Deinstitutionalization and Mortality: Findings of a Controlled Research Design in New Jersey

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Abstract

In previous studies of the mortality of deinstitutionalized persons with disabilities in California and Pennsylvania, investigators failed to employ a prospective controlled research design. We identified a sample of 150 "movers" scheduled for placement from an institution and a matched sample of 150 institutional "stayers." The matching and other risk variables were measured in 1994. Visits to all residences occurred between 1997 and mid-2000 at specified intervals after movers left the institution. Logistic regression analyses identified the 1994 preclosure risk variables of age, low self-care, medical conditions, and epilepsy/seizure disorders as the best ones for explaining all deaths. Adding mover/stayer status and community/institutional placement to the analyses did not enhance the model. Nursing home placements emerged as a postclosure risk variable.

In a recent review of research studies of the mortality of persons with developmental disabilities living in a variety of residential placements, conducted between 1960 and 1997 in the United States, Hayden (1998) identified 24 studies deemed worthy of analyzing. Eleven of the 24 studies compared mortality rates between consumers in two types of residences. In her review, Hayden noted that the researchers in California were "the first to suggest" that there might be higher rates of mortality associated with residence in the community compared to living in institutions. These studies, together with more recent updates, found that persons placed in the community were associated with a higher rate of mortality than those living in institutions—even after controlling for such risk variables as age, ambulation, motor skills, and self-care skills of eating and toileting (Strauss, Eyman, & Grossman, 1996; Strauss & Kastner, 1996; Strauss, Kastner, & Shavelle, 1998; Shavelle & Strauss, 1999). Not surprisingly, these studies aroused a great deal of attention among researchers and service delivery personnel.

In an effort to replicate the California findings of Strauss and his co-researchers, O'Brien and Zaharia (1998a) examined a California deinstitutionalized sample covering the years 1993–1995 as well as an institutionalized sample covering the years of 1991–1995. In contrast to the findings of the Strauss team, O'Brien and Zaharia (1998b) concluded that persons who moved into community placements "were at no increased risk of death" (p. 379). They noted that a major source of the discrepancy in findings between the Strauss team studies and theirs was due to the misclassification by Strauss et al. (1998) of over 50 deaths as community placements instead of correctly assigning them as institutional residents. However, independent reviewers from the Centers for Disease Control noted that O'Brien and Zaharia probably undercounted the number of actual deaths by relying on state developmental source data instead of the vital statistics used by the Strauss team from the State Department of Health for the same population and time periods (Decoufle, Hollowell, & Flanders, 1998). They concluded that they were not convinced by either study.

Results of both studies raised questions and concerns about relying on official sources that yielded incomplete or erroneous information (Taylor, 1998). In addition, both studies were limited because the investigators relied on a weak research design. As O'Brien and Zaharia (1998b) concluded, neither group of investigators used data that were

"obtained from controlled studies" based on "a formal research design" (p. 408). For example, the time periods for the collection of risk variables varied widely within the populations studied because only the last state evaluation reports were used by the research teams. Therefore, variables included in Strauss et al.'s studies (Strauss & Kastner, 1996; Strauss et al., 1998) could have been measured any time between January 1985 and December 1994. A controlled research design would have specified a comparable time period for measuring risk variables for all persons included in the study. In addition, in a controlled research design, investigators would have relied on data they collected for specific times of risk exposures—and not on incomplete or unreliable official records.

In an effort to improve on the methodological limitations of the California studies, in our study of mortality in New Jersey, we used a prospective research design that:

1. Identified a representative mover sample from one institutional closure that was initiated in January 1997 and then prospectively followed these consumers at their new places of residence 3, 15, and 27 months after leaving the institution;
2. Constructed a comparison sample of persons (i.e., stayers) remaining in the seven other state institutions (DD Centers) who were matched with the movers on age, gender, multicognitive competencies, self-care skills, mobility, and inappropriate behaviors towards others and self (we measured these competencies and behaviors in 1994, well before the mortality evaluation period of 1997 to 2000, using reliable data-collection techniques and instruments);
3. Assessed the actual whereabouts and mortality status of movers and stayers by physically visiting their residential sites 3, 15, and 27 months after the closure using research staff we hired, trained, and supervised; and
4. Identified all significant pre-1997 risk variables that were statistically associated with mortality for both groups and then assessed whether community placements or movers' status increased the risk of dying by employing a series of multivariate logistic regression procedures.

In this paper we present data documenting the implementation and findings of this controlled research design for an institutional closure in the state of New Jersey. Postclosure data were collected during 1997–2000. To the best of our knowledge, this type of prospective controlled research design of the mortality of deinstitutionalized persons has not yet appeared in the literature (Hayden, 1998; Horowitz, Kerker, Owens, & Zigler, 2000). The 1998 study of the closing of Pennhurst in Pennsylvania included a prospective follow-up of deinstitutionalized persons, but the investigators compared their mortality rates to the "expected" mortality rates they might have had if they had not moved out of the state institution (Conroy & Adler, 1998). In a recent study Hsieh (2001) reported in a newsletter published by the University of Illinois Department of Disability and Human Development that 10 years of prospective mortality data were used, but only a sample of persons who "resided in nursing homes as a baseline" was referred to.

Method

Instruments

The primary data source for constructing matched groups of movers and stayers was the New Jersey Client Assessment Form, developed by staff of the Developmental Disabilities Planning Institute in 1994 after reviewing existing forms used by the states of California, Connecticut, and New York and conducting pilot studies. The items constructed for this instrument were initially designed to assess specific domains or areas of functioning by relying on the responses of knowledgeable caregivers for a random sample of 1,190 persons residing in eight New Jersey DD Centers. The forms were completed in 20 to 30 minutes, and completion was supervised by DD Planning Institute staff. All data analyses were conducted using SAS software Version 6.12. First-order factor analyses (we employed orthogonal and oblique rotations via Varimax and Promax procedures, respectively) revealed that six distinct domains were assessed: (a) Cognition: 16 items referring to knowledge of space, time, color, size, reading, etc.; (b) Communication: 12 items referring to understanding and using speech; (c) Mobility/Motor Control: 10 items referring to ambulation and motor skills; (d) Self-Care: 21 items referring to basic skills of eating, drinking, and toileting as well as independence and household skills; (e) Socio-Emotional Functioning: 13 items referring to sociability, friendliness, and caring for others; and (f) Special Behaviors: 24 items

referring to disruptive and aggressive behavior towards others and self.

After the initial domains were statistically verified, we conducted additional second-order factor analyses in order to examine any possible overlap between factors associated with each domain of functioning (using Varimax and Promax rotation procedures). Second-order factor analyses of the 41 items that constituted the initial domains of Cognition, Communication, and Socio-Emotional Functioning revealed that there was indeed overlap among these three areas. All of the 41 items actually referred to a single broader domain of "Multicognitive" Functioning.

The 10 items referring to ambulation, motor control, and physical skills continued to function as a distinctive single domain and did not load with the multicognitive items in the second-order factor analyses. In contrast, the 21 self-care items loaded at a high level on both the Multicognitive and Mobility domains. The Self-Care domain was, therefore, conceived as an overlapping domain, dependent on both multicognitive and mobility competencies.

Separate second-order factor analyses of the special behavior items revealed that two specific domains were assessed: (a) 13 items referring to aggressive and inappropriate behaviors towards others, such as hitting and threatening others; and (b) 11 items referring to harmful and inappropriate behaviors towards self, such as head-banging and excessive scratching.

In order to test the reliability of these findings over time, we conducted a special test–retest study on a random sample of 350 of the original 1,190 consumers. The same staff caregivers were asked to complete the assessments 15 to 18 months later. The test–retest correlation coefficients between Time 1 and Time 2 were .94 for Multicognition, .98 for Self-Care, and .94 for Mobility/Motor skills. The behavior domains had lower levels of stability because the Time 1 versus Time 2 correlation coefficients were .78 for Behavior Towards Others and .73 for Behavior Towards Self (Jagannathan, Camasso, Lerman, Hall, & Cook, 1997). These results indicated that the behavioral measures were only moderately reliable compared to the strong results for the competency measures.

Besides competency and behavioral information about 1,190 persons, data were collected in 1994 on age, gender, medical conditions, medical treatments, psychiatric diagnoses and medications, types of residential cottages (i.e., medical or behavioral), the use of wheelchairs or other special aids, and family contacts. These items, as well as the matching variables, were considered to be candidates for potential risk variables in assessing mortality after 1997, based on a review of past studies (Hayden, 1998).

Sample

The study of mortality differences was part of a larger evaluation research design of the closure of a New Jersey DD Center—the North Princeton Developmental Center. This evaluation was designed to assess the quality of life and well-being of movers compared to stayers. As noted earlier, a 1994 sample of 1,190 persons from each of the eight DD Centers, including the North Princeton Center, were assessed using the New Jersey Client Assessment Form. A representative sample of North Princeton Developmental Center persons constituted the basis of the mover sample, and the random sample of those remaining in the other seven DD Centers constituted the pool of persons that could be matched as the stayer sample.

The initial mover sample assessed in 1994 consisted of 171 persons, including an oversampling of residents of medical cottages. However, by Spring of 1996, only 150 North Princeton Developmental Center persons remained in the institution because a total of 21 persons had been relocated prior to the initiation of closure placements scheduled for January 1997 or had died. Therefore, the provisional mover sample used in the mortality study consisted of 150 persons who were residents of North Princeton Developmental Center in Spring 1996.

By January 1997, further attrition of the proposed mover sample had occurred, so that 140 of the 150 persons eligible for placements remained. Therefore, an additional 10 persons were randomly chosen from the pool of remaining eligible movers to complete the final mover sample. These 10 persons were assessed with the New Jersey Client Assessment Form used in a 1996 study of the North Princeton Developmental Center population, and these assessments were used for finding matching stayers. The remaining 140 movers had 1994 and 1996 assessments, but for matching purposes only the 1994 assessment data were used to find their stayer matches. This was deemed necessary because we only had 1994 data for the pool of stayers who had not been included in the 1996 test–retest study

of instrument reliability. Of the 150 individuals in the final mover sample, there were 14 persons who resided in a medical cottage prior to January 1997.

The major characteristics of the final mover sample, as well as their stayer matches, are presented in Table 1. Using the characteristics of the final 150-person mover sample for matching, we constructed the stayer sample by finding persons in the other DD Centers who had been assessed in 1994 using the following characteristics in sequential order:

1. *Gender:* An exact gender match was found for each mover, resulting in an equal proportion of males and females (59% and 41%, respectively) in the mover and stayer samples.
2. *Age:* For the final matching for age, we used three stratification groups: young (18 to 34 years); middle (35 to 49 years); and mature (50 years and over). As can be seen in Table 1, the mean age of the movers and stayers was 52.4 and 52.2 years, respectively, a nonsignificant difference.
3. *Competency measures:* After obtaining comparable age and gender groupings, each group was then sequentially matched by multicognitive, self-care, and mobility scores. The matching was done by comparing the raw scores or rank orders for the competency measures, based on the distribution of 1994 scores. If a match on the exact raw scores could not be achieved, then movers and stayers were matched by their decile ranks on each specific competency score. Table 1 displays how comparable the movers and stayers were, based on the final average raw scores for each group. It is evident that the average scores for mover and stayer samples are quite close. Any observed differences were not statistically significant.
4. *Behavior scores:* After matching on the previous five characteristics, we conducted matches on the raw behavior scores towards others and self. Again, decile rankings were used when needed to find stayers that were comparable to the final mover sample. The raw scores of movers and stayers depicted in Table 1 are quite comparable and are not statistically significant.

Methods of Assessing Deaths

The first awareness that any deaths had occurred became apparent at the 3-month site visits to movers and stayers. Because movers left North Princeton Developmental Center at staggered times after January 1997, all movers and their stayer matches were provided with individualized follow-up dates at 3, 15, and 27 months after movers left the center. Therefore, the number of deaths was assessed at each follow-up during similar lapses of time for movers and their respective matched stayers, namely, between 0 and 3 months, 3 and 15 months, and 15 and 27 months.

At each time period, the actual whereabouts of each mover and stayer were established in order to interview staff and the consumers (whenever possible). When told by the contact person at each community or institutional site that the mover or stayer had died since the last time of contact, research staff members were instructed to find out the date and cause of death. Unfortunately, they were often unable to report the precise cause of death. A review of a sample of death certificates indicated that the primary and secondary reasons cited for the cause of death appeared to be quite general and lacked the precision of a diagnosis. A broader research effort, with trained medical professionals, would have been necessary to track down the precise cause of deaths. Therefore, we only coded the most reliable information available—the exact dates of deaths. For the purpose of the analyses to follow, *deaths* refer to confirmations by research staff members that movers or stayers had died on known dates between a specified time period since the onset of the relocation of the movers.

Analytical Design and Statistical Methods

Although the movers and stayers were initially matched on the seven variables depicted in Table 1, there were many other variables that were measured in 1994, but not controlled (e.g., presence of autism, cerebral palsy, epilepsy/seizure disorders, chronic medical conditions, special medical treatments, and residence in a medical cottage). These nonmatching variables can be considered as potential candidates as preclosure risk factors in explaining the likelihood of dying within 27 months, as can the matching variables.

It is important to note that 103 movers initially moved to group homes, and 7 moved to supervised apartments. The other 40 movers relocated to nursing homes (n = 17) or to other DD Centers or private congregate facilities (n= 23). The decision to relocate the 40 movers to alternative institutional-type residences was made by DD placement staff during a lengthy time period of preparing individual

Table 1 Comparison of Final Mover and Stayer Samples on Key Matching Characteristics

Characteristics	Final evaluation samples	
	Movers (n=150)	Stayers (n=150)
Age (mean)		
Total sample	52.4	52.2
By age group		
18–34 (*n*=14 matched pairs)	31.6	29.8
35–49 (*n*=56 matched pairs)	42.4	43.0
50 and over (*n*=80 matched pairs)	63.1	63.7
Gender		
Male	59%	59%
Competency scores[a] (mean)		
Multicognition (range of scores = 0–54)	23.3	22.1
Self-care (range of scores = 0–63)	24.2	24.7
Mobility (range of scores = 0–24)	18.5	18.5
Inappropriate behavior scores[b] (mean)		
Towards others (range of scores = 0–64)	11.8	11.5
Towards self (range of scores = 0–50)	4.5	5.2
Official retardation assessment[c] (%)		
Mild/borderline	13.5	14.8
Moderate	13.5	14.1
Severe	23.7	14.8
Profound	49.3	55.7
Not determined	0.0	0.7

Note. 1994 data were used for all except 10 movers who replaced original sample members as noted in the text.

[a]The range of scores noted for each competency and behavior measure is based on the actual distribution of scores for the original random sample for all eight DD Centers in 1994 (*N*=1,190). The average mover competency scores are significantly higher than the scores of the remaining seven DD Centers and are, therefore, not representative of the other DD Centers. The stayers, because they were matched to the movers, also have higher competency scores than do those in the remaining seven DD Centers. [b]There are no differences in the average behavior scores between the movers and stayers and the remaining seven DD Centers. [c]These assessments were not used for matching, but are presented for informational purposes. The dates of the official assessments are not noted in the official records and are unknown.

consumer assessments of medical, daily care, and social needs. A full analysis of the mortality impact of moving into the community must take into account those who did and did not relocate into community-based residences, such as group homes or supervised apartments, and use this information as a potential postclosure risk variable.

Another consideration involved taking into account the stability of placements that occurred after the initial placement. Of the 150 movers, a total of 39 moved one or more times after their initial placements. Only 5 of the 150 stayers moved one or more times during a similar time period. The potential risk of multiple placements on mover mortality was, therefore, examined but was found to be nonsignificant. Of the 22 mover deaths, only

1 person had two or more placements, meaning that 21 of the 22 mover deaths occurred in their initial placements. Therefore, in the analyses we paid primary attention to initial placements.

In order to assess whether preclosure and postclosure variables, either separately or in combination, made a significant contribution in explaining the likelihood of dying for the entire sample, we felt that it was necessary to decide on a statistical model of analysis. The model chosen, logistic regression analysis, is designed to yield a minimum amount of statistical error if the outcome variable to be explained is dichotomous (i.e., such as dying/not dying or having a stroke/not having a stroke). Researchers conducting public health studies of strokes, blood clots, and breast cancer employ logistic regression procedures in order to assess the relative likelihood of various risk factors in raising or decreasing the odds of dying (Hosmer & Lemeshow, 1989).

The first step in conducting logistic regression analyses involves identifying unique variables that are candidates for being considered as risk factors that increase the odds of explaining deaths. Hosmer and Lemeshow, in their influential text on applied logistic regression (1989), suggested that each risk factor be carefully identified in terms of its statistical probability, the relative increase in the odds of being an important explanatory variable, and whether it can help create a model that is better than if the variable were omitted. In order to make sure that we carefully consider potential risk candidates, we followed their suggestion that the initial level of statistical significance be .25, rather than the customary .05 level. In the analyses that follow, individual preclosure variables are first identified, and then considered together to find the "best model" that explains deaths. After this model is identified, the ability of any postclosure variables (e.g., type of placement) to enhance the likelihood of dying within 27 months after the closure of the institution is then assessed.

Results

Number of Deaths by 3, 15, and 27 Months

By the time of the first follow-up at 3 months, a total of 9 persons had died: 4 movers and 5 stayers. At 15 months, a total of 23 persons had died: 13 movers and 10 stayers. By the time of the last follow-up at 27 months, 35 individuals were recorded as deceased by research staff: 22 movers and 13 stayers.

The crude rate of deaths for the 150 movers at 27 months, without controlling for type of placement or other risk variables, was 14.7% compared to a rate of 8.7% for the 150 stayers. Using a test of proportions, we found that this difference had a statistical probability of $p < .11$, almost approaching a level of statistical significance (using $p < .05$ as a standard). A closer examination of the 35 deaths, using risk variables and types of placements in a series of logistic regression analyses, was performed to clarify whether deinstitutionalization increased or decreased the risk of dying during the 27-month evaluation period.

Assessing the Risks of Specific Variables

Table 2 lists two major types of risk variables for the total sample that were deemed to be potential candidates for additional multivariate analyses: preclosure 1994 variables that were assessed long before the mortality evaluation period and the postclosure initial placement variables of mover/stayer status and placement types.

Of the 12 variables listed in preclosure, 10 variables were clearly deemed to be significant and candidates for inclusion in a multivariate search for the "best model" for explaining the deaths. The last 2 variables—multicognition and gender—were not associated with a mortality risk. Both gender and multicognition have a significance level above .25 and were, therefore, excluded from further logistic analyses (as recommended by Hosmer and Lemeshow, 1989).

The variables are listed in the order of the strength of the odds ratios, or the likelihood that this specific variable by itself could account for the 35 deaths. For example, age is coded as below 60 years (with a value of 0) or 60 years and above (with a value of 1) in 1994. The odds are more than 8 to 1 that persons 60 years and above are likely to die in this total sample of 300 persons by the 27-month anniversary date. The remaining significant variables and their odds ratios can be described as follows:

1. *Medical condition (7.52:1 odds ratio)*: The New Jersey Client Assessment Form listed 14 medical conditions (e.g., cardiovascular, digestive, genital/urinary, cancer or other tumors, endocrine/hormone, swallowing dysfunction, or

Table 2 Risk Variables Associated With Mortality by 27 Months

Variable	Association with probability of being deceased	Odds ratios for 27-month deaths
Preclosure 1994		
Age (<60/60+)	.0001	8.06:1
Medical conditions (0/1+)	.0002	7.52:1
Mobility (high/low)	.0001	5.82:1
Medical treatments (0/1+)	.0001	4.22:1
Turning/positioning (no/yes)	.0005	3.62:1
Self-care (high/low)	.0018	3.54:1
Behaviors towards self (high/low)	.003	3.21:1
Epilepsy/seizure disorder (no/yes)	.002	3.12:1
Lived in medical cottage (no/yes)	.024	2.42:1
Behaviors towards others (high/low)	.043	2.15:1
Multicognition (high/low)	.649	1.18:1
Gender (female/male)	.606	0.83:1
Postclosure initial placement		
Community/institution	.02	2.98:1
Mover status (stayer/mover)	.07	1.81:1
Nursing home (no/yes)	.0001	6.99:1

Note. For each variable, $df = 1$ using total sample.

spastic quadriplegia) that caregivers responded to with a yes or no. Any person having at least one condition was coded as 1 and those with none as 0.

2. *Mobility (5.81:1 odds ratio):* The 10 mobility items (discussed earlier) were coded as below the median score (1) or above the median (0) for the total sample of movers and stayers.
3. *Medical treatments (4.22:1 odds ratio):* The New Jersey Client Assessment Form listed 9 types of special medical treatments (e.g., including ostomy, catheterization, tube feeding, dialysis, or suctioning once per day). All persons having one or more treatments were coded a 1 and those who did not receive them were coded as 0.
4. *Turning/positioning (3.62:1 odds ratio):* If persons were turned or positioned to protect skin integrity and to prevent rashes, they were scored as 1 and if not, 0.
5. *Self-care (3.54:1 odds ratio):* The 21 items (discussed earlier) were coded as below (1) or above the median scores (0) for the total sample of movers and stayers.
6. *Behaviors towards self (3.21:1 odds ratio):* The 11 items (discussed earlier) were coded as below (0) or above the median (1) scores for the total sample of movers and stayers.
7. *Epilepsy/seizure disorder (3.12:1 odds ratio):* The single item was coded as yes (1) or no (0) if this disability were present/absent in 1994.
8. *Lived in medical cottage (2.42:1 odds ratio):* All persons living in a medical cottage in 1994 were coded as yes (1) and those who did not were coded as no (0).
9. *Behavior towards others (2.15:1 odds ratio):* The 13 items (discussed earlier) were coded as below (0) or above the median (1) score for the total sample of movers and stayers.

Table 2 also indicates that two of the three postclosure initial placement variables—community/institution and nursing home—were statistically significant using the .05 level as the criteria. However, because the stayer/mover variable (coded as 0 or 1) had a probability below .25, it could also be used in a multivariate logistic regression analysis (Hosmer & Lemeshow, 1989). All persons who were initially placed in a group home or supervised apartments were coded as living in the community (0) and all persons living in a DD Center, nursing home, or any other congregate facility were coded as living in an institution (1).

Identifying the Best Statistical Model, Using Preclosure Data

All of the 10 risk variables listed in the preclosure variables in Table 2 as statistically significant were assessed simultaneously in several analytical stages in order to retain the maximum number of deaths in the analyses. Tables 3, 4, and 5 provide the findings of the multivariate logistic regression analyses that relied on the four best preclosure 1994 risk variables that emerged to predict the persons who died by the time of the 27-month follow-ups (which began in January 1997 and ended in August 2000). The analysis used the total sample of 300 persons in order to assess the relative importance of

Table 3 Full Statistical Model Using 1994 Variables to Predict Deaths at 27 Months, Using the Total Sample

		Ordered value	Deceased	Count
		1	1	35
		2	0	264
		Simple statistics for explanatory variables		
Variable	Deceased	Mean	*SD*	Minimum	Maximum
Age	1	0.628571	0.490241	0	1.000000
	0	0.174242	0.380038	0	1.000000
	Total	0.227425	0.419872	0	1.000000
Self-care	1	0.742857	0.443440	0	1.000000
	0	0.446970	0.498124	0	1.000000
	Total	0.481605	0.500499	0	1.000000
Epilepsy	1	0.600000	0.497050	0	1.000000
	0	0.325758	0.469547	0	1.000000
	Total	0.357860	0.480174	0	1.000000
Med. cond.	1	0.885714	0.322803	0	1.000000
	0	0.507576	0.500892	0	1.000000
	Total	0.551839	0.498139	0	1.000000

Note. 1996 data were used for movers without 1994 data.

each risk variable when statistically controlling for the other three variables.

Using logistic regression on data for the entire sample, the model explained the 35 deaths and the 264 persons still living by 27 months with information available for all 4 variables. Information about medical conditions was missing for 1 person still living, and, therefore, the total sample was reduced from 300 to 299. The proportions of persons who are dead or living are presented for each variable in Tables 3–5. Compared to Table 2, when age was considered alone, the result in Table 5 indicates an improvement in the odds ratio for age when the other high risk variables are present (from 8.06 to 10.95 odds ratio). Age is clearly the most important risk variable in the model.

When each of the remaining variables is considered, it is evident that each remains statistically significant and well below the .25 cutoff point recommended by Hosmer and Lemeshow (1989). However, the level of significance and odds ratio has been reduced in the multivariate analysis, compared to the univariate analysis depicted in Table 2. The following odds ratios have been reduced when the 4 risk variables are assessed simultaneously: self-care from 3.54 to 2.88:1; epilepsy/seizure disorder from 3.12 to 2.86; and medical conditions from 7.52 to 4.71.

Considering the model in its entirety, it is evident that this combination of variables is statistically significant, $\chi^2(4, N = 299) = 60.25$, $p = .0001$. Any addition of postclosure variables would have to improve on the statistical results for the entire model as well as provide evidence

Table 4 Model Fitting Information and Testing Global Null Hypothesis BETA=0

Criterion	Intercept only	Intercept and covariates	χ^2 (4) for covariates
AIC	217.890	165.645	—
SC	221.590	184.147	—
−2 LOG L	215.890	155.645	60.245*
Score	—	—	58.305*

Note. 1996 data were used for movers without 1994 data.
*$p < .0001$.

Table 5 Analysis of Maximum Likelihood Estimates

Variable	*df*	Parameter estimate	Standard error	Wald χ^2	Pr > χ^2	Standardized estimate	Odds ratio
Intercept	1	−5.2448	0.7259	52.2019	0.0001	—	—
Age	1	2.3935	0.4517	28.0780	0.0001	0.554066	10.952
Self-care	1	1.0592	0.4834	4.8021	0.0284	0.292285	2.884
Epilepsy	1	1.0513	0.4439	5.6099	0.0179	0.278312	2.861
Med. cond.	1	1.5505	0.5844	7.0394	0.0080	0.425828	4.714

Note. 1996 data used for movers without 1994 data.

that added variables were statistically important, $p < .25$.

Identifying the Best Statistical Model by Adding Postclosure Variables

Using the 4 variables identified as the critical preclosure risk variables that must be controlled for in order to assess the influence of any postclosure variables on mortality, Table 6 provides the results for entering stayer/mover status, community/institution, and nursing home status, respectively.

When the mover/stayer status variable is added to the best preclosure model, the probability is only .289 that this variable adds any improvement to the initial 4 variables. In fact, the probability of mover/stayer status having an impact has increased from .07 (Table 2) to .289 (Table 6). In addition, the total chi-square for the new model remains virtually the same as the best preclosure model. Therefore, we can infer that adding stayer/mover status does not improve the findings of the best preclosure model.

Table 6 Best Statistical Model Predicting 35 Deaths, Using Both Pre- and Postclosure Variables

	Levels of significance		
Variable	Add mover/ stayer	Add community/ institution	Add nursing home
Age (<60/60+)	.0001	.0001	.0001
Self-care (high/low)	.028	.028	.021
Epilepsy (no/yes)	.018	.018	.122
Medical conditions (0/1+)	.008	.008	.023
Stayer/mover	.289	NA	NA
Community/institution	NA[a]	.447	NA
Nursing home (no/yes)	NA	NA	.001

[a]NA = data do not apply to these analyses.

Moving to community versus institution, it is evident that categorizing the total sample by community/institutional status does not improve the model. The probability of this variable is .447. Therefore, we can infer that adding community/institution status does not improve the findings of the best preclosure model.

The results when entering the information about initial nursing home status are clearly different than using the other postclosure variables. The nursing home variable has a probability of .001, even when controlling for the best preclosure variables. Although the level of significance for age and self-care remains approximately the same, the epilepsy probability has decreased from .018 to .122, and the medical condition has decreased from .008 to .023. In addition to these changes, the chi-square of the entire model has increased beyond what might have been expected by chance (table not shown). Therefore, there is one postclosure variable that is statistically significant and improves the best preclosure model. A further analysis of nursing home placements is clearly warranted.

Assessing Nursing Home Placements

Out of 18 placements in nursing homes, 17 were movers. It is clear that staff from DD Centers in New Jersey rarely transferred consumers to this type of care facility. Further analysis revealed that 16 of the 17 movers placed in nursing homes had no additional moves prior to their deaths; therefore, stability of placements was not an issue. Besides placement stability, the length of time that persons in nursing homes survived after their initial place-

ments was examined. Those who died had survived for an average time of 640.4 days, whereas those who died in all other placements survived an average of 562.4 days since January 1997. Because this difference could have occurred by chance, $p < .49$, it is evident that placement in nursing homes did not hasten the deaths of those placed in this type of residence.

An analysis of the 1994 risk variables associated with nursing home placements (for the entire sample) indicated that the following were statistically significant: being 60 years or older, having low self-care scores, having an epilepsy/seizure disorder, and having one or more medical conditions. When these preclosure variables were simultaneously examined together with 3-month postclosure medical information, the following odds ratios were obtained in a multivariate logistic regression analysis:

1. 1994 age (60 years plus): odds ratio of 15.2:1, $p < .0001$
2. 1994 epilepsy/seizure disorder: odds ratio of 6.2:1, $p < .008$
3. 1994 medical conditions (1+): odds ratio of 4.2:1, $p < .10$
4. Post 3-month medical treatments (1+): odds ratio of 6.6:1, $p < .004$

It is evident that persons with a concentration of prior medical risk conditions and who are older are more likely to be placed in nursing home care. Persons with one or more recent medical treatments at 3 months, such as turning positioning, special feeding, and frequent medical injections, were also more likely to be selected to be placed in nursing homes. Case managers responsible for postclosure placements appear to have used a concentration of high-risk variables as indicators for utilizing nursing homes.

Reassessment of the Mover/Stayer Sample

A review of the critical preclosure 1994 variables that have emerged as important in the analysis of deaths or nursing home placements indicate that 2 (age and self-care) were used in the matching of the mover/stayer sample, whereas 2 (epilepsy/seizure and one or more medication conditions) were not used in the matching of samples. A reexamination of the total sample revealed that 44% of the movers had seizure disorders compared to only 27% of the stayers, $p < .003$. An analysis of 1994 medical conditions did not reveal any statistical difference between the movers and stayers. In addition, there were no sample differences with regard to medical treatments at 3 months.

In order to confirm the finding that the movers had a significantly higher proportion of persons with epilepsy/seizure disorders than stayers at the outset of the study, we undertook a fuller multivariate reanalysis of the final matched samples. Age, gender, the other 5 matching variables (recoded as below and above the median), and the presence of epilepsy/seizure disorders were entered into a multivariate logistic analysis to predict mover/stayer status. The only variable that proved to be statistically significant was epilepsy/seizure disorder, $p < .002$, odds ratio of 2.31:1. The finding that the movers began the evaluation period with a *higher* risk of dying because of a higher prevalence of epilepsy/seizure disorders was, of course, not known at the outset of the study. After completing the study, we discovered that North Princeton Developmental Center had been used as a special facility for persons with epilepsy until the early 1950s.

Discussion

The death ratio of 150 movers who left a New Jersey institution was quite comparable to a matched group of 150 stayers at 27 months, after controlling for critical high risk variables. The evidence from this study clearly indicates that being a mover or having stability in placement did not account for differentials in the rates of deaths. Rather, it was specific risk variables that best explained who was more likely to die in the 27 months since the institutional closure process was initiated (from January 1997 to August 2000).

A detailed statistical analysis revealed that those 60 years and above in 1994 had an odds ratio of 7.9:1 in predicting death by 27 months. In addition, those with other 1994 risk variables (e.g., having medical conditions, low self-care scores, and epilepsy/seizure disorders) had significant odds ratios between 2.1:1 and 3.9:1 in predicting deaths by 27 months. Adding mover/stayer status or institutional/community residence as variables did not change the explanatory power of the model in predicting those who died by the 27-month follow-up dates. Only adding the postclosure variable of nursing home placements improved the strength of the model.

Additional analyses disclosed that persons designated to live in nursing homes were much more likely to be persons with high risk variables in 1994,

namely, they were more likely to be older, have epilepsy/seizure disorders, and have one or more medical conditions. In addition, persons chosen for nursing home placements also received more medical treatments postclosure at 3 months.

These findings differ from the California study authored by Strauss, Kastner, and Shavelle (1998). These differences could be due to the variability in the deinstitutionalization policies and practices of the state agencies, characteristics of the state populations, or different time periods. However, it is also important to note that this study differs from the California study in certain important methodological respects:

1. This design is prospective rather than retrospective.
2. It is based on obtaining first-hand knowledge from care staff about all deaths rather than relying exclusively on archival records.
3. Measurements in this study of preclosure 1994 risk variables were performed "blindly" by DD Planning Institute staff without knowing of any deaths that occurred on future dates.
4. We relied on creating matched samples of movers and stayers on important developmental disabilities rather than using only statistical procedures to create comparable samples.
5. This study has a single exposure time rather than varying starting points and cut-off dates.
6. We employed research staff to actually identify the living arrangements at each follow-up prior to deaths rather than relying on incomplete records of the whereabouts of agency consumers.

There are, however, several limitations in generalizing our findings. First, this study pertains to only one institutional closure in one state. Second, the behavioral variables used in this study were only moderately reliable and may have affected the findings. Third, we were unable to measure the quality of health care, including routine care and supervision, as potential risk variables in any setting. Finally, it is important to note that the findings are limited by the amount of time that was used to assess deaths. If the time period were extended beyond 27 months, more persons would have died and the final model might have been different. There is clearly a need to determine whether similar risk variables within a defined time period would emerge in other states, using a controlled prospective research design.

Meanwhile, further research is clearly necessary to identify risk variables that are amenable to monitoring for preventive purposes and not just to expand our knowledge about mortality. The importance of epilepsy/seizure disorders, for example, has emerged in this study and in other studies as a disability associated with an increased risk of death (Hsieh, 2001; Isager, Mouridsen, & Rich, 1999; McKee & Bodfish, 2000; Sperling, 2001). States should be encouraged, with proper medical consultation, to update their regulations and procedures for monitoring and controlling seizures because even infrequent seizures might pose an increased risk of death (Sperling, 2001).

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