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Community placements can be dangerous, mortality figures show

Startling new statistics indicate that the death rate of mentally retarded individuals in community settings is dramatically higher than the death rate for comparably disabled individuals in institutional care.

Using records from the California Department of Developmental Services (DDS), David Strauss and Theodore Kastner studied the death rate (calculated per "person-year") of all adults with mental retardation, ages 40 or older, who received services from DDS between 1980 and 1992. (Individuals with Down syndrome were excluded because of their unique aging-related health problems.) The researchers, who controlled for age, gender, and level of functioning, divided their subjects into eight groups according to mortality risk factors. This was important, the researchers say, because in general, only very severely disabled individuals are now in institutional care.

According to Strauss and Kastner, the risk-adjusted odds on dying in a given year were an estimated 72% higher in the community than in institutions.

Four categories of residential placements were studied: in-home care; small group homes and larger community board-and-care facilities serving seven or more people; health facilities; and institutions. "Our major finding," Strauss and Kastner say, "was that the risk-adjusted mortality rates of people with mental retardation were higher in the community than in institutions, regardless of the level of risk." The researchers say that "the risk-adjusted odds on dying in a given year were estimated to be 72% higher in the community than in institutions."

Strauss and Kastner comment that data from a more recent study they conducted (currently in press) reveal a similarly elevated death rate for severely disabled children in community settings as opposed to institutional settings.

Why would the community be a riskier setting than an institution? Strauss and Kastner note that "health care in the community is generally considered to be a problem for persons with mental retardation." They note that poor coordination of care, a lack of community medical practitioners trained to treat the developmentally disabled, and problems with Medicaid reimbursement are significant barriers to health care.

"Institutions overcome many of these barriers," the researchers say, "because they offer a centralized setting in which provider training, reimbursement, record-keeping, and quality assurance functions are in place."

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"Comparative mortality of people with mental retardation in institutions and the community," David Strauss and Theodore Kastner; *American Journal on Mental Retardation*, Vol. 101, No. 1, 1996, pp. 26-40. Address: David Strauss, Department of Statistics, University of California, Riverside, CA 92521. See also: "Mortality among individuals with mental retardation living in the community," Strauss et al., *American Journal on Mental Retardation*, Vol. 98, No. 2, 1993, pp. 285-292.

Dutch study: more success with SIBIS

American researchers have reported remarkable success in curbing life-threatening self-injury using a device called SIBIS (the Self-Injurious Behavior Inhibiting System), which delivers a mild electric shock after each incident of self-injury (see ARRI 10/2, 9/4, 8/2, 1/3). In a new study, Dutch researchers report notable success using a similar device called the HSP 3012.

Unlike SIBIS, which employs a headband sensor to detect when severe head blows occur and administer a stimulus, the HSP 3012 is controlled remotely by a therapist. This may reduce the device's effectiveness, by decreasing the accuracy and immediacy of the response to self-injury. However, Pieter Duker and Daniel Seys report that of 12 mentally retarded individuals treated with the device, ten stopped or markedly reduced their self-injury.

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Autism-vaccination link in U.K.?

As this issue of the ARRI was about to go to press, we received an alarming 36-page faxed document from the Dawbarns law firm in England concerning an extraordinary upsurge in autism (and other disorders) which may be linked to the introduction of the measles-mumps-rubella (MMR) vaccine in England in October 1988.

"A small branch of the Norfolk Autistic Society is reported as having been told to expect only three or four sufferers in their area, but there are already 46 and the numbers are growing daily," the law firm notes. "Where are all these cases coming from, pediatricians—and parents, as well as school officials—are asking." Dawbarns notes that they are working with 150 families whose children became autistic following the MMR vaccine, "to find out if we can establish a clear time link with the vaccine and to try to find if there are any other connections." In addition they are working with Dr. Andrew Wakefield of the Royal Free Hospital in London, who has conducted research suggesting a strong link between MMR vaccination and Crohn's disease, a seriously debilitating intestinal disorder.

Vaccinations have become controversial in recent years amid concerns that physicians and government officials may be ignoring or downplaying their risks (see ARRI 9/1). While the diseases some vaccines prevent can be devastating—prenatal rubella, for instance, can cause deafness, blindness, autism, and retardation—there is increasing evidence that vaccines themselves can cause brain injury, retardation, seizures, and autism. Dawbarns notes, as well, that some diseases children are vaccinated against, such as measles and mumps, cause severe problems in only a small minority of cases, and may actually confer long-term benefits such as improved immune function.

Dawbarns criticizes studies on vaccination safety, noting that most are conducted on only a few subjects, over a short period of time. Many researchers with whom ARI is in contact agree, and are calling for large-scale, unbiased studies to determine if the risks of some vaccines outweigh their benefits, or if vaccinations are being given at too early an age, before infants' immune systems can cope with them. ARRI will continue its coverage of this issue.