REMINDER:
AUGUST is a great time to meet with your U.S. Representative in his/her District office near your home to seek support for H.R. 3995. Call to make an appointment today.

VOR Weekly E-Mail Update

July 11, 2008

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1. July 22 is Fragile X Awareness Day - About Fragile X

July 22, 2008 is Fragile X Awareness Day.

Fragile X Syndrome (FXS), the most common cause of inherited mental impairment. This impairment can range from learning disabilities to more severe mental retardation. FXS is the most common known cause of autism or "autistic-like" behaviors. Symptoms also can include characteristic physical and behavioral features and delays in speech and language development.

Fragile X is a family of genetic conditions, which can impact individuals and families in a wide variety of ways. These genetic conditions are related in that they are all caused by gene changes in the same gene, called the FMR1 gene. Some individuals experience significant challenges because of the effects of fragile X, while the impact on others is so minor that they will never be diagnosed.

Males and females exhibit quite different physical, cognitive, behavioral, sensory, speech and language impacts of fragile X syndrome. In general, females with fragile X either do not have the characteristics seen in males, or the characteristics show up in a milder form.

The difference is probably due to the fact that females have two X chromosomes instead of the one that males carry. As a result, females who have fragile X, have two sets of instructions for making FMRP (fragile X mental retardation protein), one that works and one that doesn't. Males with fragile X have only one X chromosome with its nonfunctioning FMR1 (fragile X mental retardation 1) gene. It appears that females are able to produce enough of the FMRP to fill most of the body's needs, but not all.

Fragile X can be passed on in a family by individuals who have no apparent signs of this genetic condition. In some families a number of family members appear to be affected, whereas in other families a newly diagnosed individual may be the first family member to exhibit symptoms.

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2. Book Review: Wrong Prescription - How the emptying of state-run mental hospitals produced a social disaster

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By PAUL MCHUGH

June 14, 2008; Page W10

Wall Street Journal

About the author: Dr. McHugh is a University Distinguished Service Professor of Psychiatry at Johns Hopkins University. His book "Try to Remember: Psychiatry's Clash Over Memory, Meaning, and Mind" will be published in October.

The Book: The Insanity Offense, By E. Fuller Torrey, Norton, 265 pages, $24.95

Summary: This book looks at the deinstitutionalization of the mentally ill, an experiment that also failed.

There are times and situations that call for prophets. Not fortunetellers or soothsayers, but biblical prophets like Amos or Jeremiah who furiously proclaim the old truths, puncture our pretensions and predict from current tribulations worse to come if what lies deeper than sin -- idolatrous worship of false gods -- continues. E. Fuller Torrey, a psychiatrist who cares for patients with schizophrenia and manic-depression, is to my mind the doctor nearest in character to an ancient Hebrew prophet.

In "The Insanity Offense," he describes the grim consequences -- in death, violence and suffering -- of laws that, beginning in the late 1960s, released the seriously mentally ill from the oversight of state mental-health services and permitted them to wander away from the treatment and protection they desperately needed. Dr. Torrey identifies an unholy alliance of rash conservatives seeking to save public money by abandoning a traditional state obligation and self-righteous liberals defining the neglect of these patients as "defending their civil rights." We need prophets to confront such alliances -- anything less will fail -- and in this splendid book we hear one.

"The Insanity Offense" is "about one of the great social disasters of recent American history," Dr. Torrey writes. "It began within the lifetime of many of us, is continuing, and today affects approximately 400,000 individuals and their families. In the annals of twentieth-century American history, it should be included among the greatest calamities."

Some of the background should be familiar. From the mid-19th century right up until the 1960s, state governments accepted responsibility for the care and treatment of the seriously mentally ill. This arrangement came about because in the 1840s such civic crusaders as Dorothea Dix (in what may be the first piece of social research ever conducted in America) revealed the special ordeal of delusional and distressed mental patients: They tended to lose their way in life and, because of their unpredictable and occasionally violent propensities, filled the country's jails, workhouses and shelters, where they often suffered ugly mistreatment. Dix reported to the Massachusetts legislature in 1843 on "the present state of Insane Persons confined within this Commonwealth, in cages, cellars, stalls, pens! Chained, naked, beaten with rods, and lashed into obedience!"

The state mental-hospital system was founded to care for these patients. Though psychiatrists before the mid-20th century could offer them little more than shelter and protection, even that modest level of care was far from inconsequential: It kept the patients and the community from harm. State mental hospitals stood as beacons of a public obligation.

By the 1950s, though, these hospitals had become overcrowded and were themselves prompting calls for reform. It was a missed opportunity: Much could have been accomplished if psychiatric leaders at the time had moved quickly to repair a failing system and to educate the public about serious mental illness. The discovery of "anti-psychotic" phenothiazines and "anti-depressants" meant that the symptoms of these patients could be greatly relieved and their dangerous behavior much reduced if such medications were used properly. Steps could have been taken to address the concerns of the growing civil-rights movement and ensure that long-confined patients were not victims of neglect. And the increasing zeal for fiscal restraint and tax reform in state government should have been met head-on with a frank discussion about the costs and benefits of shouldering responsibility for some of our most vulnerable citizens.

Instead, psychiatric leaders at the time offered little or no defense. Worst of all, they failed to explain why state responsibility should continue, no matter what changed in the settings for patient services, so that the mentally ill would be monitored and not slip from sight. Patients with schizophrenia and manic-depression, it should have been explained, often lack any sense of their own mental disorders and so need regular supervision to sustain their treatment.

Why the psychiatric establishment failed to meet these challenges is not obvious. Many doctors wilted before criticism of state-hospital services and mustered weak arguments to defend them. Many others at the time were absorbed in the psychotherapy of patients with milder mental disorders and had little interest in the seriously mentally ill, whose care they were happy to leave to the state and others. As a result, laws were passed in the late 1960s with the direct intent of emptying state hospitals, releasing the patients and saving money -- consequences be damned.

The new laws deprived psychiatrists of the authority to hold patients under surveillance. In the past, psychiatrists could keep patients in a hospital if they were "of such mental condition . . . [as being] in need of supervision, treatment, care, or restraint." Now patients could not be held unless "immediately" or "imminently" dangerous to themselves or others.

The harrowing effects were evident almost immediately, and Dr. Torrey recounts them in vivid detail in "The Insanity Offense." First he offers plenty of statistics to indicate the state of the problem as it exists today -- citing, for instance, the number of seriously mentally ill who are in prison (218,000) or homeless (175,000) at any given time. But just as "numbers are too abstract" to convey the magnitude of a large-scale tragedy such as an earthquake or flood, he says, the true horror that resulted from the "deinstitutionalization" of the seriously mentally ill is best conveyed by individual stories.

Dr. Torrey recounts murder after murder by mentally ill patients, each of whom was actively avoiding treatment. We learn about William Bruce, who was diagnosed with schizophrenia and hospitalized but refused to take his medication. His mother "tried to get help everywhere," a friend related, but "at each phase she was turned away because he never hurt anyone." Bruce bludgeoned his mother to death in 2006 and slit her throat.

The most awful example was the murder last year of 32 students and faculty at Virginia Tech by Cho Seung-Hui, a 23-year-old student who had been court-identified as in need of treatment but allowed by the college to attend classes because the school would not treat mentally ill students -- even those suffering from schizophrenia -- unless the students requested it. Mr. Cho could not be involuntarily committed because he was not an "imminent danger" to himself or others and was not "substantially unable to care for himself." As Dr. Torrey writes: "This is one of the most stringent state commitment statutes in the United States and another example of how changes in mental illness laws in the 1970s and 1980s continue to have real consequences."

Given the difficulty of committing the seriously mentally ill for involuntary treatment, our jails and prisons have become de facto mental institutions. Dr. Torrey's data indicate that more than 30% of inmates are mentally ill. He also describes the abuse they suffer in these brutal environments and the increase in suicides by mentally ill prisoners. The hellish scenes described by Dorothea Dix in 1843 have returned -- with a vengeance, given the huge increase in the American population since the mid-19th century.

What is to be done? "The Insanity Offense" calls for a restoring of some central state responsibility for these patients in ways that would permit monitoring them regularly, keeping them on their medications and insisting on a protected-care setting if they relapse. It is not necessary to reopen all the old state hospitals: The programs that are needed could be carried out in clinic offices with backup, shorter-stay hospital beds.

Dr. Torrey points to successes in a few states. He particularly endorses a program in Wisconsin that provides outpatient tracking and regular medication treatment along with resources for ready involuntary commitments when either treatment fails or the patient becomes unable to control behavioral outbursts.

The issue is whether the public can be rallied to support these reforms. One obstacle: Legions of lawyers are opposed to such changes, claiming that they are infringements on "civil liberty." More than a few such lawyers are heard to proclaim that the violence and murder committed by mentally ill people are "the price we must pay for democracy." Here is idolatry of the most blatant kind -- with human

sacrifice, no less -- and hence our need for the fury of a prophet.

Tamie Hopp

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