Deinstitutionalization in California: Mortality of Persons with Developmental Disabilities after Transfer into Community Care, 1997-1999

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Abstract: More than 2,000 persons with developmental disability transferred from California institutions into community care during 1993 to early 1996. Using data on 1,878 children and adults moved between April 1, 1993 and March 5, 1996, Strauss, Shavelle, Baumeister and Anderson (1998) found a corresponding increase in mortality rates by comparison with those who stayed behind. Shavelle and Strauss (1999) updated the study through 1996 and found similar results. The present study is a further update through 1999. There were 81 deaths, a 47% increase in risk-adjusted mortality over that expected in institutions ($p < 0.01$). As in the two previous studies, we found that persons transferred later were at higher risk than those moving earlier, even after adjustment for differences in risk profiles. The difference cannot be explained by the short-term effects of the transfer, and therefore appear to reflect an increased mortality rate associated with the less intensive medical care and supervision available in the community.

Key words: Community care, developmentally disabled, epidemiology, excess death rate, institutions, mortality, standardized mortality ratio.

1. Introduction

Budgetary constraints in the United States in general, and California in particular, have forced a re-examination of policies for caring for the developmentally disabled. Many states in the U.S. now have waiting lists for services, and only limited offerings once service is established. California is unique in that care for the developmentally disabled is an entitlement, mandated by the Lanterman Developmental Disabilities Services Act of 1969. The Act guarantees people with developmental disabilities the right to the services and supports they need to live like people without disabilities (Department of Developmental Services, 2001). A developmental disability is defined by the State of California as a condition arising prior to age 18, which is permanent and will affect the child's ability to care for himself/herself. Examples include cerebral palsy, autism, down syndrome and mental retardation.

Deinstitutionalization is a sensitive issue, with attendant philosophical and political considerations. It is often difficult to discuss the topic without emotional opinions being voiced and dogmatically defended. Because it can involve life or death, and extensive public and private financial resources, however, it is a necessary topic of discussion and inquiry.

California carried out a major deinstitutionalization during 1993-1996, with more than 2,000 children and adults with developmental disability transferred from state facilities to community care. Most were relocated to private group homes. Strauss, Shavelle, Baumeister and Anderson (1998) — hereafter, SSBA -– analyzed the mortality experience of a group of 1,878 of these movers. There were 45 deaths in their April 1, 1993 to February 14, 1996 study period. This represented a 51% increase in mortality, relative to that of comparable persons living in state institutions. Subsequently, Strauss, Anderson, Shavelle, Sheridan and Trenkle (1998) reported on the causes of death, using information from the death certificates. Most recently Shavelle and Strauss (1999) – hereafter, S&S – analyzed 1996 mortality and found an excess mortality of 88%.

Investigation of the outcomes of deinstitutionalization has continued in recent years (Crichton, 1998; Stancliffe and Abery, 1997; Stancliffe and Hayden, 1998), but work on health-related outcomes remains limited. Mortality is one important measure of quality of health care, and has the advantage of being simple and unambiguous to measure (SSBA). Here we summarize of the mortality experience in 1997 to 1999 of the same group of subjects analyzed by SSBA and S&S, using the same methods. Our aim was to see whether the results in the earlier works held true over the more recent period. This study may shed further light on the issue because the subjects are free of the extra early mortality described as the "dislocation of moving" effect.

2. Methods

There were 1,776 subjects in the study at the beginning of 1997, the 1,812 considered by S&S less 36 who died in 1996. All movers left a state institution between April 1, 1993 and March 5, 1996. For the profile of the original 1,878 subjects with respect to functional skills, type of community residence, and other characteristics, see SSBA. The risk factors used for statistical adjustment were age, gender, mobility and self-care skills. SSBA described how these were measured. Deaths were found by matching the Client Development Evaluation Report (CDER; California Department of Developmental Services, 1986) data base with 1997-1999 mortality information from the California Department of Health Services (1999). The statistical methodology here was the same as that of SSBA and S&S. Briefly, we:

a. Used previous research that identified the factors related to survival of persons with developmental disabilities. In addition to the usual factors of age and sex, these were feeding and mobility skills (SSBA, S&S).

b. Used information on the factors to develop a logistic regression (Hosmer and Lemeshow, 1989) model to predict the probability of death given various patient characteristics.

c. Applied the model to the children and adults recently moved from institutions as follows: For each person calculate his/her "exposure time", the time in months from the beginning of the observation period to the earlier of (i) the end of the study period, or (ii) death.

d. Calculated each person's expected chance of death by multiplying the probability computed in (b) by their exposure time computed in (c). The sum of these values over various groups were the expected numbers of deaths.

A fuller description of the methods is given in SSBA and S&S.

3. Results

Of the group of 1776 subjects, 81 died in the 1997-1999 study period. Table 1 shows the numbers of deaths, number of person-years at risk, and mortality rate, both on an aggregate basis and broken down by year of move. The year-specific mortality rates show an increasing trend. In part, this reflects the fact that the highest functioning individuals tended to transfer first (details not shown here).

Table 1: Mortality Rates in 1997-1999 for 1993-1996 movers.

Group	Number of deaths	Total person-years at risk[a]	Mortality rate[b]
1993 movers	14	1331.6	10.5
1994 movers	27	1682.5	16.1
1995/6 movers[c]	40	2201.0	18.2
All movers	81	5215.1	15.5

[a]Total time between January 1, 1997 and December 31, 1999 (or until death of client) for the 1,776 movers.
[b]Number of deaths per 1,000 person-years.
[c]Because there were only 7 deaths to the group who moved in early 1996, this group was combined with the 1995 movers.

In Table 2 we compare the numbers of deaths to the expected number for comparable persons residing in institutions, taking account of age, gender, and functional skills. The ratio of the two is a standardized mortality ratio (SMR).

The 81 deaths corresponds to an SMR of 1.47, i.e., a 47% increase over what would be expected ($p < 0.01$; 95% confidence interval 1.15 to 1.78).

Table 2: Comparison of movers with the institutional population in 1997-99[a].

Group	Expected mortality rate[b]	Standardized mortality ratio (SMR)[c]	95% confidence interval for SMR[d]
1993 movers	10.3	1.02	(0.49,1.55)
1994 movers	10.1	1.55	(0.99,2.18)
1995/6 movers[e]	11.2	1.63*	(1.12,2.14)
All movers	10.6	1.47**	(1.15,1.78)

[a]Based on data on all persons residing in state institutions at any time between January 1, 1987 and December 31, 1993.
[b]Expected number of deaths (x 1,000) based on the Poisson model, divided by the number of person-years at risk.
[c]The ratio of the observed number of deaths to the expected number based on the Poisson model.
[d]Computed as $SMR + 1.96 \cdot (SMR/E)^{0.5}$, where E is the expected number of deaths (Kahn and Sempos, 1989, p.101).
[e]Because there were only 7 deaths to the group who moved in early 1996, this group was combined with the 1995 movers.
*Significantly different from 1.0 at $p < 0.05$.
**Significantly different from 1.0 at $p < 0.01$.

Table 2 shows that the SMRs tend to be larger for the persons who transferred in the later years. Note that this trend has remained even after adjustment for risk factors (age, gender, and skills). The same trend was observed by SSBA and S&S for deaths in the earlier study periods.

The trend of increased death rates for persons who transferred later was likely due to those moving later having additional medical conditions or being more frail. Indeed it is reasonable to expect that those moved earlier would have been the most qualified and/or most willing to move. In addition, earlier movers may, if anything, be healthier than their data alone would indicate; that is, the available data may not fully capture the individual's mortality risk. Frailty, while a useful medical concept, is not explicitly available on the data base, and thus was not a variable in the logistic model.

In Table 3 we stratified the data (both deaths and person-years of exposure) into four groups on the basis of mobility and the use of a feeding tube. In contrast to the previous two studies (SSBA and S&S), the SMRs here were rather similar. Conversely, the excess death rates (EDRs) decreased sharply with increasing

functional ability. For example, the EDR was 36.5 per 1000 for group 1 (that is, 36.5 extra deaths per year for every 1000 persons), but only 3.1 extra deaths per 1000 for group 4.

Table 3: Observed and expected numbers of deaths in 1997-1999 among the movers, stratified by level of functioning.

	1	2	3	4	Total
Observed deaths	7	11	37	26	81
Expected number[a]	4.88	9.03	24.84	16.54	55.29
Standardized mortality ratio (SMR)[b]	1.43	1.22	1.49	1.57	1.47
Difference of mortality rates (EDR)[c]	36.5	10.0	6.5	3.1	4.9

[a]Expected numbers are on the basis of institutional rates for comparable subjects.
[b]Observed divided by expected number.
[c]Observed mortality rate less expected mortality rate, per 1000 person-years.
1 = Persons tube fed and with no motor skills (does not lift head; no hand or arm use; does not crawl, creep or scoot; does not walk)
2 = Persons either tube fed and with some motor skills, or not tube fed and lacking motor skills.
3 = Persons not tube fed and with some, but not all, motor skills.
4 = Persons not tube fed and with full motor skills (walks well alone).

As in S&S we also compared the observed number of deaths in **institutions** with the expected number according to the model used. These were 251 and 260.46. Thus, as in the previous study, the model predicted the number of institution deaths with considerable accuracy. This may increase confidence in the validity of the model-based comparisons reported here.

Underlying **causes of death** from the California Department of Health Services are shown in Table 4. The data are provided in the form of computerized numerical codes according to the International Classification of Diseases, Ninth revision (Context Software Systems, 1995). There were 6 deaths due to cancer, compared to 4 of the 36 deaths reported in S&S and 0 of the 45 reported in SSBA. This is consistent with SSBA's hypothesis that the earlier selected movers tended to be the healthiest available at the time of moving. There were 17 deaths due to pneumonia, only 1 of which was aspiration pneumonia; previously S&S found 4 of their 8 pneumonia to be aspiration pneumonia. There were 5 externally-caused deaths, including 1 drowning and 2 homicides.

Table 4: Causes of deaths 1997-1999 (number of deaths in this category).

Viral infection (1)
Cancer of esophagus (1), larynx (1), ovary (1), kidney (1), or other (2)
Other metabolic disorder (1)
Mental retardation (5)
Other cerebral degeneration (1), or parkinsons (1)
Infantile cerebral palsy (7)
Epileptic seizure (2)
Other conditions of brain (2), central nervous system (1),
        or peripheral nervous system (1)
Hypertensive renal disease (1)
Acute myocardial infarction (2), or other ischemic heart disease (5)
Other heart disease (6)
Pneumococcal pneumonia (2), other bacterial pneumonia (1),
        bronchopneumonia (3), or pneumonia, unspecified (10)
Influenza (1), chronic airway obstruction (2), or aspiration pneumonia (1)
Disease of esophagus (1), gastric ulcer (1), duodenal ulcer (1),
        or other digestive disorder (3)
Other urinary system disorder (1)
Other congenital anomaly of heart (1)
Other congenital anomaly (2)
Convulsion (1)
Unknown (2)
Other and unspecified fall (2)
Accidental drowning (1)
Homicide by stabbing (1), or by legal intervention (gunshot) of police (1)

4. Discussion

Overall, the community death rate was 47% higher than expected for comparable persons living in institutions. This figure is lower than the 88% reported by S&S – which may have been due to a temporary overload of the community care system from the rapid deinstitutionalization — but similar to the 51% of SSBA. The differences between the excess death rates in the three studies were not statistically significant. Reasons for the lower mortality rates in institutions compared to other residence types have been suggested (Strauss and Kastner, 1996). These include: continuity of care, centralized record keeping, and immediate access to medical care.

As all movers had already been living the community for at least 9 months

prior to 1997, their excess mortality cannot be ascribed to short-term relocation effects. We therefore did not analyze mortality in terms of time since transfer.

There is evidence that these results are not artifacts of the model chosen. Firstly, the model-based expected numbers of deaths were very similar under a wide choice of plausible models (see SSBA). Secondly, as noted, the observed number of deaths for persons **remaining in the institutions** was close to its model-based expected value.

The methods used here are applicable to a wide range of social and policy issues. The approach is to compare observed and expected values, where the expected values are computed from a model calibrated to past, present or optimal experience. Applications could include the effects of:

a. Variation in prison inmate reform measures on rates of residivism,

b. Experimentation with welfare payments and work requirements on subsequent finanical status, or

c. Improved teacher training or incentives on student performance.

This is by no means an exhaustive list, and the reader will undoubtedly by now have mentally compiled his/her own list of (i) past social or policy issues that should have been more appropriately studied prior to widespread implementation, or (ii) future areas in need of study. Indeed a careful analysis of potential outcomes, costs and benefits, while given appropriate mention in the planning and "public hearing" stages of policy boards, is often the first casualty of partisanship, budget cuts, and expediency. This is unfortunate, given today's often abundance of data, lightning-fast computers, and qualified personnel to perform the analyses.

Given the higher mortality rates outside institutions, it might be asked why deinstitutionalization was considered, implemented, and continues to this day. Among other reasons — we attempt to avoid political issues here — major factors include the long history of this movement, the fact that the evidence about increased mortality has only recently emerged, and increasing financial pressures on public agencies. We address each of these in turn.

The deinstitutionalization movement began many years ago, at the same time as efforts to "mainstream" the mentally ill. The 1962 book by Ken Kessey, "One Flew Over The Cuckoo's Nest", and the 1975 film with Jack Nicholson based on it, helped shape the public's view of mental institutions. In the U.S. in the 1960's, institutions were disparaged as "snake pits" and thought to offer little benefit to patients. A recent book by Michael D'Antonio (2004) describes the "dark era of institutionalization" in the 1940's and 1950's. The author chronicles a history of injustice and poor care at the Fernald School in Massachusetts, home to "the feeble-minded and disabled." The school was forced to change only after lawsuits mandated improved care and the development of community programs. Medical

care, patient rights, and social justice have since advanced quite substantially in the U.S., no doubt a result of similar parent advocacy and lawsuits.

The deinstitutionalization movement in California began prior to any long-term studies of health outcomes. Only later did studies show increased mortality (SSBA; Strauss, Anderson, Shavelle, Sheridan and Trenkle, 1998; Strauss and Shavelle, 1997; Strauss and Shavelle, 1998; Strauss, Kastner and Shavelle, 1998; Strauss, Shavelle, Anderson and Baumeister, 1998; S&S; Strauss and Kastner, 1996; Strauss, Eyman and Grossman, 1996). By then the movement was in full swing, and — due to large fixed and opportunity costs — the per patient costs in the depleted institutions were even higher.

Deinstitutionalization was one putative way to cut costs, at least temporarily. The current fiscal situation in California, however, is now worse than when deinstitutionalization began in 1993. Services to the DD population have already been cut, and patient co-payments increased. This trend will undoubtedly continue, as the state must find ways to cut costs in order to comply with the entitlements guaranteed by The Lanterman Act.

Cost may be one drawback of institutional care (though the total cost to society of community living is difficult to assess). Another consideration is that children and adults are not integrated into society as a whole. The Lanterman Act grants clients the right to receive services in the least restrictive environment; that is, a place close to the parents' home community where others without disabilities also receive their services. The services here include medical care and, most recently, living accommodations. There is an analogous law governing education of the disabled in the United States. This is "The Education For All Handicapped Children Act", Public Law 94-142. According to PL 94-142 all handicapped children must be provided with educational services in the least restrictive environment; this is called "mainstreaming" as it mandates that the disabled be educated as closely as possible to their non-handicapped peers. But movement from large group care facilities to community care is not always the best choice. Voice of the Retarded, a U.S. organization that advocates for the disabled, is now "fighting to prevent another failed experiment at Fernald [the facility cited above]: namely, the relocation of 275 adult and elderly people with mental retardation who will give up familiar staff, peers and physical environment without the capacity to understand or talk about any of those losses. We believe the risks of these forced relocations far exceed the benefits to our family members" (Voice of the Retarded, 2004).

The results in this and previous studies indicate an increased mortality rate, above that which would be expected. The cost savings of deinstitutionalization and social value of integration must be balanced against this increased risk.

Acknowledgements

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