# Mortality of Persons With Developmental Disabilities After Transfer Into Community Care: A 1996 Update

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More than 2,000 persons with developmental disabilities have recently been transferred from California institutions into community care. Using data on 1,878 clients moved between April 1993 and December 1995, Strauss et al. (1998) found a corresponding increase in mortality rates. In the present report we update that study by analyzing 1996 data. There were 36 deaths, an 88% increase in risk-adjusted mortality over that expected in institutions, $p < .01$. We again found that persons transferred later were at higher risk than those moving earlier, even after adjustment for differences in risk profiles. In the highest functioning group, the community mortality rate was tripled. Death certificate information was also analyzed.

Strauss, Shavelle, Baumeister, and Anderson (1998) analyzed the mortality experience of a group of 1,878 persons with developmental disabilities who transferred into the community. There were 45 deaths in the 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.

This brief report is a summary of the mortality experience of the same group of subjects in 1996, using the same methods employed by Strauss et al. (1998). Our purpose was to determine whether the results in the earlier work held true over the more recent period. For simplicity we took the whole of 1996 as the study period, even though this had a 45-day overlap with the study period used by Strauss et al. (1998). An additional reason for considering the 1996 period was that the state's official mortality record for that year had become available.

## Method

There were 1,812 subjects in the study at the beginning of 1996. This represents the 1,878 subjects considered by Strauss et al. (1998) minus those who died or had not been evaluated for the variables used in the study prior to moving. All movers left a state institution between April 1, 1993, and February 14, 1996. For the profile of the original 1,878 subjects with respect to functional skills, type of community residence, and other characteristics, see Strauss et al. (1998). The risk factors used for statistical adjustment were age, gender, mobility, and self-care skills. Strauss et al. (1998) described how these factors were measured. Deaths were found by matching the Client Development Evalu-

 

ation Report (California Department, 1986) database with the 1996 mortality tape from the California Bureau of Vital Statistics. The methods for matching have been described elsewhere (see, e.g., Strauss, Kastner, & Shavelle, 1998). We supplemented these data with the death certificates of all persons who died in 1996. The statistical methodology here was the same as that used by Strauss et al. (1998), and readers are referred to that article for a description.

# Results

## *Mortality Counts*

Of the group of 1,812 subjects, 36 died in 1996. 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 (for details see Strauss et al., 1998).

**Table 1**
**Mortality Rates in 1996 for 1993–1996 Movers**

| Movers | No. of deaths | Total person-years at risk[a] | Mortality rate[b] |
|---|---|---|---|
| All | 36 | 1782.4 | 20.8 |
| 1993 | 7 | 449.1 | 15.6 |
| 1994 | 10 | 579.1 | 17.3 |
| 1995 | 15 | 668.3 | 22.4 |
| 1996 | 4 | 85.9 | 46.6 |

[a]Total time between January 1, 1996 (or date of transfer from institution, if later) and December 31, 1996 (or until death of client, if in 1996), for the 1,812 movers. [b]Number of deaths per 1,000 person-years.

Table 2 shows the numbers of deaths among movers compared with what would have been expected for persons residing in institutions, taking into account age, gender, and functional skills. The ratio of the two groups (movers and persons residing in institutions) is a standardized mortality ratio (see Strauss et al., 1998). The 36 deaths correspond to an standardized mortality ratio of 1.88 (i.e., an 88% increase over what would be expected), $p < .01$.

**Table 2**
**Comparison of Movers With the Institutional Population in 1996**

| Movers | Expected mortality rate[a] | Standardized mortality ratio (SMR)[b] | 95% confidence interval for SMR[c] |
|---|---|---|---|
| All | 11.0 | 1.88** | (1.32,2.60) |
| 1993 | 10.4 | 1.50 | (0.60,3.08) |
| 1994 | 10.6 | 1.62 | (0.78,2.99) |
| 1995 | 11.8 | 1.91* | (1.07,3.14) |
| 1996 | 10.7 | 4.35* | (1.18,11.13) |

*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 (× 1,000) divided by the number of person-years at risk. [b]Ratio of observed number of deaths to expected number 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 2 shows that the standardized mortality ratios tend to be larger for the persons who transferred in the later years. Note that this trend remained even after adjustment for risk factors (age, gender, and skills). The same trend was observed by Strauss et al. (1998) for deaths in an earlier study period.

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. As

**Table 3**
**Observed and Expected Numbers of Deaths in 1996 Among Movers by Level of Functioning**

| | Level of functioning[a] | | | | |
|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | Total |
| Observed deaths | 1 | 7 | 11 | 17 | 36 |
| Expected number | 1.83 | 3.47 | 8.55 | 5.78 | 19.63 |
| Standardized mortality ratio | | 1.37[b] | — | 2.94 | — |
| Difference of mortality rates[c] | | 6.95 | — | 10.82 | — |

*Note.* Expected numbers are on the basis of institutional rates for comparable subjects.
[a]1 = Persons tube fed and with no motor skills; some were in a persistent vegetative state (Ashwal, 1994). 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. [b]Observed divided by expected number, based on levels 1–3 combined. [c]Per 1,000 person-years.

may be seen, the greatest mortality ratio (community to institution) was observed among the highest functioning individuals. The standardized mortality ratio for the highest-functioning group was 2.94, compared to 1.30 for the three lowest groups combined. The difference of these standardized mortality ratios was significant at the 5% level, $\chi^2(1) = 5.5$. The *excess* mortalities, however, were much more similar (Table 3).

Finally, we compared the observed number of deaths in *institutions* with the expected number according to the model used, 94 and 92.21, respectively (based on 4,860.66 person-years). Thus, the model, based on earlier institutional data, predicted the number of institution deaths in

**Table 4**
**Causes of Deaths in 1996**

| Cause of death | Age | Gender | RTC[a] | A[b] |
|---|---|---|---|---|
| Diseases of circulation | | | | |
| Subarachnoid hemorrhage | 21 | F | Y | N |
| Acute myocardial infarction | 22 | F | Y | Y |
| Probable cardiac arrhythmia; due to atherosclerotic heart disease | 36 | F | Y | Y |
| Arteriosclerotic cardiovascular disease | 42 | F | Y | Y |
| Pulmonary infarction; due to hypertension; due to gastroenteritis; due to spastic paralysis | 52 | M | Y | N |
| Cardiopulmonary arrest; due to arteriosclerotic heart disease | 53 | F | Y | N |
| Cardiopulmonary arrest; due to acute myocardial infarction; due to arteriosclerotic heart disease | 54 | F | Y | N |
| Cardiopulmonary arrest; due to arteriosclerotic heart disease | 68 | M | Y | N |
| Myocardial infarction; due to arteriosclerotic disease | 74 | F | N | N |
| Cancer | | | | |
| Metastatic spindle-cell sarcoma | 22 | M | Y | N |
| Respiratory failure; due to right-sided plural effusion; due to metastatic cholangiocarcinoma | 22 | M | N | N |
| Carcinomatosis; due to metastatic adenocarcinoma; due to adenocarcinoma of colon | 67 | M | Y | N |
| Cardiorespiratory arrest; due to adenocarcinoma of stomach | 74 | M | N | N |
| Pneumonia (other than aspiration pneumonia) | | | | |
| Cardiopulmonary arrest; due to anoxia; due to pneumonia | 27 | F | Y | N |
| Sepsis; due to pneumonia | 34 | F | Y | N |
| Cardiorespiratory arrest; due to sepsis; due to pneumonia; due to hiatal/diaphragmatic pneumonia | 58 | M | N | N |
| Acute pneumonia; due to cachexia; due to anorexia; due to mental retardation | 68 | M | Y | N |
| Aspiration pneumonia | | | | |
| Cardiopulmonary arrest; due to aspiration pneumonia; due to mental retardation | 33 | F | N | N |
| Respiratory failure; due to aspiration of gastric contents; due to interstitial pneumonia | 45 | F | Y | N |
| Cardiorespiratory failure; due to aspiration pneumonia, body fluids | 45 | M | Y | N |
| Aspiration pneumonia; due to aspiration; due to altered mental state (Lithium toxicity) | 47 | M | Y | Y |
| Choking | | | | |
| Choking (food aspiration) | 22 | M | Y | Y |
| Respiratory failure; due to obstructive apnea; due to deformed oropharynx | 41 | F | N | N |
| Asphyxia; due to aspiration of food; due to mental retardation and seizure disorder | 44 | M | Y | Y |
| Trauma | | | | |
| Cardiac arrest while restrained in a prone position; due to explosive behavior episode; due to severe developmental delay | 40 | M | Y | Y |
| Probable pulmonary embolus; due to scald injury to 40% of body surface | 51 | M | Y | N |
| Complication of cerebral contusions/hemorrhage; due to blunt trauma to head (automobile vs. pedestrian accident) | 54 | M | Y | Y |
| Other | | | | |
| Cardiopulmonary arrest; due to chronic renal failure; cerebral palsy | 11 | M | N | N |
| Cardiac arrest; due to methicillin-resistant staphylococcus; due to mental retardation | 29 | M | N | N |
| Cardiac arrest; due to cardiogenic shock; due to urinary tract infection | 30 | F | N | N |
| Hepatic encephalopathy | 34 | M | Y | N |
| Cardiopulmonary arrest; due to severe malnutrition; due to esophagitis; due to AIDS | 36 | M | Y | N |
| Respiratory failure; due to septic shock syndrome; due to congestive heart failure | 39 | M | Y | N |
| Cardiac arrest; due to pulmonary arrest; due to organic brain syndrome; due to Down syndrome | 53 | F | Y | N |
| Cardiopulmonary arrest; due to multisystem organ failure; due to massive upper GI bleed; due to esophageal ulcer | 61 | F | N | N |

*Note.* Information was taken directly from the death certificates.
[a]Reported to coroner. [b]Autopsy.

the recent period with considerable accuracy. This may increase confidence in the validity of the institution–community comparisons.

Causes of death, quoted directly from the death certificates, are given in Table 4. The number of deaths reportedly due to heart disease among relative young women is somewhat surprising. There were 4 deaths due to cancer compared to none at all among the 45 deaths reported in Strauss et al. (1998). This is consistent with Strauss et al.'s hypothesis that the selected movers tended to be the healthiest available at the time of moving. It is also conistent with our finding that the excess community mortality (51%) in the earlier study is somewhat lower than that reported here. Eight deaths were due to pneumonia, 4 of which were aspiration pneumonia. The remaining causes were quite various, though the 3 listed under "trauma" are noteworthy.

## Discussion

Overall, the community death rate was 88% higher than expected for comparable persons living in institutions. This finding is consistent with that found by Strauss et al. (1998), who reported a 51% increase. There is evidence that these results are not artifacts of the model chosen. First, the model-based expected numbers of deaths were very similar under a wide choice of plausible models (see Strauss et al., 1998). Second, as noted, the observed number of deaths for persons remaining in the institutions was quite close to its model-based expected value.

Strauss et al. (1998) investigated whether mortality rates were different in the period immediately after the transfer to the community. They found that mortality was substantially elevated during the first few months. In the present study, however, the great majority of the movers (88%) had already been living in the community for at least 3 months before the beginning of the study period (January 1, 1996). For this reason we did not analyze mortality in terms of time since transfer.

As in Strauss et al. (1998), we found that the relative mortality in the community seemed to be greatest among the highest functioning persons. This trend was not statistically significant in the earlier study, but it was in the present study. Indeed, the risk-adjusted community rate in the best-functioning group was roughly three times higher than in the institutions. Possibly, this reflects the generally closer supervision of higher functioning persons in institutions as opposed to the community. The finding should not be overinterpreted, however, as the *excess* mortalities (rather than the ratio) in the two residence groupings proved to be much closer.

## References


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