

Causes of Death of Persons With Developmental Disabilities: Comparison of Institutional and Community Residents

David Strauss, Terence W. Anderson, Robert Shavelle, Frank Sheridan, and Steven Trenkle

Abstract: Between 1993 and 1995, 1,878 persons transferred from California institutions into the community. By early 1996, 45 had died—significantly more than expected (Strauss, Shavelle, Baumeister, and Anderson, 1998). We report here on the death certificates for this group, using a comparison group of 45 certificates for institutional residents. Thirty-two of the community deaths versus 10 of the institution deaths were “sudden” or “subacute.” All of the institution deaths versus 79% of the community deaths were reported to the coroner, and 55% of the institutional deaths were followed by autopsy compared to 33% in the community. Six deaths were due to perforated bowels, 5 of which were in individuals residing in the community.

The quality of medical care of persons with development disabilities who live in the community has been extensively studied (Felice, DeCock, & Repp, 1986; Friedman, Kastner, Pond, & O'Brien, 1989; Garrard, 1982; Kastner & Luckhardt, 1990; Kastner, Nathanson, & Friedman, 1993; Minihan, 1986; Minihan, Dean, & Lyon, 1993; U.S. House of Representatives, 1993). Mortality is an outcome measure widely accepted as a good proxy for quality of care (Teusch & Churchill, 1994). Recent California studies have compared mortality in community homes with that in state institutions (Strauss, Eyman, & Grossman, 1996; Strauss & Kastner, 1996; Strauss, Shavelle, Baumeister, & Anderson, 1998). After adjustment for risk factors, such as age and severity of disabilities, these studies indicated higher mortality in the community than in the institutions.

Recently, California has carried out an extensive deinstitutionalization program. Between April 1993 and December 1995, 1,878 persons were moved from institutions into the community, primarily to small, privately owned group

homes. Forty five of these persons had died by February 14, 1996 (Strauss et al., 1998). This represents a 51% increase over the expected number for comparable persons living in institutions. Here we report on the causes of deaths and duration of final illness. The issue of time between transfer to the community and death was analyzed in Strauss et al. (1998).

The source of information for this report was death certificates. The community deaths were compared to an approximately matched set of certificates for deceased persons who had lived in institutions. There are limitations to the use of death certificates to ascertain cause of death (Lilienfeld & Lilienfeld, 1980), but we were unable to access medical records or other information on the circumstances surrounding the deaths.

Persons living in institutions are, on average, much more debilitated than those living in the community (Strauss et al., in press). For example, a large proportion of the former are fed by gastrostomy tube and have very limited mobility. To obtain an approximate matching group from the institutions, therefore, we strati-

fied on the basis of mobility (four levels) and the use of gastrostomy feeding (yes/no). The mobility levels were the same as those used by Strauss and Kastner (1996) and were taken from the same data source. Because two of the eight strata were sparsely represented in the community group, we collapsed them with others, thus obtaining six strata. For each community death within a given stratum, we selected an institutional resident who died at roughly the same age. As part of the matching, we attempted to select the more recent institutional deaths because the community deaths were all relatively recent. No deaths occurring earlier than 1989 were selected. Note that the selection was carried out without any information on the causes of the death in either group; this was obtained later from the death certificates.

General Comparisons

The average age at death was 33.5 years in the community group, slightly less than the institution average of 36.7 years. According to data from the Client Development Evaluation Report (California Department of Developmental Services, 1978), which is completed annually for all persons receiving services from the California Department of Developmental Services as well as when an individual moves to a different placement, 35 of the 42 community placements had severe or profound mental retardation compared to 41 of the 45 individuals in the institution group. Motor skills were recorded as poor or none in 23 community placements compared to 25 institution subjects. Feeding had been by gastrostomy in 11 community versus 12 institution subjects.

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Causes of Death

Most of the death certificates contained some information on the proximate cause of death, although 3 certificates (1 community, 2 institution) had only the original underlying cause of developmental disability (e.g., "hydrocephalus, 28 years").

The most common cause of death in both groups was pneumonia and other respiratory disease, for a total of 32 deaths, or 37% of the

total 87 cases. Eleven of the 32 were in the community and 21 were institutional. We will subsequently use the notation (11:21) to abbreviate such statements, the first number referring to community deaths and the second to institutional deaths. In 17 of the respiratory cases (5:12), death was simply ascribed to *pneumonia*. In another 10 cases (4:6) the term *aspiration pneumonia* was used, and in a further 5 cases (2:3) other causes of respiratory death were given, such as asthma, respiratory failure, and bronchitis. The large number of respiratory deaths presumably reflects the well-recognized vulnerability to respiratory problems of those with profound mental retardation and few motor skills.

Diseases of the gastro-intestinal system accounted for 12 deaths (7:5). Six involved perforation of the bowel (5:1) due to ruptured appendix, diverticulitis, fecal impaction, ischemic bowel, and "etiology unknown." The institution case was due to swallowing a plastic glove. Three deaths (1:2) were due to upper GI lesions involving perforation. In two (1:1) the problem arose in connection with a gastric feeding tube. In a further 3 deaths (1:2), 2 were due to postoperative complications (1:1) and 1 (0:1) to volvulus.

Cardiovascular disease was the cause in 12 patients (8:4). Seven deaths were attributed to ischemic heart disease (5:2). In the other 5 cases (3:2) the causes were mitral valve degeneration, cardiomyopathy, ruptured aortic aneurism, rupture of an angiomyolipoma, and 1 (0:1) to congenital heart disease.

Seizures were often mentioned on death certificates, usually as an associated condition, but appeared as the main cause of death in only 11 patients (7:4). We found in a separate analysis that the prevalence of epilepsy was lower in the outplaced community group prior to moving than it was in the institution population.

In the remaining 11 death certificates (4:7), there were 4 neoplasms (0:4): cancer of the pancreas (2), esophagus, and rectum. Another 4 deaths were due to infections (2:2): sepsis (unspecified), urinary tract infection, pyelonephritis, and viral hepatitis. Finally, there were 3 externally caused deaths: gunshot wounds inflicted by a police officer (community), child maltreatment (community), and subdural hematoma due to a fall (institution).

Duration of Final Illness

Death certificates record "time interval

between onset and death" for each cause. Deaths whose time interval for the proximate cause was less than one hour are shown in Table 1. Table 2 shows the causes of death with an interval between one hour and one week (including the term *days*). Table 2 includes those deaths for which the proximate cause most

likely occurred within one week of death but the certificate did not specify the duration. In Table 1 three causes appear: asphyxia, seizures, and diseases of circulation. In Table 2 only two groups of death are listed: respiratory disease and gastro-intestinal disease. For completeness, Table 3 shows all the other certificates.

Table 1
Sudden Deaths by Category

| Category/ residence | Gender | Age | Description |
|--------------------------------------|--------|-----|--|
| Asphyxia & suffocation | | | |
| Comm | F | 32 | Positional asphyxia—duration unknown [head got wedged between bed and bedrail] |
| Comm | M | 33 | Asphyxiation (minutes) due to choking on food bolus (minutes) |
| Comm | M | 40 | Cardiopulmonary arrest (minutes) due to aspiration (minutes) |
| Comm | F | 41 | Respiratory failure (minutes); obstructive apnea (minutes); deformity of oropharynx (20 years) |
| Inst | F | 13 | Acute aspiration asphyxia (minutes) due to emesis from unknown cause (unknown) |
| Inst | M | 41 | Asphyxia (minutes) due to aspiration of food bolus (minutes) |
| Seizures | | | |
| Comm | M | 22 | Status epilepticus (minutes) due to mental retardation with seizure disorder (years) |
| Comm | F | 29 | Cardiopulmonary arrest (10 minutes) due to chronic seizure (30 minutes) |
| Comm | M | 34 | Cardiopulmonary arrest (seconds) due to seizure disorder (years) |
| Comm | F | 40 | Respiratory failure (1 hour) due to seizures (1 hour) |
| Diseases of circulation | | | |
| Ischemic heart disease | | | |
| Comm | F | 27 | Myocardial infarction (1 hour) due to coronary artery disease (1 year) |
| Comm | F | 36 | Probable cardiac arrhythmia (minutes) due to atherosclerotic heart disease (years) |
| Comm | F | 53 | Cardiopulmonary arrest (sudden) due to arteriosclerotic heart disease (1 month) |
| Comm | M | 67 | Cardiopulmonary arrest (minutes) due to arteriosclerotic heart disease (years) |
| Other diseases of circulation | | | |
| Comm | F | 27 | Cardiac arrest (5 minutes) due to cardiomyopathy (1 year) |
| Comm | F | 32 | Cardiac arrest (instant) due to myxoid degeneration of mitral valve (years) |
| Other | | | |
| Comm | M | 35 | Gunshot wound [officer-related shooting] |
| Comm | M | 36 | Ruptured aortic aneurysm (unknown) [place of death: sidewalk] |

Note. Information in square brackets is from the "other significant conditions" section of the death certificate. Time interval for sudden deaths = 1 hour or less. Comm = community, Inst = institution

Table 2
Subacute Deaths

| Category/ residence | Gender | Age | Description |
|------------------------|--------|-----|---|
| Respiratory | | | |
| Comm | M | 17 | Pneumonia (days) due to respiratory failure (years) |
| Comm | M | 26 | Sepsis (days) due to pneumonia (days) |
| Comm | F | 29 | Respiratory failure (1 week) due to recurrent aspiration pneumonia (years) |
| Comm | F | 32 | Pneumonia (48 hours) due to hydrocephalus (birth) |
| Comm | F | 45 | Aspiration of gastric contents (1 day) due to interstitial pneumonia (6 days) |
| Comm | F | 57 | Cardiopulmonary arrest (sudden) due to bronchitis (1 week) |
| Comm | M | 64 | Aspiration pneumonia (days) due to seizure disorder (years) |

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Table 2 (continued)

| Category/ residence | Gender | Age | Description |
|------------------------|--------|-----|--|
| Inst | M | 2 | Bilateral pneumonia (days) due to sequelae of nolooprosencephaly (years) |
| Inst | F | 24 | Adult respiratory distress syndrome (days) due to spina bifida (years) |
| Gastrointestinal | | | |
| Comm | M | 13 | Septic shock (8 hours) due to perforated bowel, etiology unknown (24 hours) |
| Comm | M | 38 | Sepsis (8 hours) due to ischemic bowel disease (unknown) |
| Comm | M | 48 | Large bowel necrosis (days) due to fecal impaction (days) |
| Comm | F | 58 | Intestinal obstruction (days) due to perforated diverticulitis (days) |
| Inst | M | 25 | Acute GI hemorrhage (hours) due to pressure ulcer (days) due to gastrostomy (months) |
| Inst | M | 33 | Obstruction of colon (hours) due to adhesions following gastrostomy (years) |
| Inst | M | 35 | Complications of volvulus (hours) |
| Other | | | |
| Comm | F | 7 | Childhood maltreatment syndrome [homicide] |
| Comm | F | 19 | Sepsis (4 days) due to mucopolysaccharidosis (birth) |
| Comm | F | 30 | Cardiogenic shock (3 hours) due to urinary tract infection (4 hours) |
| Comm | F | 31 | Peritonitis (unknown) due to appendicitis with rupture (unknown) [Second trimester pregnancy] |
| Comm | M | 37 | Postoperative ileus (5 days) due to urethral stricture (2 months) due to urinary tract infection (years) |
| Inst | F | 26 | Ruptured angiomyolipoma (24 hours) [Tuberous sclerosis] |
| Inst | F | 30 | Perforation small bowel (unknown) [Ingestion of plastic glove] |
| Inst | F | 35 | Acute traumatic subdural hematoma (days) |

Note. Information in square brackets is from the "other significant conditions" section of the death certificate. Time interval for subacute deaths = 1 hour to 1 week. Comm = community, Inst = institution

Table 3
Deaths Due to Longer Term Conditions

| Category/ residence | Gender | Age | Description |
|---------------------------------------|--------|-----|---|
| Seizures | | | |
| Comm | M | 25 | Seizure disorder (years) |
| Comm | M | 33 | Renal failure (1 month) due to rhabdo-myolysis (1 month) due to status epilepticus (1 month) [acute endocarditis] |
| Comm | F | 45 | Sequelae of cerebral palsy with seizures (years) |
| Inst | M | 30 | Epilepsy (minutes) due to encephalitis after immunization (years) |
| Inst | M | 36 | Epileptic seizure disorder (years) due to internal hydrocephalus (years) |
| Inst | M | 44 | Epileptic seizure disorder (unknown) due to phenylketonuria |
| Inst | M | 44 | Idiopathic seizure disorder (unknown) due to mental retardation + cerebral malformation |
| Circulation | | | |
| Comm | F | 51 | Arteriosclerotic cardiovascular disease (unknown) |
| Inst | M | 39 | Ischemic cardiomyopathy (unknown) due to calcific aortic stenosis (bicuspid aortic valve) (unknown) |
| Inst | F | 39 | Congestive heart failure (unknown) due to congenital heart disease (life) [Down syndrome] |
| Inst | M | 57 | Myocardial infarction (unknown) due to occlusive coronary arteriosclerosis |
| Respiratory with aspiration pneumonia | | | |
| Comm | M | 29 | Aspiration (8 days) [Down syndrome] |
| Inst | M | 16 | Aspiration pneumonia (unknown) due to seizure disorder + mental retardation |
| Inst | M | 31 | Aspiration pneumonia (unknown) due to Down syndrome [congenital heart disease] |
| Inst | F | 31 | Sequelae of aspiration pneumonia + seizure disorder (unknown) due to mental retardation (unknown) |
| Inst | M | 32 | Recurrent aspiration pneumonitis (2 months) due to mental retardation and schizophrenia (30 years) [seizures] |
| Inst | M | 32 | E-coli sepsis (unknown) due to aspiration pneumonia due to mental retardation + seizure disorder |
| Inst | M | 52 | Aspiration pneumonia (unknown) due to mental retardation [epileptic seizure] |

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Table 3 (continued)

| Category/ residence | Gender | Age | Description disorder, arteriosclerotic cardiovascular disease] |
|------------------------|--------|-----|---|
| Other respiratory | | | |
| Comm | M | 45 | Respiratory failure (10 days) due to diaphragmatic hernia (unknown) due to cerebral palsy |
| Inst | M | 16 | Respiratory infection (unknown) due to congenital hydrocephalus (unknown) [seizure disorder] |
| Inst | M | 42 | Arteriosclerotic cardiovascular disease + acute bronchial asthma (unknown) [cerebral malformation and mental retardation] |
| Inst | M | 53 | Chronic and acute hypoxia (unknown) due to massive hiatal hernia (unknown) [mental retardation + megacolon] |
| Comm | F | 29 | Pneumonia (17 days) due to hypoxic encephalopathy (15 years) due to drug intoxication (15 years) |
| Comm | M | 50 | Respiratory arrest (20 minutes) due to pneumonia (4 weeks) due to malnutrition (6 weeks) due to mental retardation [Gastrointestinal bleeding + pulmonary tuberculosis] |
| Inst | F | 6 | Klebsiella pneumonia (unknown) due to trisomy C syndrome (years) |
| Inst | F | 23 | Respiratory failure (weeks) due to recurrent pneumonia (weeks) due to spastic quadriplegia (years) [complicating spinal meningitis] |
| Inst | M | 24 | Congestive heart failure (unknown) due to acute bronchopneumonia (unknown) due to Down syndrome with seizure disorder |
| Inst | F | 27 | Bilateral bronchopneumonia (unknown) [mental retardation + seizure disorder] |
| Inst | M | 32 | Acute pneumonia (unknown) due to multiple congenital anomalies (unknown) [bowel obstruction] |
| Inst | M | 32 | Bronchopneumonia (unknown) [multiple congenital anomalies, gastric ulcer] |
| Inst | F | 37 | Pneumonia (unknown), consequences of congenital malformation |
| Inst | M | 45 | Pneumonia (unknown) [seizure disorder, diabetes] |
| Inst | M | 53 | Respiratory insufficiency (unknown) due to recurrent pneumonia (unknown) due to mental retardation + quadriplegia [seizure disorder] |
| Inst | F | 58 | Pneumonia (unknown) due to Alzheimer's disease (years) [asthma, Down syndrome] |
| Gastrointestinal | | | |
| Comm | M | 50 | Posterior mediastinitis with left lung abscess (weeks) due to perforated esophagus (weeks) due to tubal erosion + inanition (years) |
| Inst | F | 56 | Acute esophageal bleed (unknown) due to esophagopulmonary fistula venous (unknown) [lung abscess + mental retardation] |
| Neoplasms | | | |
| Inst | M | 28 | Carcinoma of esophagus with regional metastases |
| Inst | M | 41 | Metastatic carcinoma of rectum (2 months) |
| Inst | M | 45 | Carcinoma of pancreas (unknown) [gastrostomy] |
| Inst | M | 50 | Carcinoma of pancreas (unknown) [Down syndrome] |
| Infections | | | |
| Inst | M | 34 | Sepsis (1 month) due to acute and chronic pyelonephritis (months) due to hydronephrosis (years) due to neurogenic bladder (years) [seizure disorder, hydrocephalus] |
| Inst | F | 34 | Hepatic submassive necrosis (unknown) due to probable viral infection (unknown) |
| No information | | | |
| Comm | F | 28 | Hydrocephalus (years) due to cerebral palsy + epilepsy + mental retardation |
| Inst | F | 10 | Consequences of encephalopathy (unknown, perinatal) due to hypoxia (years) |
| Inst | M | 37 | Sequelae of mucopolysaccharidosis |

Note. Information in square brackets is from the "other significant conditions" section of the death certificate.

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Received 8/25/97, first decision 12/9/97, accepted 2/6/98.

Editor-in-Charge: Steven J. Taylor

The provision of data from the California Departments of Developmental Services and Health Services is gratefully acknowledged. We thank the editor of *Mental Retardation*, the reviewers of an earlier draft, and Stephen Ashwal for helpful suggestions. We thank James White and Linda Andress for assistance with obtaining death certificates and other data for this study. The research was supported in part by grants to the University of California, Riverside from the National Institutes of Health (Grant No. HD21056) and from the California Association of Psychiatric Technicians and allied groups.

Authors: DAVID STRAUSS, PhD, Professor, Fellow of the American Statistical Association, and ROBERT SHAVELLE, PhD, Visiting Professor, Department of Statistics, University of California at Riverside, Riverside, CA 92521. TERENCE W. ANDERSON, PhD, Department of Health Care and Epidemiology, Faculty of Medicine, University of British Columbia, Vancouver, BC, Canada V6T 1Z3. FRANK SHERIDAN, MD, Chief Medical Examiner, and STEVEN TRENKLE, MD, Deputy Medical Examiner, Office of the County Coroner, 175 S. Lena Rd., San Bernardino, CA 92415-0037. Requests for reprints should be sent to the first author.