The crime of epilepsy

Victims of epilepsy and other seizure disorders are perhaps among the most misunderstood and discriminated-against members of society. For many such persons, "the most serious feature of their disability is social ostracism, from which they suffer because of their spells," writes Maurice W. Van Allen of the University of Iowa Hospitals in the Journal of the AMERICAN MEDICAL ASSOCIATION (Vol. 239, No. 25). "This does not speak well for a society that is approaching an expenditure of 10 percent of its income on medical care and that makes an issue of equal opportunity for its citizens," he says. "This ostracism is especially damaging to the school-aged child who is embarrassed by his spells and is set apart from his friends."

Understandable outgrowths of this discrimination include low self-esteem and perhaps antisocial problems such as alcoholism and drug abuse, Van Allen suggests. But a study in the same issue of JAMA indicates that the problems could be more widespread and intense than may have been thought.

The study — a survey of the medical records of more than 12,000 prisoners in 10 Illinois correctional institutions — indicates that 1.9 percent of the prisoners suffer from seizure disorders (determined by the number taking continuous anticonvulsant medication). This is more than three times the prevalence rate in the general population, as measured in a 32-year study in Rochester, Minn., report Lambert N. King and Quentin D. Young of the Cook County Hospital Department of Medicine. Previous studies yielded similar or higher rates of epilepsy-type disorders among

prisoners in New York City and North Carolina, according to King and Young.

The statistics point to a need for improved diagnostic and treatment facilities for seizure-prone prisoners, say the researchers. But beyond that, they say, the results raise several questions about "the possible relationships between seizure disorders and incarceration. To what extent does the onset of seizures in childhood or adolescence predispose to unemployability and social rejection with subsequent antisocial or criminal behavior?" they ask. "What role do previous open or closed head injuries play as a cause of epilepsy among residents of our jails and prisons?" And finally, "Could improved diagnosis, treatment and education regarding seizure disorders decrease the recidivism among such individuals?'

Van Allen suggests that while epilepsy by no means lends itself to the development of "planned or premeditated criminal acts," it may predispose an individual toward "poor social adjustment" and "may make the epileptic more likely to appear in court and in prison than the average citizen."

Officials of the Epilepsy Foundation of America say they are "not surprised" by the study's results. "It has long been felt by authorities worldwide that prison populations have a higher incidence of epilepsy than normal populations," says Pamela McGarvey, the foundation's director of research and professional education. "It's not that epilepsy predisposes a person toward criminal behavior - that would be a misinterpretation [of the study]. The problem is with society's view of a person with epilepsy," she says. "The social, psychological and behavioral problems associated with the stigma and prejudice surrounding epilepsy are more handicapping than the seizures themselves."

since shortcomings in the Inspector General's report "may only fuel the charges of 'coverup' already voiced...we are compelled to request a full General Accounting Office investigation not only of the propriety of the Department's termination of Dr. Mancuso's project, but also the manner in which the Inspector General carried out

Those "shortcomings," outlined in a 10-page summary and critique prepared by their subcommittee, involved:

• Failure to interview key people.

the investigation."

- Failure to explain adequately "how the study could be transferred [from Mancuso at the University of Pittsburgh] to Oak Ridge Associated Universities when the agency had found that organization unqualified to perform the work required."
- Failure to include transcripts of all interviews particularly those of three agency administrators who had played key roles in the decision to terminate Mancuso and transfer the study he began 13 years earlier to ORAU.
- Failure to include all pertinent memoranda, especially two "critical" ones.
- Failure to offer conclusions "as to the merits of the charges against DOE either by fixing blame, or, if there was no blame to be fixed, by pointing out where or how DOE personnel acted properly."

The Inspector General's office was charged with investigating the reason for Mancuso's termination. The agency had initially said it was because of his "imminent retirement," although Mancuso said he had not considered retiring nor would he otherwise have had to for eight years. The "imminent retirement" excuse, later retracted apologetically by the agency, led Mancuso and supporters to question whether the agency (or its predecessor, the Energy Research and Development Administration) was trying to keep him from publishing findings of a positive correlation between cancer and a worker's exposure to radiation. The IG was also asked to see whether there was an attempt by one laboratory whose workers were being surveyed to discredit positive cancer findings by a Samual Milham, and if Mancuso was faulted for not publishing findings that would have refuted Milham's. The report found all allegations unsubstantiated.

The subcommittee critique concludes, however, that doe's "explanations for the termination still are not supported by the evidence." In addition, "the report inadvertently raises new and serious questions about doe personnel" — namely why it granted Sidney Marks, the administrator overseeing Mancuso's contract, an exemption from a conflict-of-interest restriction that would have prevented him from representing a contractor before the agency for a year. Marks left erda to join a contractor who later was asked to aid ORAU in analyzing some Mancuso data.

A formal request for the GAO investigation should be issued this week.

GAO to look at Mancuso investigation

The question of alleged unethical conduct by the Department of Energy surfaced again last week when the agency released findings of an investigation by its own Inspector General into the termination of Thomas F. Mancuso's research contract to study the human-health effects of government workers exposed to radiation (SN: 2/18/78, p.103). "Our staff has been analyzing the report for two months and basically find that it is totally deficient. Rather than clarifying the incident, it only muddles it," Rep. Paul G. Rogers (D-Fla.) said last week on behalf of the House Subcommittee on Health and the Environment, which he chairs.

Last February it held two days of hearings on the Mancuso controversy. It was at one point in those hearings, after listening to and trying to sort through several hours of conflicting testimony, that Rogers threw up his hands in anger saying, "This is the

most disordered, unstructured mess that I've looked into in some time....I hope the Inspector General is listening because we need some policy changes."

Rogers went on to say that as a result of the contradictions and general "questionable" operating policies outlined by agency witnesses that "I'm not sure that I don't question the whole issue of the Energy Department conducting health work." He said that although his subcommittee lacked the oversight authority to strip the agency of such work he would consider encouraging the proper people to do so.

This was the first time that the agency's policies came under scrutiny by the subcommittee since the abolition of the once-powerful and paternalistic Joint Committee on Atomic Energy.

In a letter to DOE Secretary James R. Schlesinger last week, Rogers and Rep. Tim Lee Carter (R-Ky.) complained that

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