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Topics for Our Times

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Editorials and Comments

Editorial: Beyond Mortality—Residential Placement and Quality of Life among Children with Mental Retardation

The idea that society at large has a responsibility to provide care and protection to persons with mental retardation is not very controversial in the United States today, where public funds of close to \$20 billion are spent annually on residential services for this population.¹ What is controversial—and has been in the field of mental retardation for decades—is whether this care is best provided in large institutional settings or in smaller community-based facilities and homes.² Those in favor of large institutions include some parents and professionals who feel that these settings are better equipped to provide the health support required to sustain individuals with multiple and severe disabilities.³ There is also a perception that these facilities are more likely to provide long-term security and continuity of care (which is especially important as children with severe developmental disabilities increasingly are outliving their parents). On the other hand, advocates of community placement (who also include a broad range of parents and professionals) argue that institutionalization is an unnecessary restriction on the person's quality of life, social integration, and basic human rights.⁴

What is lacking in the debate about institutional vs community placement is a body of research based on controlled comparisons with clearly conceived and measured outcomes and with adequate statistical power.⁵ Notwithstanding the controversy and lack of scientific evidence, in the past 25 years, the United States and the developed world in general have experienced a sea change in the way residential services and health care are provided to persons with mental retarda-

tion. The shift has entailed a steady process of deinstitutionalization, along with the rapid proliferation of group homes and other community-based residential facilities. In the United States between 1970 and 1993, the prevalence of residence in state-funded facilities among persons with mental retardation remained relatively stable, at 1.2 to 1.3 per 1000 population. In the same period, the average number of residents per state-operated facility dropped by 96% (from nearly 1000 to 39 per facility), and the total number of facilities receiving state and federal funding (including private, usually smaller facilities) increased by more than sixfold.¹ Ideologically speaking, this paradigm shift was facilitated by normalization, the idea that the social environments of people with intellectual disabilities should be as much as possible, like those of their nonretarded peers.⁵ On a practical level, the shift was facilitated by the establishment of programs such as Medicaid and Medicare in the mid-1960s. These programs allowed parents to keep a mentally retarded child at home or in a community facility and still have access to medical support.⁶ Finally, legally, the shift was facilitated by Public Law 94-142 (enacted in 1975), which mandated states to provide to all children with developmental disabilities and special needs, a free public school education in the least restricted environment possible.⁷

Today there is no going back to the model of institutional care for the majority of children with mental retardation. Yet it may still be worth asking whether

Editor's Note. See related article by Strauss et al. (p 1422) in this issue.

the large institution should have a place at all in the range of current and future residential choices to be made available to mentally retarded persons and their families. In this context, the study by Strauss and colleagues in this issue of the Journal has a profound policy implication and is a welcome contribution for its sound research methodology.⁸ In their research of mortality among more than 7000 severely disabled children with mental retardation in the state of California over a 12-year period, Strauss et al. found that children in institutional care, as expected, were both more severely disabled and at greater risk of death than children in smaller community facilities and homes. The authors then developed a way to control statistically for indicators of level of disability. In previous landmark work⁹ as well as in the present study, they have shown these indicators to be strong predictors of mortality in developmentally disabled children. The indicators include immobility, tube-feeding, and paucity of interaction with peers. In the controlled analysis, the adjusted mortality differential is reversed, and the rate of death is actually 25% higher for residents of less restrictive environments (community facilities and homes) than for residents of institutions. The implication is that children with severe developmental disabilities may be safer in institutions than in community settings.

This is a provocative finding. For two reasons I will discuss, I believe that it calls for further research rather than direct translation into policy. One reason is that the adjusted analysis does not distinguish between impairment and disability. This omission may have resulted in overcontrol for level of impairment, thus producing a mortality disadvantage for children in community settings that is apparent but not real.

The distinction between *impairment*, *disability*, and *handicap* originated in medical sociology^{10,11} and later was developed into a system of classifying health outcomes by the World Health Organization in its *International Classification of Impairments, Disabilities and Handicaps*.¹² Impairment refers to a loss of function at the level of the organ or body part (e.g., spasticity, brain disorder); disability refers to functional limitation at the level of the individual (e.g., inability to walk or learn language); and handicap refers to limitation in social roles and activities such as school, work, recreation, and family life. Others^{13,14} have used different terminology to distinguish similar levels of func-

tioning to make the point that distinct prevention strategies are needed to target each of the three levels. For example, given an impairment resulting in a person's inability to walk, handicap may be prevented and disability minimized by assistive devices, such as ramps, curb cuts, elevators, and other environmental modifications, and by legal and educational interventions, thereby allowing fuller access and mobility.

How might the distinction between impairment and disability affect the finding of Strauss et al.? Severity of disability, as indicated by variables such as mobility, tube feeding, and frequency of peer interactions, is a strong predictor of mortality. It is nonetheless possible that severity of brain impairment leading to mental retardation has an effect on mortality that persists after one controls for the level of disability. If, among children with all degrees of impairment, residence in community settings promotes better mobility, peer interactions, and language skills than do institutions, then children in community settings with a given level of disability may actually be more severely impaired and at higher risk of death than individuals with comparable disability ratings in institutions.

The finding reported by Strauss et al. that "as more variables . . . are statistically controlled, the more the comparison favors placements with higher levels of care" is consistent with the possibility that controlling for each additional disability indicator results in a comparison that spuriously favors children in institutions. Studies have suggested, if not unequivocally shown, that the change from institutional to community residence can enhance the functioning (e.g., communication, social interaction, employment opportunities) of individuals with developmental disabilities.^{15,16} If this is true, it follows that children in community settings with high levels of functioning may actually be more severely impaired and at higher risk of mortality than children with comparable functional scores residing in institutions.

Thus, controlling for level of disability in the analysis to isolate the effect of residential placement may spuriously inflate the adjusted mortality rate in community settings relative to that in institutions. If the researchers had controlled for level of impairment rather than, or in addition to, disability, they might have found the advantage of institutional care to be reduced. Unfortunately, routine data systems such as that available to Strauss et al.

often do not contain indicators of the distinct dimensions of impairment and disability, not to mention handicap.

Another limitation of the study by Strauss et al. is the narrowness of its outcome (mortality). The study thus neglects social integration and quality of life, outcomes more difficult to measure and hard to come by, but perhaps no less important. No advocate for children or for public health in general would recommend institutionalization as a strategy for reducing mortality in children without mental deficiencies. Yet it is not implausible that a strategy involving restrictions of environment and opportunity as severe as institutional placement could reduce mortality by as much as 25% or more in all children. We would not recommend such a course because the costs in terms of quality of life and human rights would outweigh any reductions in mortality. Should these considerations be any different for children with mental retardation?

The large institution may still have a place in the range of residential services for persons with mental retardation. However, we cannot determine that place from studies that look only at effects on mortality. Badly needed are scientific studies and cost-benefit analyses that consider a fuller range of outcomes, including mortality; measures of physical, cognitive, and social functioning; and individual and family satisfaction (i.e., quality of life).

The *International Classification of Impairments, Disabilities and Handicaps*, in conjunction with the *International Classification of Diseases*, provides a framework and draft classification system for use in routine data systems, allowing systematic monitoring of these outcomes.^{12,17} The onus is on public health researchers and practitioners to use this system, to criticize and improve it, and to attend to the multiple ways in which disability affects peoples' lives and the multiple dimensions to be targeted by prevention programs and services. □

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Editorial: Social Class and Asthma—Distinguishing between the Disease and the Diagnosis

Recent work has identified inner cities as areas of high asthma morbidity and mortality.¹ Much interest has centered around whether these areas also have high rates of asthma prevalence. At least one inner-city area, the Bronx in New York City, has been identified as an area with an extraordinarily high level of asthma—12.8%—among children less than 18 years of age.² More recent work has discovered that high asthma prevalence is not limited to inner cities. Los Alamos, NM, a predominantly White middle/upper-class community, was reported to have an asthma rate of 13% among 12- to 14-year-olds.³ Prevalence differences tend to be more consistent across racial groups. In both US national health surveys, the National Health and Nutrition Examination Survey (NHANES) and the National Health Interview Survey (NHIS), African-American children reported higher rates of asthma than White children.^{4,5}

In this issue of the Journal, Cunningham and colleagues⁶ report the results of a school-based survey among 9- to 11-year-olds in Philadelphia, Pa. Diagnosed active asthma was more common among African-American children than among White children. However, there was no racial difference in the presence of persistent wheeze. Seventy-two percent of African-American children with wheezing had been given the diagnosis of asthma, as compared with only 57% of White children. Potential confounders, including

social position, did not "explain" these differences.

From these data, it appears that, at least in Philadelphia, a racial difference exists in the acquisition of the diagnosis of asthma, given that a child has persistent wheezing. In the United States, race is a surrogate for social position. Disparities in social position play a large role in the racial differences in many forms of morbidity and mortality.⁷ What is the potential role of social position in this difference in the diagnosis but not in the symptoms of disease?

A number of studies have obtained results similar to those of Cunningham et al.: among children 6 months to 11 years old from the 1976-1980 NHANES, diagnosed asthma and wheezing were more frequent among Blacks than among Whites, but in the final logistic models, wheezing was not associated with social position although diagnosed asthma increased with decreasing family income and inner-city residence.⁸ In the Bronx, among children younger than 18 years, wheezing for those without the diagnosis of asthma was not related to family income.² Again, the frequency of the diagnosis of asthma increased with decreasing family income. In East Boston, Mass, among predominantly Italian-American children 4 to 10 years old, persistent wheezing did not relate to density of persons per room.⁹ In rural Pennsylvania, by contrast, among children 5 to 14 years old, social position had no

influence on either wheezing or diagnosed asthma.¹⁰ Thus, in urban settings and among the US population as a whole, the prevalence of wheezing seems to be independent of social position, but that of diagnosed asthma is not.

An early national British study yielded somewhat different results. The 1958 British Birth Cohort study found that, among children aged 11 years, wheezy bronchitis without the diagnosis of asthma had no relation to social position, but diagnosed asthma increased with increasing social position.¹¹ More recent work in Great Britain found that among 5- to 17-year-olds, diagnosed asthma was not related to social position.¹² Similarly, in Montreal, Canada, a school-based survey of 5- to 13-year-old children found that social position was not related to either wheezing or diagnosed asthma.¹³

The absence of an excess of diagnosed asthma among the lower social classes in Canada and Great Britain and its presence in urban United States possibly could be a reflection of differences in health care systems. St. Peter et al.¹⁴ evaluated access to care among children less than 18 years of age, using data from the 1988 Child Health Supplement of the NHIS. Children receiving Medicaid were less likely than children living above the poverty line to identify a physician's office as their site for routine

Editor's Note. See related article by Cunningham et al. (p 1406) in this issue.

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After our phone conversation about the article "Comparative Mortality of People with Mental Retardation in Institutions and the Community" authored by Strauss and Kastner in the current issue of AJMR, I re-read their article for a second time focusing on the issues we discussed.

So far as I can see, their methodology is sound and their conclusions would be difficult, if not impossible, to assail on statistical or methodological grounds. However, they are dealing with huge samples. Consequently, even substantively minor differences can attain statistical "significance." The question for policy makers, however, is whether those differences are "substantively" different. Whether, in the real world, they are something to be concerned about.

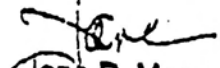
To answer that question, I looked closely at Figure 2. In Figure 2 the authors present the mortality rates as a % of person-years by placement (community vs institution) for each of the risk categories. The Mortality Rates in the Lowest Risk group are approximately the same for both types of placement and are very low -- about half a percent. In Risk Category two, the rate for institutions rises to 1% while that in the community rises to 2%. In Risk category three, the rate is 1% for institutions and slightly over 2% for the community. In category four, the institutional rate jumps to slightly over 2% while the community rate is 3%. In category five, the institutional rate remains around 2% while the community rate moves to 4%. In category 6, the institutional rate moves up to just under 4% while the community rate moves to just over 6%. In category 7, the institutional rate is just under 6% and the community rate is 7%. In category 8 which contains individuals at very high risk, both rates move up dramatically--the institutional rate is just under 11% while the community rate is just over 12%.

What impresses me about these figures is how very close they are to each other, substantively. One chance in a hundred of dying vs two chances in a hundred, 2 chances in a hundred vs three chances in a hundred, and so forth. And these differences are consistently small across all risk categories. There is only a 1% difference in even the highest risk category.

It seems to me that the negligible increases in the risk of dying that are associated with living in the community seem reasonable, given the increased exposure to infectious diseases, to accidents, and to the ordinary hazards of living in an open rather than a cloistered environment. In short, such small differences can be viewed as the price that each of us pay for living in the community rather than in a bubble. And that price is surprisingly small!

I think it would be a mistake to exaggerate the importance of these differences and go searching for a smoking gun. It seems to me that those of us who have advocated desegregated settings should be delighted to learn that the price is so small for improvements in the quality of life that are so great.

Sincerely yours,


Jane R. Mercer

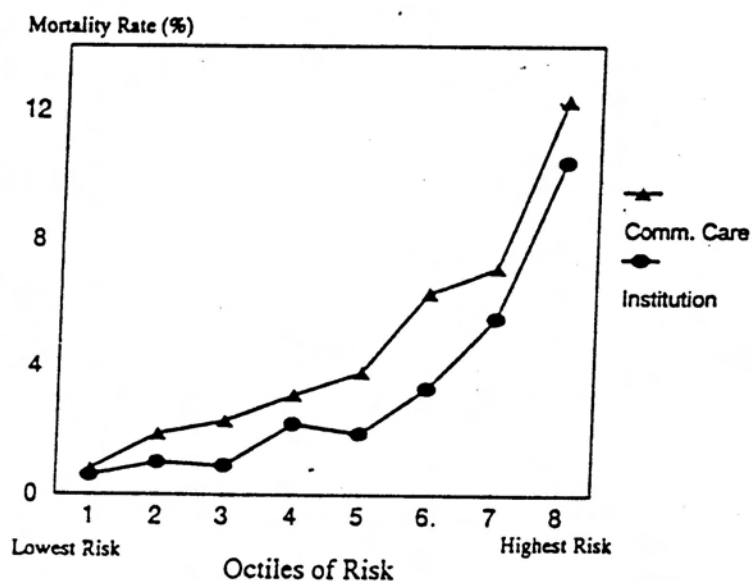


Figure 2. Mortality rates for community care and for institutions within risk octiles. (Using community care as referent population, we directly standardized institution rates). Note that the finding of a 72% increase in mortality in the community refers to the ratio of the odds of dying in a given year. Although the ratios of community to institutional rates appear to vary across the eight groups in the figure, there is no suggestion of any systematic trends in these ratios. As explained in the Appendix, it is not appropriate to base statistical tests or confidence intervals on the results of Figure 2; such procedures are more properly applied to the logistic model itself (Table 4).