

'THE BROKEN CORD' - A WRITER'S LONG JOURNEY TOWARD UNDERSTANDING

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Michael Dorris spent nine years trying to understand the chronic problems that plagued his adopted son: Adam's small size, his slow physical and mental development, his short attention span and his inability to comprehend the most basic abstractions

"The real problem, I persuaded myself, was not with Adam but with other people's perception of him," writes Dorris in "The Broken Cord," his new book about fetal alcohol syndrome.

"In those years of Adam's early childhood, I trusted no diagnosis that wasn't encouraging, no road that didn't lead to a normal adult life for him," he adds. "I rejected as impossible the judgments of the 'experts' I had so far encountered, so the only choice was to become an expert myself."

As it turned out, Dorris didn't need the counsel of "experts" - he only had to notice three young boys who "could have been Adam's twin brothers" during a 1982 visit to South Dakota's huge Pine Ridge Indian reservation. There, for the first time, he heard the phrase "fetal alcohol syndrome" and learned of the physical and mental "deficits" that its victims share - all conditions he had observed in Adam.

That revelation plunged Dorris into a

world of scientific research that has been pioneered at the University of Washington's School of Medicine, in particular by Ann P.

Streissguth, a professor in the medical school's department of psychiatry and behavioral sciences.

In June 1973, Streissguth and Seattle colleagues Christy N.

Ulleland, Kenneth L. Jones and David W. Smith published a paper in the British medical journal *The Lancet* that described eight children, all born of chronic alcoholic mothers, who shared a surprising pattern of physical and mental abnormalities and disabilities. Later that year, a subsequent paper by Jones and Smith, also published in *The Lancet*, added three more children to the study and coined the term fetal alcohol syndrome (FAS).

Since then, Streissguth - who is out of the country and unavailable for comment - and other UW researchers have been recognized at the forefront of research into FAS and the related but slightly less severe condition, fetal alcohol effect (FAE). Perhaps their most significant contribution has been to follow their research subjects over a number of years, documenting how FAS and FAE are manifested in adolescents and adults.

"It's clear to us that that's where the action is now," said Dr. Sterling K. Clarren, a professor of pediatrics and director of Children's Hospital's Craniofacial Clinic who has co-written a number of papers with Streissguth. "Even if we are able to find a solution to the problem of FAS in infants, our society is going to have to learn what to do with the adult victims of FAS and how to provide proper work and living situations for them."

A decade after the 1973 studies, Clarren, Streissguth and Jones followed up the original research to see how those children had fared.

Of the original 11, one had disappeared and two had died; the remaining eight included four who were "substantially retarded" and four who were in the borderline retarded-to-dull-normal range. The study was published in *The Lancet* in 1985.

Their significant finding was that the adolescents with higher IQs experienced the most difficult social and behavioral problems - in fact, they often were not recognized as impaired: "They were described by their teachers as poorly motivated, restless, inattentive and poor students," Streissguth later wrote. "They were not usually described by their teachers as mentally handicapped."

Streissguth conducted a subsequent study in the mid-'80s that expanded the sample to 61 persons diagnosed with FAS/FAE and, more recently, a study involving 92 such persons. Despite intellectual differences, (FAS victims had a mean IQ 15 points lower than the FAE victims), Streissguth found no significant differences in academic performance or "adaptive behavior quotient" - that is, although they ranged in age from 12 to 42, all the FAS/FAE adolescents and adults behaved like a typical 8-year-old child.

"What we're learning now is exactly the problem Michael Dorris describes in his book," said Clarren. "These young adults are 'stuck.' They're often too intelligent to qualify as mentally retarded, and yet their personality profiles are not adaptable to independent living."

Although the majority of Streissguth's subjects have been Indians from reservations, where alcohol abuse is particularly rampant, Clarren cautions against thinking of FAS and FAE as simply affecting Native Americans.

“There's a big danger in picking out high-risk groups and saying it's just their problem,” said Clarren, noting that Indian groups have often been unwilling to address the problem for fear of being singled out.

“Alcohol,” he said, “is also middle-class white America's drug of choice.”

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