American Journal on Mental Retardation, 1998, Vol. 102, No. 6, 569–581

Mortality in Persons With Developmental Disabilities After Transfer Into Community Care

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More than 2,000 persons with developmental disabilities have been transferred from California state institutions into community care in recent years. We investigated whether this has been accompanied by a change in mortality rates, using data on 1,878 clients moved since April 1993. Mortality rates were compared to those expected for comparable persons in institutions. Risk-adjusted mortality rates for movers exceeded institutional rates by 51%, $p < .05$. After removal of cancer deaths in both groups, this increased to 67%. The effect was largest shortly after the move and in the subjects who had moved most recently. The deinstitutionalization process in California appears to have resulted in a substantial increase in mortality, indicating the need to ensure continuous, consistent, and competent medical care and supervision in the community.

Large state residential facilities for persons with developmental disabilities are continuing to be downsized in favor of community placement, primarily group homes. In California and many other states, this movement has resulted predominately from advocacy-inspired initiatives and class-action litigation. Congressional action to provide Medicaid funding through the Home and Community-Based Waiver Program has also reduced states' incentives to maintain large facilities. The result has been a major and rapid shift in funding strategies in most states (Smith, Prouty, & Lakin, 1996). Numbers residing in facilities accommodating 16 or more residents decreased from 200,000 in 1968 to fewer than 100,000 in 1995 (Prouty & Lakin, 1996). By 1995, more than half of the individuals living outside their own homes were in community placements with 6 or fewer residents.

Claims have been made repeatedly—in the professional literature, the mainstream media, in testimony before courts and legislative hearings, and in other forums—that community residence promotes superior development, improves direct care, enhances quality of life, is less expensive than institutional placement, and is mandated by constitutional provisions. A considerable literature, ideological and empirical, has accumulated over the past 25 years in support of what has

been termed *inclusion* and/or *normalization*. For instance, Larson and Lakin (1989) have presented data showing psychological benefits of living in the community versus a more restrictive setting.

There can be little doubt that deinstitutionalization has become integrated in contemporary social and legal consciousness. Conclusions regarding the benefits or pitfalls of community placement, however, particularly for people with severe medical or behavioral problems, have not gone unchallenged. In a detailed conceptual, ethical, and political analysis, Rose-Ackerman (1982) examined logical and philosophical premises underlying the normalization movement. The inconsistences that she observed are no less salient today and remain at the crux of the controversy, which often reaches acrimonious proportions (e.g., Erb, 1995; West, 1995).

Disputes as to whether there are to be large congregate institutions or complete community inclusion are fundamentally an expression of normative values. Over the past century, the history of mental retardation services has been characterized by sharp ideological shifts between epochs of pessimism and optimism, fear and compassion, denial and acceptance, nature and nurture. Science and the technologies it spawns can neither span these ideological fault-lines nor resolve the underlying philosophical challenges. The most that can be expected from research is to inform the debate and perhaps to affect implementation of policy decisions (Baumeister, 1981).

Although many researchers, representing different professions, points of view, and methods of inquiry, have studied the effects of movement from larger segregated congregate facilities to smaller community living environments, the literature is replete with discordant results and conclusions. Quite aside from ideological considerations, methodologically sound research in this area has been difficult to conduct because of myriad confounding factors. After reviewing the research literature on alternative living arrangements, Butterfield (1987) stated that "Most of what has been found so far is scientifically uninteresting because the methods used to find it are biased" (p. 43). The primary inferential difficulty is assuring comparability of groups. Random assignment of people to living conditions has rarely been attempted because of ethical and legal considerations. Although much research has been reported since Butterfield published his review and conclusions in 1987, this is an area of inquiry still beset with problems of uncontrolled variables that compromise comparative analyses.

An instructive exception is the careful study reported by Landesman (1987), who found little behavioral change between institutional residents randomly assigned to larger or smaller living arrangements. She stressed that size of residential unit may matter less than their functional aspects. Some may argue that with regard to functional considerations, the inclusionary strategy is inherently superior. The Landesman study was conducted within an institutional setting and did not compare community and institutional effects.

A number of measurable aspects can and should be considered—not with a view toward resolving the ethical issue of institutions versus community but, rather, to maximize health and social status of a vulnerable population. One is that fluctuations in the provision of basic care are common in the community; for example, rate of staff turnover is known to be high (Baumeister & Zaharia, 1987; Braddock & Mitchell, 1992). In other recent studies, investigators focusing on health indexes and risk factors have pointed to some advantages of institutional residence over group home and natural family settings (Rimmer, Braddock, & Marks, 1995). Rimmer et al. monitored body fat, serum lipoprotein concentrations, smoking, alcohol consumption, and exercise among ambulatory adults. Their findings led to the conclusion that "Clearly the institu-

tional group had the most attractive health-risk profile" (p. 498). These results point to the necessity for greater attention to health promotion and disease prevention in group homes, supported living environments, and in natural homes. Risk assessment is a crucial element for determination of accommodations that are required to ensure safety, health, and well-being.

Given the problems of prospective cohort studies with random assignment, the alternative is statistical adjustment for effects of critical variables. Mortality is widely recognized to be a primary outcome measure (Lilienfeld & Stolley, 1994): It has high reliability and clinical importance and is known to be a good proxy for morbidity. In several early studies in which investigators compared mortality rates in the community and institutions, lower rates in the community have generally been found (McCurley, Mackay, & Scally, 1972; Miller & Eyman, 1978). These studies, however, lacked adjustment for confounding variables. As we shall see, our own data also give this result before adjustment for the effect of confounders.

More recent and methodologically superior research has confirmed that mobility is the most powerful indicator of survival, with other important markers being deficits in self-help skills and need for tube feeding (Eyman, Grossman, Chaney, & Call, 1990; Eyman, Olmstead, Grossman, & Call, 1993; Eyman, Strauss, & Grossman, 1996; Strauss, Eyman, & Grossman, 1996; Strauss & Kastner, 1996). After adjustment for risk factors, results of two California studies indicated higher mortality risks in the community health system than in institutions (Strauss et al., 1996; Strauss & Kastner, 1996). No previous investigators, however, have analyzed mortality in a large cohort of institutionalized individuals who transferred into the community; the rapid transfers have been implemented with little or no research on possible health risks.

Since 1993, more than 2,000 residents of California institutions have transferred to the community. In part, this has been in response to the settlement of the Coffelt litigation (*Coffelt, William et al. v. California Department of Developmental Services et al.*, 1994). We compared mortality in the movers' group with expected rates based on institutional residence and adjusted mortality risks using established predictors of mortality. We used data from a time frame reflecting current service delivery conditions, thus avoiding historical bias. Finally, we used data on subjects' covariates prior to community placement, eliminating any possible bias due to effects of community care on covariates.

Method

Subjects and Data

Subjects were the 1,878 persons with developmental disabilities who transferred from the state developmental centers (institutions) between April 1993 and March 1996. Roughly equal numbers transferred each month. The locations of the subjects immediately after transfer are shown in Table 1. The great majority of the movers were placed in private group homes (community care). To avoid bias, we retained the data from the 91 persons who later returned to institutions.

Table 1
Placement of the 1,878 Movers

Placement	*n*
Community care facility	900
ICF/DD[a]	19
ICF/DD-Habilitation[b]	440
ICF/DD-Nursing	242
Foster family	7
Own home	111
Supported living	58
Skilled nursing facilities	13
Other/Unable to locate	88

[a]Developmental disability. [b]Four to 15 beds.

Information on individuals' characteristics was taken from the Client Development Evaluation Report (California Department of Developmental Services, 1978), which is administered annually to all persons receiving services from the

state of California as well as when an individual moves to a different placement. This instrument includes a 66-item Evaluation Element grouped into six domains of adaptive skills and behavior, including motor and self-care skills. The reliability of the Client Developmental Evaluation Report has been investigated elsewhere and is considered to be satisfactory (Arias, Ito, & Tagaki, 1983; Harris, Eyman, & Mayeda, 1982; Widaman, Borthwick-Duffy, & Powers, 1994; Widaman, Stacy, & Borthwick, 1985). The study period employed in the present investigation was from April 1, 1993, to February 14, 1996. Except for the 45-day period at the beginning of 1996, mortality data were obtained from California Department of Health Services computer tapes. We were able to obtain death certificates in 42 of the 45 cases. The other 3 were confirmed independently, 2 from vital statistics tapes (with cause of death codes) and 1 from Department of Developmental Services records.

Covariates used were age group, gender, tube feeding, and motor and self-care skills, which, as noted earlier, had been established in previous research to be powerful predictors of mortality. Tube feeding is a binary indicator for the use of a gastrostomy tube, whereas motor and self-care skills are ordinal 4-point scales. The scale for motor skills, for example, is based on five Client Development Evaluation Report items: hand use, arm use, rolling and sitting, crawling and standing, and ambulation. Each item was initially recoded on a 3-point scale (high, intermediate, or none). The motor scale was then defined as follows: none = *none* on all 5 items, poor = more *none* than *high*, fair = at least as many *high* items as *none*, good = *high* on all 5 items.

Table 2 shows general characteristics of the movers. To avoid bias due to possible effects of residential setting, we used the last evaluation *before* the move. The table shows that movers tended to be higher functioning and had fewer severe medical conditions than did the stayers. Further, a breakdown by year of move (not shown in the table) indicates that the 1993 movers tended to be the highest functioning individuals, followed by the 1994 movers, with the 1995 movers being the most similar to the stayers.

Statistical Methods

A cohort's mortality rate is the number of deaths divided by the total time at risk. Here, the *time at risk* is the time between a subject's move and the end of the study period (or death). *Mortality rates* are expressed as deaths per thousand person-years. We report *standardized mortality ratios*, which are ratios of the observed number of deaths to the number expected on the basis of rates in a standard population (Breslow & Day, 1987, p. 65). Confidence intervals were computed using standard methods (Breslow & Day, 1987).

Movers differed markedly from the institutional population with respect to age and risk factors such as mobility and the need for tube feeding. To standardize movers' mortality rates with respect to the institutional population, we needed to adjust for these factors simultaneously. We used Poisson regression (Breslow & Day, 1987) to model hazards rates in institutions and applied the fitted rates to the exposure time of the movers' cohort, obtaining expected numbers of deaths based on institutional rates. For further information, see the Appendix. We considered a wide range of choices for the set of covariates. As the Appendix shows, once the key variables of age, gender, use of tube feeding, and motor skills were included, the addition of other covariates had little effect on the computation of the expected number of deaths. For example, the addition of up to 30 additional binary risk factors would change the expected number of deaths by at most 1.0. The model we ultimately chose was conservative, in the sense that there would be some justification for choosing a model with a slightly lower expected number (see the Appendix for details).

Table 2
Comparison of Movers and Stayers (in %)

Variable/Level	Movers	Stayers
Rolling and sitting		
Low—does not lift head when lying on stomach	4.9	12.9
Medium	15.0	19.0
High—assumes and maintains sitting position independently	80.1	68.1
Ambulation		
Low—does not walk	20.8	34.2
Medium	11.5	13.8
High—walks well alone at least 6.1m. Balances well	67.7	52.0
Eating		
Low—does not feed self, must be fed completely	15.1	26.3
Medium	52.2	59.5
High—uses eating utensils with no spillage	32.7	14.2
Toileting		
Low—no toilet trained or habit trained	27.1	41.3
Medium	33.8	39.9
High—goes to toilet by self, completes by self	39.2	18.8
One-to-one interaction with peers		
Low—does not enter into interaction	36.1	50.9
Medium	48.8	41.6
High—initiates interaction in both familiar and unfamiliar situations or settings	15.1	7.6
Aggression		
High—had one or more violent episodes causing serious physical injury in past year	15.8	16.4
Medium	45.7	38.9
Low—episodes of displaying anger are undetected or rare and appropriate to the situation	38.4	44.7
Auditory perception		
Low—does not react to sound	3.8	7.2
Medium	53.7	64.6
High—recognizes same sounding words	42.5	28.2
Receptive nonverbal communication		
Low—does not demonstrate understanding of gestures or facial expressions	31.1	38.7
Medium	50.6	52.9
High—demonstrates understanding of a series of gestures	18.4	8.4
Mental retardation level		
Mild	23.2	7.7
Moderate	12.2	6.7
Severe	11.9	14.6
Profound	51.0	70.2
Suspected	1.8	0.9
Tube feeding		
Yes	5.1	13.0
No	94.9	87.0
Severe medical conditions		
None	76.9	59.4
One	11.8	18.0
More than one	11.3	22.6
Gender		
Male	62.2	61.0
Female	37.8	39.0
Age group[a]		
1–4	0.4	0.3
5–9	1.4	1.4
10–19	9.4	5.1
20–39	56.4	46.1
40–59	29.7	39.3
60+	57.4	41.2
Motor skill		
None	2.6	8.1
Poor	16.7	22.7
Fair	23.5	28.0
Good	57.4	41.2
Self-care skill		
None	12.6	22.8
Poor	27.6	35.2
Fair	36.6	34.3
Good	23.2	7.8

[a]In years.

In subsequent analyses the community person-years were stratified in various ways, so that observed and expected numbers of deaths could be compared within strata. For each stratum, we computed expected numbers by applying the Poisson regression equation separately to the exposure time and covariate pattern for each person. We also repeated the analysis after deleting cancer deaths from both the movers and the comparison group; that is, we refitted the Poisson model after excluding institution deaths with International Classification of Diseases—ICD-9 (1995) codes 140-239 (neoplasms).

Results

There was a total of 45 deaths between April 1, 1993, and February 14, 1996, and 2,552.5 person-years of exposure among the movers, for a mortality rate of 17.6 per 1,000 person-years (see Tables 3 and 4). The corresponding (age-adjusted) rate in the general California population was 2.4. The standardized mortality ratio of 7.3 (= 17.6/2.4) does not in itself demonstrate poor community medical care but serves as both a reminder and a quantification of their medical vulnerability. We note for comparison that in a separate computation we found the standardized mortality ratio for California community residence as a whole to be 2.1, and the standardized mortality ratio for institutional residence to be 4.2. These figures, of course, are uncorrected for the effect of any risk factors except age and gender.

More interesting are the comparisons with the institutional population.

Table 3
Mortality Statistics for Movers

Group	No. of deaths	Total person-years years at risk[a]	Mortality rate[b]
All 1993–1995	45	2552.5	17.6
1993 movers	16	1163.8	13.7
1994 movers	17	939.9	18.1
1995 movers	12	448.8	26.7

[a]Total time between date of transfer from institution and Feb. 12, 1996 (or until death of client for clients transferring in 1993–1995. [b]Number of deaths per 1000 persons-years.

Table 4
Comparison of Movers With Institutional Population

Group	Expected mortality rate[a]	Standardized mortality ratio (SMR)[b]	95% confidence interval for SMR[c]
All causes			
All	11.7	1.51*	(1.10,2.02)
1993 movers	10.9	1.26	(0.72,2.05)
1994 movers	12.2	1.48	(0.86,2.38)
1995 movers	12.6	2.12*	(1.10,3.70)
Cancer-deleted causes			
All	10.5	1.67**	(1.22,2.24)
1993 movers	9.8	1.40	(0.80,2.27)
1994 movers	11.1	1.63	(0.95,2.61)
1995 movers	11.3	2.37*	(1.23,4.14)

Note. Based on data on all persons residing in state institutions at any time between January 1, 1987, and December 31, 1993.
[a]Expected number of deaths based on the Poisson model, divided by the number of person-years at risk. [b]Ratio of observed number of deaths to number expected based on the Poisson model. [c]See Breslow and Day (1987, p. 69) for the method of calculation.
*Significantly different from 1.0 at $p < .05$. **Significantly different from 1.0 at $p < .01$.

Table 4 showed that institutional residents with the same characteristics as the movers had an overall expected mortality rate of 11.7. This corresponds to an standardized mortality ratio of 4.9 (11.7/2.4). The relative risk was 1.51 (17.6/11.7), representing an estimated 51% overall increase in risk-adjusted mortality in the community. The 95% confidence interval for the relative risk is (1.10, 2.02), indicating that the increase was statistically significant at the 5% level.

Client Development Evaluation Report data show that clients with major medical conditions were less likely to be selected for community placement (Table 2). This biases the preceding comparisons in favor of community care. The bias was partially corrected by removal of cancer deaths from the whole analysis. The expected number of community deaths not due to cancer was 26.9, giving a 67% mortality increase (45/26.9 = 1.67; 95% confidence interval, 1.22 to 2.24, $p < .01$). Possibly the 67% increase may be considered the more appropriate figure because persons with critical or terminal medical

conditions are unlikely to be candidates for transfer.

We also explored the use of a binary variable for presence of any severe medical conditions prior to the move. The reduction in expected number of community deaths was 1.0 (from 29.8 to 28.8). Correspondingly, the excess community risk increased from 51% to 56% (45/28.8 = 1.56). We opted not to include medical conditions in our primary analysis because the effect was relatively small and the reliability of the medical data is not known. We note, however, the implication that results presented are conservative, in that our reported excess mortality rates in the community are likely to be underestimates.

The breakdown of the movers according to year of move reveals an interesting trend. The 1993 cohort's standardized mortality ratio (relative to the institutions) was 1.26, while the standardized mortality ratios for the cohorts transferring in 1994 and 1995 were 1.48 and 2.12. The 1995 standardized mortality ratio was by itself significantly larger than 1.0.

Three of the deaths occurred in the group of 13 persons who moved to skilled nursing facilities. This large proportion is not unexpected, given that such facilities serve very severely compromised individuals. A further 3 occurred among the group of 111 who moved to the home of their parents or relatives. This proportion (3/111 = 2.7%) is comparable to the proportion of all the movers who died in the study period (2.4%). This does not support the hypothesis that the overall excess mortality observed among the movers can be explained by "compassionate leave" for terminally ill clients. That hypothesis is also not supported by the lower frequency of severe medical conditions among the movers (Table 2).

Timing

Table 5 shows the distribution of times between transfer and death. There was a trend: Shortly after the move, risk appears to be elevated. For example, 3 of the 45 deaths occurred within the first 10 days after the move, and 10 within the first 60 days. The latter was significantly larger than expected (χ^2 test contrasting number of deaths before and after 60 days, based on expected numbers re-scaled to sum to 45, $\chi^2(1) = 4.51$, $p < .05$. This is a test of the null hypothesis that an individual's mortality risk is constant during his or her time after transfer against the alternative that the risk is different during the first 2 months).

Stratification by Level of Functioning

We stratified the movers into four groups according to two key variables: need for tube feeding and motor skills. The results are given in Table 6, both for all deaths and for deaths excluding cancer. The observed numbers are the same in both cases because no movers died of cancer. The excess community mortality appears to be expressed primarily at the higher functional levels. However, this trend was

Table 5
Observed and Expected Numbers of Deaths Stratified by Time After Move Into Community Care

	Time after the move (days)					
Number	1–10	11–30	31–60	61–240	241+	Total
Observed	3	2	5	9	26	45
Expected[a]	0.60	1.19	1.77	9.73	16.50	29.79
Adjusted expected[b]	0.91	1.80	2.67	14.70	24.92	45

[a]On the basis of institutional rates for comparable subjects. [b]The expected numbers scaled to sum to 45.

not significant (cancer-deleted case, with expected values scaled to total to 45, $\chi^2(3) = 3.4$, $p > .10$.

Table 6
Observed and Expected Numbers of Deaths in the Movers, Stratified by Level of Functioning

	Level of functioning				
Number	1[b]	2[c]	3[d]	4[e]	Total
Observed deaths	7	5	21	12	45
Expected number[a]					
All causes	4.44	5.88	11.42	8.05	29.79
Cancer deleted	4.37	5.75	10.08	6.70	26.90

[a]On the basis of institutional rates for comparable subjects. [b]Persons tube fed, with no motor skills; some were in a persistent vegetative state (Multi-Society Task Force, 1994). [c]Persons either tube fed and having some motor skills, or not tube fed and lacking motor skills. [d]Persons not tube fed and having some, but not all, motor skills. [e]Persons not tube fed and having full motor skills.

Causes of death, determined primarily from death certificates, are summarized in Table 7. The pattern of causes is very different from that of the general population, where cardiovascular disease and cancer account for more than 75% of deaths. It appears that at least some of the deaths (e.g., sudden asphyxia, homicides, and perhaps the seizure deaths) should not occur under optimal conditions.

Table 7
Causes of Death

Cause	No.
Respiratory	11
Cardiovascular	10
Gastrointestinal	7
Seizures	7
Sudden asphyxia	4
Infection	2
Infantile cerebral palsy[a]	1
Homicide	1
Officer-related shooting	1
Unknown[a]	1
Total	45

[a]Death certificate currently unavailable.

Discussion

This is the largest study to assess mortality consequences of a public policy to transfer large number of persons with developmental disabilities from state institutions to community care. The movers group were subject to a significant increase in mortality; the increase was estimated at 51% ($p < .05$, 95% confidence interval for odds ratio: 1.10 to 2.02) or 67% ($p < .01$, 95% confidence interval: 1.22 to 2.24), if cancer deaths were excluded. To the extent that those with serious conditions other than cancer did not transfer, the discrepancy between community and institution becomes even greater. Results of the analysis confirm and extend those of Strauss and Kastner (1996), who reported 72% higher risk-adjusted mortality in the community.

Durkin (1996) noted that previous results showing differential mortality rates favoring institutions over community placements could be spurious because the control was for disability rather than for impairment (loss of function at the level of the organ). Thus, if the community programs are more effective in reducing disabilities, then it is conceivable that those in the community might still be more severely impaired and, therefore, at greater risk of dying. We are not aware of any evidence that such a difference exists. In any event such a bias could not explain the present findings because covariates were assessed *before* clients moved to community placements.

Some may argue that such excess risks for community placement are small or even negligible. In epidemiological terms, however, elevated odds ratios of this magnitude are cause for concern. For instance, a 72% excess mortality risk is comparable to the effect of smoking on heart disease and represents a significant public health problem.

Three types of stratification contributed to a more refined interpretation of the results: (a) cohorts by year, (b) duration of stay in the community, and (c) level of functioning.

Concerning the first point, the earlier study by Strauss and Kastner (1996) was based on the period January 1980 to December 1992. One might suggest that community services have improved since that time, particularly in the medical do-

main. If so, the elevated risk of mortality associated with community placement should be smaller than previously observed. However, the trend in standardized mortality ratios (community compared to institution) for 1993, 1994, and 1995 indicates that the trend is in the opposite direction (see Table 4). These figures take account of differences in risk factors between the three cohorts. Clearly, the 1995 cohort experienced much higher mortality risk than did the 1993 cohort. Note also that institutional baseline data are drawn from a slightly earlier period than are the community data. One possible explanation for the trend is that our statistical adjustment for risk did not fully capture the generally better health of the 1993 movers compared to their institutional counterparts. If that is the case, this study has actually underestimated the community mortality increase, to the extent that the unmeasured differences would dispose to mortality.

Another possible explanation of the higher mortality among those transferred later is that because of the rapid movement of large numbers of people, the group homes best equipped and staffed to provide high-quality care were fully occupied towards the latter part of the study period, and subsequent transfers were to homes where, on average, the care was not as good. If so, the difference we have identified would be expected to persist in future years. This possibility deserves attention in future studies on this population.

Regarding the second type of stratification—duration of stay—risk in the community was significantly elevated shortly after the move, being particularly high within the first 60 days. There may be an interactive process at work, in that although relocation is known to be stressful (Heller 1985), the effects may be particularly strong among people who are the most dependent (Carsrud, Carsrud, Henderson, Alisch, & Fowler, 1979). This phenomenon has been termed the *relocation syndrome* (Kasl, 1972). Much attention has been paid to effects on people with mental retardation of transfer from institutions to community settings, with highly mixed results (Eyman, Borthwick-Duffy, & Sheehy, 1987). Of course, the effects of intra-community transfers also deserve attention, although our data on these transfers are limited.

A more straightforward explanation for the timing effect is that critical medical services for people with serious health complications were less adequate or less timely for community clients. Minihan and Dean (1990) reported that although primary health care services were generally adequate for their sample of persons with mental retardation residing in the community, these individuals had less access to specialized services. High quality specialty care would be particularly critical for those with serious disabilities. In another recent study, Walsh, Kastner, and Criscione (1997) revealed that length of hospitalization was dependent on payment source. Hospital stays were shorter for those whose care was covered by public funds (Medicaid or Medicare). Community health care may be compromised to the extent that clinical hospital services are sensitive to payment source.

Concerning stratification on level of functioning (Table 6), the data suggest that the relative risk in the community was at least as large for the higher functioning movers as it was for those with the greatest disabilities. This is interesting, as one may have expected the relative risk to be largest among the persons with the most medical needs. The findings here were not statistically significant, however, and more data will be required to reach firm conclusions.

The issue of "avoidable" deaths becomes a serious health and legal dilemma. In a detailed study of 14 deaths among community residents in New Jersey, about half were considered preventable (Kastner, Nathanson, & Friedman, 1993). Our own report (Strauss, Anderson, Shavelle, Sheridan, & Trenkle, in press) on the causes of death of the 45 deceased per-

sons in this study is currently under review elsewhere; for this reason, we have not discussed cause of death in detail in the present study.

A limitation of this study is the absence of full medical records on all movers and stayers and detailed information on the new residential arrangements. This information, which is currently unavailable to us, could provide a fuller explanation of the findings reported here. The requisite studies would be complex and would require the full cooperation of numerous public and private agencies. It seems unfortunate that, so far, state and federal agencies have sponsored no analysis of the extensive Medicare data already available. We also note that other states, such as New York, have carried out extensive deinstitutionalization efforts. It would be valuable to know whether the patterns we have observed for California obtain elsewhere.

We emphasize that neither here nor in our related work (e.g., Strauss, Eyman, & Grossman, 1996; Strauss & Kastner, 1996; Strauss, Shavelle, Anderson, & Baumeister, in press) do we argue the relative merits of institutional retention and community placement. Rather, our interest is in the improvement of medical care where it is needed. We conclude by outlining some possible measures for improving health care delivery in the community. No claim is made for originality here, but we believe these suggestions deserve consideration.

1. When transfer from institutions to community care is considered for an individual, the family should be fully informed both of the potential risks and benefits; the individual's health and special needs should be assessed and care taken that the new home is fully able to accommodate these needs.
2. Because the period shortly after the move is one of particularly high risk, movers' health and safety should be monitored especially closely during that time.
3. A computerized data base on all clients served could be established. This would contain, for example, data on all current and previous medications; physical, behavioral, and medical problems; types and amounts of services received; names, addresses, etc. of all caregivers. The data, which would be updated frequently, would be conveniently available to all caregivers and to researchers concerned with evaluating trends and outcomes.
4. As suggested by Walsh (1992) and others, institutions could coordinate the delivery of medical care for persons living in the catchment area. The medical experience and expertise available in institutions would thus be available to serve the larger community population.
5. Staff members in community homes could be trained in basic emergency procedures, such as cardiopulmonary resuscitation and the Heimlich maneuver, and periodically tested to ensure that they retain such skills.
6. *Unannounced* inspections of group homes could be carried out, perhaps by teams of trained family members or other volunteers, to ensure that quality is maintained.

This is, of course, only a very tentative outline of some possible measures. We hope that these ideas will stimulate debate among our colleagues in the field.

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Received 8/6/97, first decision 10/28/97, accepted 12/1/97.

The authors thank the editor, three consulting editors, and two additional reviewers for their thoughtful and detailed comments on an earlier version of this manuscript. The present work was supported by Grants No. HD21056 and HD22953 from the National Institute of Child Health and Human Development. Additional funding was provided by the California Association of State Hospitals—Parents' Councils for the Retarded, and allied groups. Provision of data from the California Department of Developmental Services and the California Department of Health Services is gratefully acknowledged. **Requests for reprints should be sent to David Strauss, Department of Statistics, University of California, Riverside, Riverside, CA 92521, e-mail: strauss@citrus.ucr.edu.**

Appendix

Statistical Modeling of Institution-Based Expected Numbers of Deaths

We used the historic Client Development Evaluation Report data base on all persons who resided in a state developmental center at any time between January 1, 1987, and December 31, 1993. This 7-year interval was chosen as a compromise between (a) having a long period so as to increase precision and (b) being relatively recent, but without great overlap with the study period (when the transfers began to increase). There were 760 deaths based on a total of 47,307.4 person-years of available data, drawn from 9,572 clients.

The 47,307.4 person-years were cross-classified according to the covariates age group, gender, need for tube feeding, motor skills, and self-care skills. Poisson regression was used to model mortality rates for each combination of the predictor variables. As with the standardization with respect to the general California population, these rates were then applied to the exposure time for the community group, resulting in an expected number of community deaths on the basis of institution rates. Because the sole purpose of the modeling here was to derive such expected numbers of deaths, it was desirable to choose a model that (a) contained a relatively large number of terms (to avoid bias) and (b) resulted in an expected number that appeared stable over a wide variety of plausible candidate models.

The following table shows some candidate models that were considered. Not surprisingly, Models 1 and 2, which ignore the important motor and self-care skills variables, were rejected on the basis of the chi-square deviance test (McCullagh & Nelder, 1989, p. 35). For example, the deviance statistic to compare Models 2 and 4 is 11,527 - 11,391 = 136, highly significant as a chi-square with 6 degrees of freedom. Models 3 through 6 give expected numbers of deaths that differ by at most 1.0, and all give satisfactory fits according to the Hosmer-Lemeshow test (Hosmer & Lemeshow, 1989). We chose Model 4 because (a) apart from the age variables, it is the same model as used in Strauss and Kastner (1996), and (b) it is somewhat conservative, in the sense that use of Models 5 and 6 would result in a still larger contrast between movers' and institutions' mortality rates.

Appendix Table
Candidate Models for Prediction of Expected Numbers of Deaths in the Community Group

Model number/terms	*df*[a]	−2 ln(L)[b]	*p*-value for fit[c]	Expected number of deaths[d]
1. Age[e]	15	11,935	0.00	42.8
2. Age, gender, feed tube[f]	17	11,527	0.12	34.4
3. Age, gender, feed tube, Motor[g]	20	11,392	0.08	30.1
4. Age, gender, feed tube, Motor, Self	23	11,391	0.14	29.8
5. Model 4 + two-way interactions with feed tube	35	11,377	0.16	29.6
6. Model 5 + interactions of age and gender	50	11,361	0.74	29.1

Note. Data were based on institutions in 1987–1993. Model 4 was selected as the basis for subsequent comparisons. [a]Degrees of freedom. [b]Negative of twice the logarithm of the likelihood function. If one model is a submodel of another, the difference of the two statistics is a deviance statistic that may be compared to the χ^2 distribution. [c]According the Hosmer-Lemeshow (1989) test, a χ^2 test with eight degrees of freedom in each case. [d]Model-based expected number of deaths for the movers' group if they had remained in the institutions. [e]Age, stratified as under 1 year, 1 to 4 years, 5 to 9 years, 10 to 14 years, and so on. [f]Binary variable for presence/absence of gastrostomy tube. [g]Motor skills were coded as none, poor, fair, and good. See text.