992 were compared, with the aim of improving our understanding of the capacity of the community health system to support deinstitutionalization. Risk-adjusted odds on mortality were estimated to be 72% higher in the community than in institutions. Some problems with health care delivery in the community were reviewed; these may help account for the difference. Consumers and guardians should weigh these considerations when making choices between institutional versus community-based care.

As recently as 40 years ago, professionals and consumers believed that the ideal location for services for people with mental retardation was the congregate care setting. Public concern over the quality of institutional care peaked with revelations in the 1970s of abuse and neglect in institutional settings, including the Willowbrook Center in New York City and the Pennhurst Center in Philadelphia. Congress passed certification procedures related to funding received by states through the Medicaid Program and gave civil rights protection to residents through the Civil Rights of Institutionalized Persons Act of 1980.

These protections not withstanding, the belief that institutional delivery systems were fundamentally flawed gained currency among social activists. This belief reflected a reformulation of principles for building social service systems. Chief among these was the concept of *normalization*, defined by Wolfensberger (1972) as the "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" (p. 28). This is closely allied to the concept of the least restrictive environment—that the places where people live and work should not restrict their participation in the mainstream of society. Almost all agree that normalization and provision of services in the least restrictive setting are important social goals. As means to achieving these

goals, however, there is significant debate over the current practice of deinstitutionalization (Erb, 1995; MacNamara, 1994).

Normalization and an emphasis on least restrictive care settings have significantly affected the service system for persons with mental retardation. Between 1967 and 1991, the institutional population shrank by 60% (Lakin, Braddock, & Smith, 1994). Two states and the District of Columbia have closed all of their state-operated facilities. There is, however, a growing public and consumer concern that not all institutional residents can be successfully integrated into community settings (Sundram, 1994). National organizations such as Congress of Advocates for the Retarded and The Voice of the Retarded have resisted the movement to close all state-operated facilities (U.S. House of Representatives Committee on Small Business, 1993). They have noted that although states may close residential facilities for people with mental retardation, there is an ever increasing business of contracting with private organizations for services previously provided by the state. In these instances, there may be less state supervision and, thus, less public input into the quality and appropriateness of services provided (Agency for Health Care Policy and Research, 1993; Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1995; Sundram, 1994; U.S. House of Representatives Committee on Small Business, 1993).

Despite the intensity of public debate, there have been relatively few empirical studies in which the quality of care in institutional and community settings has been compared. Landesman-Dwyer (1981), in a study conducted for the President's Committee on Mental Retardation, reviewed more than 500 articles on deinstitutionalization and normalization and found that fewer than 20% presented empirical data. She identified three major problems affecting research in this area: (a) the absence of standardized terminology and nomenclature for describing and evaluating residential environment; (b) inadequate attention to pre- and postplacement measures, bias in selection of subjects from different environments, and insufficient objective descriptions of the type of residential treatment received; and (c) investigator bias in regard to the measurement and interpretation of clients' "quality of life." Consequently, the effects of normalized services on the function of people with mental retardation are largely unknown.

Mortality rates in specific developmental disability populations are strongly related to clinical variables. Those that best predict premature death include immobility, incontinence, and inability to eat without assistance (Eyman, Grossman, Chaney, & Call, 1990). The placement of a feeding tube is also associated with a shortened life-span, particularly for clients with less severe disabilities (Eyman, Grossman, Chaney, & Call, 1993; Kastner, Criscione, & Walsh, 1994).

Only a few published studies have been conducted to compare institutional and community mortality rates of people with mental retardation. McCurley, MacKay, and Scally (1972) observed higher rates for institutional residents, particularly for children with profound mental retardation. When a few characteristics, such as level of developmental disability were controlled, however, mortality rates among alternative placements were comparable (Miller & Eyman, 1979). A similar finding was reported by Silverman, Zigman, and Silver (1992). There have been no published studies, however, in which investigators have controlled for a large array of client characteristics.

Mortality is generally considered a useful proxy measure of quality of care when studying health care outcomes for large groups (Eyman, Grossman, Tarjan, & Miller, 1987). In this study we compared the mortality of people with mental retardation in the community and in institutions, based on a large population of Californian adults, with the goal of improving our understanding of the ability of the community health care system to support deinstitutionalization.

Method

Instrument

The source of the study data is the Client Development Evaluation Report (California Department of Developmental Services, 1978). The reliability of this instrument has been investigated elsewhere and considered to be satisfactory (Arias, Ito, & Takagi, 1983; Harris, Eyman, & Mayeda, 1982; Widaman, 1984; Widaman, Stacy, & Borthwick, 1985). A Client Development Evaluation Report is completed annually, and additionally when a client moves to a different placement, for any person receiving services from the California Department of Developmental Services. The report includes a 66-item Evaluation Element grouped into six domains of adaptive skills and behavior: motor and self-care skills together with social, emotional, cognitive, and communication domains.

Sample

The sample consisted of all adults with mental retardation, ages 40 or over, who had received services from the Department of Developmental Services between January 1980 and December 1992. The 40+ age group corresponds to one subgroup of interest, namely older adults; other subgroups, not considered here, include high-risk children (studied in Strauss, Eyman, and Grossman, in press) and younger adults. All persons in the study had been referred to one of the 21 regional centers that contract with the state to provide services to individuals in their area. Approximately 9% of this population, in accordance with the International Classification of Diseases etiology (U.S. Department of Health and Human Services, 1980), were categorized as having Down syndrome. These people were excluded from consideration, as older individuals with Down syndrome are known to have a very different aging pattern from other older persons with mental retardation (Eyman, Call, & White,

1991; Strauss & Eyman, in press; Zigman, Seltzer, & Silverman, 1994) and would require a separate study. Information on deaths was obtained from both Client Development Evaluation Report sources and the California Bureau of Vital Statistics.

In this study the unit of analysis was not an individual person, but rather a *person-year*. A person-year is taken to be the interval between two birthdays. Person-years are included only if there is evidence that the subject was in the Department of Developmental Services system at the beginning of the year and either died or was still in the system at the end. Further details and theoretical justification are provided in the Appendix. The procedure resulted in a set of 105,099 person-years, drawn from 18,362 subjects. The number of years contributed range from one to a maximum of 12, with an average of 5.73. For 92% of subjects, the person-years contributed were consecutive.

Variables

Our primary focus was on the relation of mortality and residence type. We controlled for variables such as age, gender, and levels of functioning as determined from the Client Development Evaluation Report. First, however, we present some descriptive statistics.

Table 1 shows the prevalence rates and mortality rates for selected variables. Each of the original Client Development Evaluation Report adaptive skill items has between four and nine levels, but all were collapsed here to a 3-point scale: the highest level item (score = 2), all intermediate levels (score = 1), and the lowest level (score = 0). This seemed appropriate because the mortality rates (computed as the ratio of number of deaths to number of person-years) proved to be generally rather similar among the intermediate levels, and the grouping substantially improved the discrimination when different variables from the same domain were additively combined. In addition, the

Table 1
Proportions of Person-Years Classified as High, Intermediate, and Low by Skill Variables and Corresponding Mortality Rates (in %)

Skill	Person-years	Mortality rates
Motor		
Ambulation (3.36)[a]		
Low: does not walk	12.9	4.2
Intermediate: walks with support/walks steadily alone at least 3.05 m	13.7	2.9
High: walks well alone at least 6.2 m, balances well	73.4	1.3
Rolling and sitting (4.11)	.	
Low: does not lift head when lying on stomach	1.5	6.6
Intermediate: lifts head when lying on stomach/rolls from side to side or front to back/maintains sitting with minimal support for ≥ 5 minutes	8.5	4.00
High: assumes and maintains sitting position independently	90.1	1.6
Crawling and standing (3.70)		
Low: does not crawl, creep, or scoot	6.3	5.1
Intermediate: crawls, creeps, or scoots; pulls to standing/stands with support at least 1 minute/or unsteadily alone for 1 minute	16.0	3.1
High: stands well alone, balances well for at least 5 minutes	77.7	1.4
Arm use (4.09)		
Low: no functional use of arm	1.5	6.7
Intermediate: moves arm, but does not extend/or partially extends	10.7	3.1
High: fully extends arm	87.8	1.6
Hand use (4.03)		
Low: no functional use of hand	2.0	6.4
Intermediate: raking motion or grasps/uses thumb and fingers in opposition	16.1	2.7
High: uses fingers independently of each other	81.9	1.6
Self-care		
Eating (4.90)		
Low: does not feed self, must be fed completely	4.6	6.2
Intermediate: attempts to finger feed/finger feeds/feeds self with spoon and fork with spillage	39.6	2.2
High: uses eating utensils with no spillage	55.8	1.3
Toileting (3.81)		
Low: not toilet trained or habit trained	7.5	4.9
Intermediate: habit trained/indicates need/goes by self needs help	26.3	2.5
High: goes to toilet by self, completes by self	66.2	1.3
Bladder control (4.13)		
Low: no control	7.1	5.4
Intermediate: some control/control during day only	18.3	2.0
High: complete control	74.6	1.3
Bowel control (4.13)		
Low: no control	6.7	5.3
Intermediate: some control/control during day only	12.3	3.3
High: complete control	81.1	1.4
Dressing (4.73)		
Low: does not put on any clothes by self	6.6	5.4
Intermediate: cooperates in putting clothes on/puts some on self/puts on clothes but does not do details	42.1	2.2
High: dresses self completely including all fasteners and other details	51.4	1.1
Mental retardation level (1.51)		
Mild	33.1	1.5
Moderate	24.7	1.8
Severe	17.1	2.1
Profound	18.5	2.2
Suspected/other	6.5	2.3
Tube feeding (6.82)		
Has feeding tube	.54	12.4
Does not have feeding tube	99.5	1.8
Placement		
Own home	23.6	1.1
Community care	53.3	1.6
Health facilities	7.1	2.2
Institutions	16.1	1.8

Note. Data are based on the full set of 105,099 person-years. The overall mortality rate (number of deaths divided by number of person-years) was 1.88%. The crude relative risks are the ratios of mortality rates for the highest and lowest categories.

[a] Numbers in parentheses are crude relative risks.

simple high/intermediate/low scale may be more interpretable and usable by those working with other instruments.

The first variable, ambulation, shows a typical pattern. A substantial majority of individuals were at the highest level, and mortality rose sharply as the level of skill decreased. The relative risk for persons at the highest and lowest levels was 3.36 (= 4.23/1.26), 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. Very few of the cases were in the lowest category, and these had a high mortality rate. Again the relative risk is large. Also shown in Table 1 are three other motor skill variables used in subsequent analysis—crawling ability, arm use, and hand use—followed by the five predictors from the self-care domain. All show a similar pattern of association with mortality.

Not shown in Table 1 are the variables from the social, emotional, cognitive, and communication domains. Nearly all of these variables were associated with mortality, but more weakly so than the variables shown in Table 1. Preliminary multivariate modeling indicated that these domains provided little additional predictive information. Severity of mental retardation (Eyman et al., 1990; Eyman, Grossman et al., 1993; Eyman, Olmstead, Grossman, & Call, 1993) is included in Table 1, but it was not an important predictor in the presence of the other variables and, therefore, was not included in the subsequent analysis.

Tube feeding refers to use of either nasogastric or gastrostomy tube. Overall prevalence of tube feeding was 0.5% (Table 1), although the rate was much higher within the most debilitated subgroups. For example, it was 41% in the group of people who were age 70 or over and lacked all the motor skills. Although precise figures are unavailable, it is believed that the great majority (more than 90%) of tube-fed clients are fed by gastrostomy

tube. Such clients generally suffer from chronic difficulties with the swallowing reflex, often in combination with severe cerebral palsy or epilepsy. The crude relative risk associated with tube feeding (see Table 1) is strikingly large. A similar, though less dramatic, result had been noted in a group of children with severe disabilities (Eyman, Olmstead et al., 1993; Kastner et al., 1994). These findings do not demonstrate that tube feeding elevates mortality; to a large extent, the necessity for tube feeding serves as a marker for the presence of serious health problems.

Residential placements were grouped into four categories: own home, community care, health facilities, and institutions. Parent/relative homes were counted as own home. Community care included both small group homes and larger board-and-care facilities serving seven or more people. Health facilities provide intermediate health care. Institutions, now called Developmental Centers in California, are state operated. The most common placement was community care, and health facilities had the highest crude mortality rate (Table 1).

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 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, although these are difficult to interpret because of the confounding of age and cohort effects (Baltes, Cornelius, & Nesselroade, 1979).

Table 3 is stratified according to the four residence types instead of age groups. As expected, levels of skill are on average much lower in health facilities and institutions than in own home and small group homes. Table 3, interestingly, indicates that the lower mortality in community placement (see Table 1) largely disappeared when just one major factor, such as ambulation, was controlled.

The five motor-skill variables were of roughly comparable predictive value

Table 2
Person-Years (N = 105,099) by Age Group and Subject Characteristics

| | Age groups | | | | | | | |
| | 40–49 | | 50–59 | | 60–69 | | 70+ | |
Characteristic	%[a]	Mortality[b]	%	Mortality	%	Mortality	%	Mortality
Gender								
Male	54.7	1.0	52.6	2.0	50.7	3.6	40.8	8.9
Female	45.3	1.0	47.4	1.7	49.4	3.0	59.2	6.4
Ambulation								
High: walks well alone at least 6.10 m, balances well	77.8	.7	74.9	1.4	69.7	3.5	54.2	5.2
Intermediate	12.5	1.5	14.8	2.6	20.1	4.5	30.3	9.2
Low: does not walk	9.7	2.9	10.2	3.9	10.3	6.7	15.5	12.0
Eating								
High: uses eating utensils with no spillage	58.7	.7	55.7	1.3	50.1	2.6	40.7	6.3
Intermediate	36.4	1.1	40.1	2.2	46.3	3.4	53.6	7.6
Low: does not feed self, must be fed completely	4.9	4.2	4.2	6.5	3.7	11.3	5.7	14.6
Rolling and sitting								
High: assumes and maintains sitting position independently	90.5	.8	90.1	1.6	90.4	2.9	83.5	6.8
Intermediate	7.9	2.3	8.5	3.7	8.5	6.6	15.1	10.4
Low: does not lift head when lying on stomach	1.6	5.6	1.4	5.8	1.2	9.9	1.4	15.5
Toileting								
High: goes to toilet by self, completes by self	68.0	.7	67.3	1.2	62.1	2.4	52.9	5.9
Intermediate	24.3	1.3	25.8	2.6	31.0	4.0	36.9	7.8
Low: not toilet trained or habit trained	7.7	2.9	6.8	5.2	6.9	7.9	10.1	13.9

[a]Breakdown of person-years. [b]Percentage of annual mortality rate.

Table 3
Person-Years (N = 105,099) Classified by Residence Type and Subject Characteristics

| | Placement | | | | | | | |
| | Own home | | Community care | | Health facility | | Institution | |
Characteristic	%[a]	Mortality[b]	%	Mortality	%	Mortality	%	Mortality
Gender								
Male	52.9	1.2	52.9	1.7	51.8	2.1	56.4	1.9
Female	47.2	1.1	47.0	1.5	48.2	2.3	43.6	1.7
Ambulation								
High: walks well alone at least 6.10 m, balances well	84.5	.8	84.2	1.3	43.9	1.8	58.3	1.1
Intermediate	10.7	2.1	13.0	2.9	27.4	2.2	17.3	1.7
Low: does not walk	4.8	4.3	2.8	2.6	28.7	2.8	24.4	3.5
Eating								
High: uses eating utensils with no spillage	80.2	.8	63.8	1.3	25.2	1.9	15.8	.8
Intermediate	17.7	1.9	35.4	2.0	65.3	2.1	69.5	1.5
Low: does not feed self, must be fed completely	2.1	8.1	.8	5.3	9.6	3.7	14.7	4.1
Rolling and sitting								
High: assumes and maintains sitting position independently	95.0	.9	96.8	1.5	73.9	2.1	75.5	1.2
Intermediate	4.3	3.7	3.1	2.4	23.8	2.1	18.5	3.1
Low: does not lift had when lying on stomach	.6	8.7	.2	2.5	2.3	7.1	5.9	5.0
Toileting								
High: goes to toilet by self, completes by self	86.7	.8	79.3	1.3	32.9	1.9	20.2	1.2
Intermediate	11.5	2.8	19.5	2.4	52.6	2.2	51.4	1.3
Low: not toilet trained or habit trained	1.9	7.1	1.2	5.1	14.5	2.8	28.3	3.0

[a]Breakdown of person-years. [b]Percentage of annual mortality rate.

and showed substantial intercorrelation. Rather than make a somewhat artificial selection, we preferred to combine the items by summing the five values, resulting in a 10-point motor skills 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 multivariate modeling. The relative risk for the two extreme categories is 8.5. Similarly, the five main self-care variables (Table 1) were transformed to a 10-point scale, which also naturally grouped into the same four homogeneous categories. The five motor skills, not surprisingly, were all positively associated with the five self-care skills; correlations ranged from .37 to .62. The correlation between the summary motor and self-care 4-point scales was .59. This was not so large as to raise serious concerns over multicollinearity in the subsequent modeling.

Statistical Analysis

In this section we offer a relatively nontechnical outline of the statistical methods. Further details, together with issues of statistical theory, are provided in the Appendix. As explained there, the modeling procedure, based on person-years data derived from longitudinal repeated observations, is not new. For example, it has been routinely used in the Framingham Heart Study (Cupples, D'Agostino, Anderson, & Kannel, 1988).

Our focus in the present study was on the relation of the outcome variable, survival, to the predictor variables. The latter included residential placement—the variable of main interest—and the covariates, or potential confounding variables: for example, age, gender, motor skills, self-care skills, and tube feeding. It was convenient to treat the data as cross-sectional rather than longitudinal, with the chance of surviving in a given person-year being modeled in terms of residence type and the covariates. Logistic regression (Hosmer & Lemeshow, 1989) was used.

According to this, the logarithm of the odds on survival in a person-year are expressed as a linear function of the various predictor variables. In symbols,

$$\ln[Prob(Survive)/Prob(Die)]$$
$$= \beta_0 + \beta_1 \cdot Age + \beta_2 \cdot Mobility\ score + \ldots$$

For binary predictors, such as presence or absence of tube feeding, the logistic regression coefficients give the *odds ratio* for mortality when other variables are controlled (Hosmer & Lemeshow, 1989). Except for age, all predictor variables in the analysis were binary. For the four-category motor-skills variable, three binary variables MOTOR1, MOTOR2, MOTOR3 were constructed, each representing a contrast of one of the three lower levels of motor skill (i.e., 0, 1 to 5, and 6 to 9) against the highest level (10). This fourth level thus serves as referent group.

The residence types were modeled with a binary variable for each of the following: own home, health facilities, and institutions. Each variable represents a contrast with community care, used as referent group here because it was by far the largest (Table 1). The logistic model was developed using standard variable selection techniques (Hosmer & Lemeshow, 1989). The fit of the final model appeared to be satisfactory, according to the Hosmer-Lemeshow test (Lemeshow & Hosmer, 1982).

To provide a graphical comparison of community care and institutional mortality rates at different levels of risk, we partitioned the person-years into eight groups (risk octiles) that were homogeneous with respect to risk. Thus, for example, the first group (lowest risk) consisted largely of person-years where the subject was in his or her early 40s and had optimal mobility and self-care skills. By contrast, a person-year in which the subject was tube fed, immobile, and was 90 years old would fall into the eighth group. This procedure allowed us to graph two quantities across the risk octiles—(a) the fraction of the person-years that were

lived in each residence type and (b) the mortality rates (number of death divided by number of person years)—separately for each residence type. Details on the construction and statistical theory of the risk octiles is provided in the Appendix.

Results

The main findings of the study are condensed into the logistic regression model of Table 4. This shows only those variables making a substantial contribution. Unlike the relative risks in Table 1, the odds ratios here were corrected for effects of the other risk factors.

Table 4
Logistic Regression Model Predicting Annual
Mortality Probability

Variable	Odds ratio*	95% confidence interval for odds ratio* (lower, upper)
Intercept	—	—
Age		
Males	1.070*	(1.06, 1.08)
Females	1.087*	(1.07, 1.10)
Gender	.53	(.33, .84)
Self1ᶜ	30.05	(11.96, 75.51)
Self2ᵈ	13.04	(6.52, 26.10)
Self3ᵈ	3.74	(1.99, 6.99)
Age*Self1ᵉ	.96	(.94, .97)
Age*Self2	.97	(.96, .98)
Age*Self3	.98	(.97, .99)
Feed tube	3.12	(2.30, 4.24)
Motor1ᶠ	3.35	(2.36, 4.75)
Motor2	1.61	(1.33, 1.95)
Motor3	1.40	(1.25, 1.57)
Own homeᵍ	1.00	(.87, 1.16)
Health facilitiesᵍ	1.04	(.87, 1.25)
Institutionsᵍ	.58	(.49, .68)

Note: Based on 105.099 person-years.
*Some odds ratios and confidence intervals are in plain text, rather than bold text, to acknowledge the fact that they lack a natural intuitive interpretation. *Because age interacts with self-care, these figures hold only for the referent self-care group. *Contrast of lowest self-care (lowest level on all 5 scales) with referent group (highest level on all 5 scales). *Contrast of intermediate self-care and referent group. *Interaction term, product of Age and SELF1-indicator variable. 'Contrast of lowest motor skill level with referent (highest) level. *Contrast of placement with community care as referent.

The age and gender rows of the table indicate that, other variables held constant, mortality rates increased at 7.0% per year for females and 8.7% per year for ⸱

males. Male mortality rates were about equal to female rates at age 40, but were nearly 50% higher by age 65. (It is not surprising that a simple linear age term proved adequate; a mortality rate whose logarithm increases linearly with age corresponds to the classical Gompertz model [Cox & Oakes, 1984], known to fit the age range of roughly 35 to 75 years in many demographic applications [Keyfitz, 1985].)

Tube feeding use was a strong predictor even when other risk factors in the table were taken into account, increasing mortality odds by 3.1. The first motor skill entry in Table 4, MOTOR1, compares the mortality odds for those scoring zero on the motor variable (i.e., lowest level on all five motor items) with the odds for the referent group (full motor skills). The odds ratio, 3.3, indicates a strong predictive effect. The intermediate levels correspond to smaller, but still substantial, odds ratios. The self-care variables show a similar pattern, though an interaction with age was present. (The interaction took the form of a tendency for the differences between the risks associated with the four self-care variables to diminish with increasing age. Note that the odds ratios for the age and self-care interaction terms lack a simple intuitive interpretation; in recognition of this, these quantities are not boldface in Table 4.)

As stated previously, we were primarily interested in the residence variables. Community care (small group homes) was taken as referent group. Odds ratios for both own home and health facilities were estimated at 1.0. As can be seen from Table 4, the 95% confidence intervals indicated no significant mortality differences between these placements and community care. The institution term, however, was highly significant, with the odds ratio of .58 corresponding to a 42% reduction in mortality odds compared to community care. Equivalently, the risk-adjusted odds on dying in a given year were estimated to be 72% higher in the community than in institutions.

Figure 1 shows how the person-

years were distributed among the four residence types, within each of eight homogeneous risk groups. As explained in the Appendix, these risk octiles were derived from the logistic model of Table 3. Institutions had disproportionately many higher risk subjects, which explains their elevated crude mortality rate (Table 1). Figure 2 offers a graphical comparison of mortality rates in institutions and community care within the risk octiles. As explained in the Appendix, it would not be appropriate to carry out formal statistical tests etc. on the results of Figure 2. Nevertheless the lower mortality in institutions, which was expected from Table 3, seems consistent across the risk spectrum.

Figure 1. Breakdown of person-years by placement within eight homogenous risk octiles.

Figure 2. Mortality rates for community care and for institutions within risk octiles. (Using community care as referent population. we directly standardized institution rates). Note that the finding of a 72% increase in mortality in the community refers to the ratio of the odds of dying in a given year. Although the ratios of community to institutional rates appear to vary across the eight groups in the figure, there is no suggestion of any systematic trends in these ratios. As explained in the Appendix. it is not appropriate to base statistical tests or confidence intervals on the results of Figure 2; such procedures are more properly applied to the logistic model itself (Table 4).

Discussion

Our major finding was that the risk-adjusted mortality rates of people with mental retardation were higher in the community than in institutions, regardless of the level of risk. Because the study was observational rather than experimental, this result should be viewed tentatively: It is conceivable that the difference was due to the confounding effect of unobserved variables. This, however, may appear somewhat less likely in view of our finding (not detailed here) that the addition of each mortality predictor to the model tilted the comparison in favor of institutions. For example, the crude mortality rates strongly favored the community (Table 1), but control for a single major risk variable largely canceled this out (Table 3). The findings, moreover, are consistent with those of a corresponding study of children with severe disabilities (Strauss et al., in press).

In this study we do not offer an explanation for the findings. Possible causes of increased mortality in community settings can only be inferred from other sources in the field. However, a significant body of literature exists. Health care in the community is generally considered to be a problem for persons with mental retardation. Shortcomings have been noted regarding Medicaid reimbursement, the lack of trained practitioners, and coordination of care (Crocker & Yankauer, 1987; Garrard, 1982; Kastner & Luckhardt, 1990; Minihan, 1986; Minihan, Dean, & Lyons, 1993; Ziring et al., 1988). Problems noted in a survey of physicians in Maine included poor quality of medical records
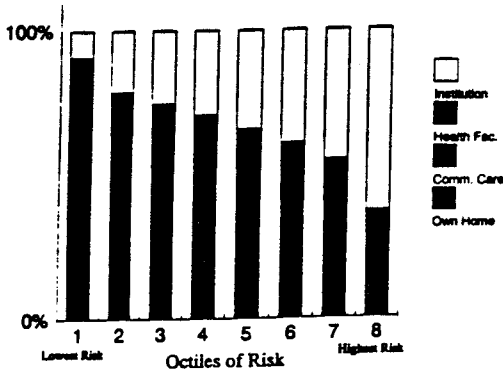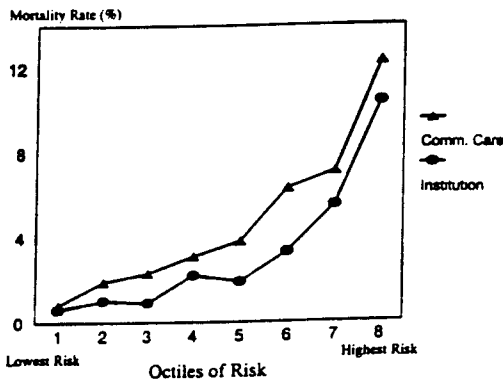
and information; cognitive/verbal limitations of these patients, which hinder diagnosis and treatment; difficulty for physicians in communicating with multiple caregivers; maladaptive behavior of patients in office; and potential liability issues (Minihan et al., 1993). In two studies of previously institutionalized persons residing in the community, rates of undiagnosed thyroid disease and undiagnosed heart disease in persons with Down syndrome were elevated (Barnett, Friedman, & Kastner, 1988; Friedman, Kastner, Pond, & O'Brien, 1989). In another such study Knobbe, Carey, Rhodes, and Horner (1995) found an 80% reduction in annual per-client medical expenditure. Kastner, Nathanson, and Friedman (1993) examined causes of 14 deaths in the community; nearly half of the deaths were judged preventable. Finally, persons with mental retardation lacking access to health care coordination services required longer and more frequent hospitalizations than did a comparable group receiving coordinated care (Criscione, Walsh, & Kastner, 1995; Criscione, Kastner, Walsh, & Nathanson, 1993). Each of these weaknesses, either alone or in combination, could contribute to the findings of the present study.

Institutions overcome many of these barriers because they offer a centralized setting in which provider training, reimbursement, record-keeping, and quality assurance functions are in place. However, many institutions suffer from professional isolation, poor morale, and administrative and financial neglect on the part of policy makers and advocates. To an extent, the lack of support for institutions has lead to an erosion in their ability to provide high quality care.

What does this mean for persons with mental retardation who currently reside in institutions? There is no certain answer. Results of the present study do not allow us to conclude that either institutional care or community-based care is superior. Each service system offers strengths and weaknesses with potential risks and benefits. The individual needs of

persons with mental retardation vary greatly, and for some individuals care in one setting may be more desirable than in the other. These risks and benefits can only be understood in the context of an individual person's needs and their subjective experience of the care received. The inability to fully quantify these risks and benefits in an objective fashion has led to a high level of confusion and anxiety among consumers, guardians, and families, which, in turn, has fueled the vocal public debate over the future of institutional care.

On the basis of our findings, we have several recommendations. First, we recommend a policy of selective deinstitutionalization, as originally proposed in 1974 by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded and later adopted in the 1975 Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103) (Landesman & Butterfield, 1987). These policies will likely support a continuing role for institutions in the treatment of some people with mental retardation. Second, we recommend that consumers who consider relocation from institutional settings to the community be fully informed of the potential risks and benefits of this choice. Given the limited knowledge about the likelihood of specific outcomes in either setting, we believe that policy makers and advocates should defer choices of residential care to consumers and professionals. Third, the health and other service needs of institutional residents could be evaluated and alternative placement decisions made dependent on the availability of adequate access within the community.

Finally, and most important, we encourage additional research to determine whether the findings of this study are consistent with experiences in states other than California. If so, it will be important to learn the causes of elevated mortality rates in community settings in order to improve outcomes. In the meantime, con-

sumers should be allowed to weigh the available evidence against their personal needs, desires, and aspirations.

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APPENDIX

Statistical Issues and Procedural Protocol Related to the Person-Years Analysis

Statistical Modeling

At first sight it may appear attractive to treat the individuals in the study as a cohort and model the survival time in terms of residence type and the covariates, perhaps with a Cox regression (Collett, 1994). There were reasons not to adopt a cohort perspective, however. One issue is that the Client Development Evaluation Reports did not contain precise information on when the client was at risk. One should not "credit" a client for surviving time periods during which he or she may have been out of the service system, so that if death had occurred it would not have been recorded. Second, many clients entered the system after the beginning of the study period or were older than 40 in 1980. In either case there are issues of left censoring, in addition to the more customary right censoring. There were even cases of clients who left the system for several years and then returned. Finally, the focus in this study was entirely on prediction of risk rather

Note. Some of the discussion in this Appendix concerns advanced topics in biostatistics.

than of survival times, so that it was not essential to work with a cohort.

The approach taken here was the standard epidemiological one of analyzing mortality rates in terms of risk factors (Breslow & Day, 1987). Mortality rates were, as is customary, taken to be the number of deaths divided by the number of person-years at risk. One convenient approach to the analysis is through logistic regression on the person-years. If the data had actually been derived from a cohort, this approach would be a version of discrete survival analysis (Cox, 1972; Efron, 1988; Singer & Willett, 1991).

As noted in the *Method*, this procedure is not new (Cupples et al., 1988; Prentice & Gloeckler, 1978). Although we were not working with a cohort, the analysis could alternatively have been carried out with a Cox regression; the results are generally very similar (Prentice & Gloeckler, 1978). As noted by Cupples et al. (1988), the model is based on three assumptions that are important to check, as additional terms would be needed in the model if they were violated. In the context of this study the assumptions are:

1. The "baseline" hazard function does not depend on calendar year.
2. The relation of the risk factors to the mortality does not depend on calendar year.
3. A Markov assumption: only the current risk profile is needed to predict the outcome.

Using additional variables that allow for departures from these assumptions (Cupples et al., 1988; Kahn & Dawber, 1966), we found no suggestion of any such model violations.

Details of Construction of the Person-Years Data

The *ith person-year* means the period between ith and (i+1)th birthday. The ith person-year is included only if a number of conditions are met, such as that the year does not begin in 1992 (reason: incomplete year, because the study period ended on 12/31/92).

The following are rules for deciding which Client Development Evaluation Report should be chosen to represent the ith year:

1. If the person has exactly one Client Development Evaluation Report in ith year, this report is used.
2. If none, the most recent previous Client Development Evaluation Report or the earliest subsequent one is used—whichever is closest in days to the ith year.
3. If more than one, let their times be ordered as
   ith birthday $= t_0 < t_1 < ... < t_k < t_{k+1} =$ (i+1)th birthday or death date.

For j $= 1,...,k$, let the jth SPAN $s_j = t_{j+1} - t_{j-1}$. Rule: pick the j with the biggest span. (Reason: it is the most representative)

The Theory and Construction of the Risk-Octiles

We were interested in comparing mortality rates for the various types of residence within groups at different risk levels. It may be, for instance, that relative risks of living in an institution compared to the community are different among individuals who are old and infirm than among those who are young and healthy. For this purpose it was necessary to stratify the person-years into groups that were homogeneous with respect to risk. A familiar strategy for this is simply to stratify (cross-classify) the person-years according to the risk factors, such as age-group, mobility score, presence/absence of tube feeding, etc. As is common in models with many predictors, however, the difficulty here is that

the result will be too many strata containing too few data (Kleinbaum, Kupper, & Morgenstern, 1982).

The procedure followed here was based on that of Miettinen (1976). (a) We computed a logistic regression function that included all the variables, including those for placement (see Table 4). (b) For each person-year, we calculated a predicted mortality probability by substitution into the logistic function, but with all placement variables set to zero. This rank-ordered the person-years according to predicted mortality risk, after adjustment for placement effects. (c) We then partitioned the person-years into eight homogeneous risk octiles. Cut-points were selected so that the expected number of deaths in institutions, computed on the basis of the community care mortality rates, were equal. (Miettinen often preferred five risk groups in his applications. The large data set in the present study was sufficient to support a substantially larger number of strata, however. We judged that in this case it would not be helpful to work with more than eight strata in our application. Also, by using groups with equal numbers of deaths, we ensured that the stratum-specific standard errors were approximately equal.) (d) Finally, we plotted mortality rates for community care and institutions for each risk octile. The rate for institutions was first directly standardized (Fleiss, 1981) with respect to risk, using community care as standard population. (This corrects for bias arising from the fact that even within an octile, the institution person-years tend to be associated with slightly higher risk covariate patterns than do the community person-years.)

It would be tempting to take advantage of the stratification to test for mortality differences between the placements, perhaps using the Mantel-Haenszel procedure (Kleinbaum et al., 1982). It is known, however, that in the present context this is not valid (Pike, Anderson, & Day, 1979). Even less appropriate would be to test the differences separately for each risk group, as this would in addition result in great loss of power. For this reason we followed accepted practice by confining our testing and computation of confidence intervals to the logistic regression modeling (Table 4). See also Breslow and Day (1980) on this point.