

# Policy Implications of Mortality Research: Authors' Perspectives

## What Can We Learn From the California Mortality Studies?

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In six recent studies Strauss and his colleagues have examined mortality and its causes for Californians with developmental disability. We begin this commentary by briefly reviewing the findings. In the first study, Strauss and Kastner's (1996) sample was adults ages 40 or over during the period 1980 through 1992. The authors found that after risk factors such as age and mobility were taken into account, the mortality risk was 72% higher in community care (predominantly small group homes) than in institutions. In a companion study, Strauss, Eyman, and Grossman (1996) reported a 25% higher mortality in the community than in institutions for their population of children with severe mental retardation. Subsequently, Strauss, Shavelle, Anderson, and Baumeister (1998) considered externally caused deaths (e.g., accidents, homicides) and found such events to be more prevalent in the community, and especially in supported and semi-independent living. For example, homicides were most likely in supported living arrangements, whereas the majority of deaths due to medication overdoses occurred in group homes. More recently, Strauss, Kastner, and Shavelle (1998) analyzed data for the period 1985 through 1994, using different statistical methods from those of Strauss and Kastner (1996) and obtained very similar results. Finally, Strauss, Shavelle, Baumeister, and Anderson (1998) analyzed mortality in a cohort of 1,878 persons who had transferred from California institutions to the community and found a higher death rate than for comparable persons who did not transfer. Causes of death were also reported and deaths of a roughly matched group of institutionalized individuals were compared (Strauss, Anderson, Shavelle, Sheridan, & Trenkle, 1998).

An isolated epidemiological study is rarely decisive by itself. In this series of studies, how-

ever, several different groups of individuals and different statistical methodologies were used, and both numbers and causes of death were examined. We believe that, taken together, the studies demonstrate shortcomings in both health care and supervision in California's community living arrangements.

We emphasize that we were *not* attempting to evaluate the merits of institutional versus community living per se. Neither were we arguing that persons living in the community should move or return to a state institution. Our concern was with the quality of health care and supervision currently available in the community.

Our studies are not the only evidence of health care problems in California's community programs. In 1993, several years before our studies, a Congressional subcommittee investigating California and other states reported that:

An area of increasing healthcare quality and cost-containment concern, however, is the long-term treatment of the mentally retarded and developmentally disabled. Increasingly, millions of Americans with these life-long handicaps are at risk from poor quality care, questionable and even criminal management practices by service providers, and lackluster monitoring by public health and welfare agencies. . . . A disturbing pattern of abuse, neglect and fiscal mismanagement has emerged (U.S. House of Representatives, 1993).

In addition, there have recently been several dozen newspaper reports of avoidable deaths and injuries in California's group homes (e.g., Christiansen, 1997a, 1997b, 1997c; Lempinen, 1997a, 1997b, 1997c; Warchol, 1997a, 1997b). Most recently, the federal Health Care Finance Agency, which administers the Medicaid Home and Community-Based Waiver program, issued their review of California's compliance (Health Care, 1998). They stated:

Providers of services were found to be lacking in skills and training to serve this population. Many residential care facilities and day programs were found to be unsani-

tary, lacking in supervision, unsafe, failing to meet nutritional requirements and restricting of consumer choice.

Access to timely and appropriate medical, dental, and behavioral services is inadequate and/or there are cumbersome barriers to these services. (p. 3)

Referring to essentially the same the population as studied in Strauss, Shavelle, Anderson, and Baumeister (1998) and in Strauss, Anderson, Shavelle, Sheridan, and Trenkle (1998), they concluded:

Coffelt-class consumers (individuals who under a court order were transferred from California's Developmental Centers into the community) showed significant signs of loss of functional ability or health status since being placed in the community. (p. 3)

There is also no reason to believe that problems we have reported are confined to California. The Congressional report (U.S. House of Representatives, 1993) documented shortcomings in 4 other states. Hall (1996) wrote an illuminating review of the history of nonprofit organizations for individuals with developmental disabilities in Connecticut, in which he traced the evolution of problems with delivery of care in the community.

It appears to us that the change from the medical to the behavioral/social/legal model is one cause of the difficulty. Although the new emphasis has undoubtedly been beneficial in many respects, it seems to have resulted in a dramatic reduction in attention to health issues. To single out just one example, we note that Pennsylvania's Pennhurst study (Conroy & Bradley, 1985) was, according to its authors, a 5-year in-depth review of the effects of the court-ordered deinstitutionalization of Pennhurst residents. Although Conroy and Bradley covered psychological and behavioral issues in great detail in the study's 410 pages, they listed no physicians among the project staff, and we found no reference at all to health issues.

We are not aware of any state-sponsored peer-reviewed research of health issues. Although the peer-review process does not guarantee independent or high quality research, studies that have not passed peer-review should be viewed with skepticism (Angell, 1996). Further, few states even keep records that could serve as the basis of such studies (Zaharia & O'Brien, 1997). This is disturbing, and one questions why it has been permitted. Responsible policymaking is hardly possible without solid studies based on good information.

Different people will draw different conclu-

sions from the California mortality studies. We fear that the lesson for many administrators will be to refrain from keeping records that could be used for independent research and to keep researchers away from records that do exist. In our view, however, the main conclusion is this: When policymakers and advocates assure us that their programs are working just fine, they should be asked: Where are your data? Where are your peer-reviewed studies?

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