

A photograph of a young man with dark hair, wearing large, clear-rimmed glasses and a bright red hooded sweatshirt. He is smiling broadly, showing his teeth. He is sitting down, with his hands resting on his lap. The background is dark and out of focus.

The Challenge of Fetal Alcohol Syndrome

Overcoming Secondary Disabilities

Edited by
Ann Streissguth and Jonathan Kanter

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Edited by
Ann Streissguth
and
Jonathan Kanter

Foreword by
Mike Lowry

Introduction by
Michael Dorris

University of Washington Press
Seattle and London

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Foreword

Governor Mike Lowry

I believe that research on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) clearly is one of the most important issues in all the world today.

Why does a Governor care so much about FAS? First, Governors are human beings, too, and supporting this research is simply the right thing to do.

Second, every one in elected office has many good governmental reasons to care about and support efforts to find answers to this tremendous problem. For example, most of the children that become dependent on the state of Washington for support, and not on their own families, do so through Children's Protective Services or related programs. Sixty-three percent of the children who became dependent on the state of Washington in 1995 became dependent because of reasons related to substance abuse. This is not to say that 63% of children in state care were victims of FAS, but that substance abuse was the major factor in 63% of the decisions that social workers, other professionals, and judges made to have the state protect our children and remove them from their homes.

We simply have not met our very first responsibility: protection of our children. We will not meet this responsibility until we commit ourselves to finding answers to the problems of substance abuse and its effects on our children. This must be done or we must seriously question ourselves when we claim to care about our dependent children.

I am not an expert about Fetal Alcohol Syndrome. However, I have had numerous discussions with judges about some of the absolutely incomprehensible crimes that have been created and committed in this and other states, crimes committed by and against teenagers and young adults. These judges were certain that the major cause of these crimes was FAS. These judges were certain that the perpetrators of these crimes simply did not have the ability to judge what was happening around them.

The crimes perpetrated by victims of FAS are on the terrible, extreme end of a continuum of secondary effects of FAS and FAE that result in a huge cost to society. It is the job of all elected officials to

respond to this problem. It is our job to identify the problems that our society faces and then work with everyone to find solutions to these problems.

A meaningful investment by the public sector in addressing these problems actually is very affordable. The Washington State budget (which I happen to know a little bit about) currently is funding a number of programs such as the Birth to 3 program, described in this volume (see chapter by Grant, Ernst, Streissguth, and Porter). This program has been shown, among other things, to be effective at preventing high-risk women from birthing fetal-alcohol affected babies. It is very well run and is very important. We could increase the funds available for this program by a factor of 25 and this would cost the average homeowner in the state of Washington 25 cents per month. Our economy currently is doing very well, and our budget is in great shape, so I am not suggesting a 25 cent per month tax increase. Rather, I am suggesting not cutting taxes by 25 cents per month. Twenty-five cents per month! Those 25 cents would go a long way.

One thing I have never understood is why the financially well-to-do are so against paying taxes. The only things their money cannot buy are the things that taxes pay for: clean air, clean water, safe streets, enlightened society. Even Bill Gates cannot buy these things. The well-to-do should be lining up in the streets demanding to pay higher taxes, so that they can achieve safety in the streets for their children and the other things that, strictly speaking, their money cannot buy. It is understandable that low and middle income people do not like taxes. But some commitments make sense. A commitment to addressing the problem of FAS makes sense.

By the year 2000 in Washington state, we will have one billion dollars more in our general fund per year than our present law allows us to spend. We will have the resources necessary to invest in human capital to support the programs and ideas, and address the problems, that are presented in this book. All we need is a political and social commitment. It is up to us as a society to come together and answer these questions.

I was delighted and proud to be a part of the conference that inspired this book. This conference, held in Seattle, Washington in 1996, drew together people from 39 states and eight countries to discuss these issues, and it demonstrated that this is a situation that we are all in together. It is a situation that forces us to ask ourselves: In what ways do we care about our society and our children?

My wife, Mary Lowry, always has been the most effective lobbyist on this particular Governor. She received information from Ann

Streissguth's Fetal Alcohol and Drug Unit and other organizations, and educated both of us about this problem. Once I learned about this problem, and realized that this is a problem that truly can be prevented, I became a strong advocate.

Now we all must become advocates. The information in this book, added to the facts already known about FAS, can make a difference. You should use this information; use it to inform legislators, governors, the news media, and all the people who are a part of our society's decision-making process. Tell them that there is only one right decision about FAS. Tell them that in order to meet the basic responsibilities of their jobs they must support the ideas and programs in this book that aim to overcome and prevent secondary disabilities in FAS and FAE. They must find answers to Fetal Alcohol Syndrome and Fetal Alcohol Effects. This is vitally important material and with it we can make a tremendous difference to many people in this world.

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Preface

This book commemorates 25 years of research on Fetal Alcohol Syndrome (FAS) at the University of Washington School of Medicine. From the initial identification and naming of FAS in 1973, through the first international conference on FAS in 1980, the major non-human primate studies of FAS, and the first follow-up study of adolescents and adults with FAS, Seattle researchers have been actively involved in both research and clinical work with people with FAS and their families.

In September 1996, 653 people from 8 countries and 39 states gathered at the University of Washington School of Medicine to hear new research findings from the Fetal Alcohol Follow-up Study, and to hear what 62 colleagues representing many different professional backgrounds, national and community organizations, and types of families were doing to actually help people with FAS. This book contains 22 selected papers from this three-day conference, and a Rapporteur's Report summarizing the individual presentations of most of the rest of the presenters.

Fetal Alcohol Syndrome was named as a birth defect in 1973 when two University of Washington dysmorphologists (Drs. Kenneth Lyons Jones and David W. Smith) identified 11 unrelated children from three racial backgrounds with a similar pattern of craniofacial anomalies, growth deficiency, and central nervous system (CNS) dysfunction. All were born to alcoholic mothers. The news was shocking, and met at first with disbelief.

Within four years, experimental animal studies clearly established that alcohol is a teratogenic drug and a case-comparison group study was carried out showing that children of alcoholic mothers, even when compared to carefully-matched controls, have more growth deficiency, smaller head circumference, and more borderline to moderate mental retardation. By 1978, 245 patients with FAS had been reported in the medical literature, and FAS was described as the most frequent known cause of mental deficiency. Several necropsy reports on children with FAS revealed serious brain anomalies, and experimental animal studies, including a series of nonhuman primate studies carried out at the University of Washington Primate Center by Dr. Sterling Clarren and colleagues, confirmed the vulnerability of the fetal brain to prenatal alcohol exposure.

Because FAS was clearly an entirely preventable birth defect, prevention efforts were underway within a few years of the initial identification. In 1981 the Surgeon General issued a Health Warning on Alcohol and Pregnancy, recommending that women who are pregnant or considering a pregnancy refrain from alcohol use. By 1989 national legislation was passed mandating warning labels about the harmful effects of drinking during pregnancy, and many cities and states now have mandatory posting of warning signs at point of purchase of all alcohol beverages. Public awareness of the risks of drinking during pregnancy is high.

However, intervention efforts to help people with FAS and their families have not kept pace. A Dysmorphology Unit and a Craniofacial Clinic at the University of Washington Medical School and Children's Hospital and Medical Center over the years between 1973 and 1991, identified many local infants and children, either with FAS or with Fetal Alcohol Effects (FAE) or Possible Fetal Alcohol Effects (PFAE). FAE and PFAE were terms used for patients who had some but not all of the characteristics of FAS, but had a history of significant prenatal alcohol exposure. A ten-year follow-up study of the first eleven children identified with FAS revealed a surprising degree of psychosocial distress, especially in those who had the highest IQ scores. Larger studies of more adolescents and adults revealed similar findings, not only from Seattle, but from other cities and countries as well.

Further data were clearly needed to document and understand the breadth and magnitude of the problems faced by people with FAS and FAE as they grew up. In 1992, the Centers for Disease Control (CDC), through the National Center for Environmental Health, Disabilities Prevention Program, funded researchers at the University of Washington Medical School to carry out two important studies with practical significance for people with FAS/FAE and their families.

Drs. Clarren and Astley in the University of Washington Department of Pediatrics were funded to run a weekly FAS diagnostic clinic, ostensibly as a vehicle for studying birth mothers of such patients, but which actually provided the first opportunity for the systematic examination of hundreds of people of all ages born to alcohol-abusing mothers.

Our team at the Fetal Alcohol & Drug Unit in the Department of Psychiatry and Behavioral Sciences was funded to carry out a study of secondary disabilities in people with FAS/FAE. This CDC study was designed to reduce the incidence and severity of primary and secondary disabilities and to promote the independence, productivity

and integration into the community of persons with disabilities. For the purpose of this current work, primary disabilities were defined as those that reflect the CNS dysfunction inherent in the FAS or FAE diagnosis. Secondary disabilities were those that a person is not born with and that could presumably be ameliorated through better understanding and appropriate interventions. The secondary disabilities under particular investigation were those that our clinical experience with hundreds of similar patients suggested were frequently a problem. They included mental health problems, disrupted school experiences, trouble with the law, inappropriate sexual behaviors, alcohol and drug abuse, difficulty with independent living, difficulty with employment, and problems with parenting. It was our hope that good descriptive data on the frequency of these secondary disabilities in people with FAS/FAE would draw attention to this problem, generate interest in understanding and responding to the needs of this population of under-served people, and stimulate further research and more effective service delivery.

In 1996 The Institute of Medicine (IOM) published a review of *Fetal Alcohol Syndrome: Diagnosis, epidemiology, prevention, and treatment* (Stratton, Howe, & Battaglia, 1996) in which a new term for FAE and PFAE was introduced: "Alcohol-Related Neurodevelopmental Disorder" (ARND). The terms FAE and PFAE as used in the papers by Clarren and colleagues and Streissguth and colleagues are interchangeable with ARND.

Because the intent of our study was to generate interest and action toward effective intervention efforts, research also was undertaken on the risk and protective factors associated with these secondary disabilities. We wanted to be able to say to communities: Here's a huge problem, but here are some things that happen to a child postnatally that are related to an increase or a decrease in this problem. Once communities have this information, they should be a giant step ahead in planning for the needs of people with FAS/FAE and their families, in ways that should specifically improve their lives.

This book, like the conference and study that inspired it, arose from the need for more information about Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). What do we know about the brain damage that causes FAS, what are people with FAS like, what are their predictable disabilities, and what are some promising ways of overcoming these disabilities? Thanks to substantial funding from the CDC, we are now able to move forward with information about these disabilities and the interventions that might help. This information was published in a Final Report to the CDC, but that was

only our preliminary medium of dissemination. The next step was the three-day international conference "Overcoming and Preventing Secondary Disabilities in Fetal Alcohol Syndrome and Fetal Alcohol Effects" held September 4 to 6, 1996 at the University of Washington Health Sciences/Medical Center in Seattle, Washington. We thought of it not so much as a research meeting, but as a working meeting where people could learn from each other, be inspired by each other, and take ideas back to their own communities. In inviting the speakers, we sought out people from around the world who were doing something new that could have direct implications to promoting understanding and help for people with FAS/FAE in the hope of preventing and overcoming the secondary disabilities of FAS/FAE.

This book is the next step in disseminating this information. This book is for anyone who is concerned about doing something to help people with FAS/FAE and their families. There are papers describing programs and interventions from many different professionals — and from family members too — who must work together to provide the network of appropriate services for people with FAS. This book is for people in mental health, the schools, criminal and juvenile justice, politicians and government administrators and policy planners; it is also for families with the hope it will generate ideas about where to turn for help. This book is for people who want to be part of the solution, who want to be aware of the latest ideas on overcoming and preventing secondary disabilities in people with FAS/FAE. This book is for those who want to find inspiration for how to proceed in every community for the improved welfare and humane understanding of this underserved population.

The book opens, as did the conference, with a Foreword by then-Governor Mike Lowry, who truly put the weight of his office energetically behind efforts to overcome and prevent these disabilities in our state. He supported legislation about warning signs about not drinking during pregnancy and legislation to mandate an FAS coordinating committee of state executives whose activities relate to people with FAS across all branches of state government. He supported legislation to guarantee access to a network of FAS diagnostic clinics across the state, and used money from his emergency fund to set up a new program of Birth to 3, the Seattle Advocacy model for strenuous intervention with the very highest risk group of mothers. Governor Lowry set a new standard for the governors of our states. As you read his words, determine to make *your* Governor involved to the same fruitful extent.

Since 1973, FAS has been the topic of extensive research and thousands of children have been diagnosed with this birth defect.

Enormous efforts have been undertaken to get the word out about FAS. But not until 1989, with the gift of Michael Dorris's word, was that milestone finally achieved. His book, *The Broken Cord*, written with tenderness and understanding about his son with FAS, has done more than all my research to bring the reality of FAS to the public eye. In the Introduction to the present book, Michael Dorris speaks as a "parent with issues" about his son Abel, who "... lived for 23 years, endured daily loneliness and confusion and hardship and frustration, and in all that time never once did anything that was intentionally cruel or hurtful to another living creature." As Dorris says, "He was maddening in his inability to learn from experience, to grasp a larger picture, but he was also sweetness distilled." Dorris points out what is seldom noted, that the vast majority of people afflicted with FAS or FAE in this world are not children, but adults. And he reminds us that Fetal Alcohol Syndrome can be eliminated, "but it is a slow and painstaking process . . . one rescued human life at a time."

Drs. Sarah Mattson and Ed Riley present a scholarly review of the literature documenting the research of the past 20 years on the effects of prenatal alcohol exposure on intelligence, language, visual spatial functioning, verbal learning and memory, motor abilities, and attention. They also document research findings relating to neuro-anatomic features of FAS and FAE from the early autopsy findings to the latest imaging studies, much of the latter carried out on their patients. They conclude that prenatal alcohol exposure has pervasive and often devastating consequences to the brain, but also that there is some evidence for a specific pattern of effects in individuals with FAS and FAE.

Dr. Marita Aronson, a long-time FAS researcher, presents a summary of 25 years of research on children of alcoholic mothers in Göteborg, Sweden. She finds that although good foster homes could not fully compensate for the prenatally acquired handicap, it was her clinical impression that the fostered children were better able to cope with difficulties than were those who remained in the biologic home when the mother continued to abuse alcohol.

My colleagues and I present a summary of the CDC study, described above, primary disabilities, measured with tests of IQ, achievement and adaptive functioning, observed in the latest study of 473 people with FAS/FAE, who range in age from 3 to 51 years of age. We also present a summary of the frequency of secondary disabilities observed in a similar group of 415 patients. Specific factors associated with increased risk of secondary disabilities, as well as specific "protective" factors associated with a decreased risk of

secondary disabilities that communities and families could provide are described. One of the strongest factors that protects against secondary disabilities is an early diagnosis, something still too difficult to obtain in many states and communities.

Drs. Clarren and Astley present a comprehensive report on how they developed a fetal alcohol diagnostic and prevention network in Washington State that is underway at seven sites, serving the FAS diagnostic and prevention needs of communities. This model grew out of Dr. Clarren's long experience diagnosing FAS within a medical clinic context, and his resolve to develop a new type of clinic that is responsive to the medical, psychiatric, psychologic, educational, and social needs of the patients and their parents. Developing these clinics within a community context where local professionals are involved at the outset in the diagnostic examination and recommendations means that the diagnosis leads directly to workable intervention and treatment recommendations. Experience with the first 511 patients evaluated at the UW clinic site is described as well as methods for development, funding and staffing of such statewide networks.

Chapters by Dr. Kathleen Dyer and colleagues and Jill Snyder and colleagues describe two small intervention studies with patients with FAS. The former describes a neuropsychologic and behavior modification approach, the latter a controlled medication study for patients with FAS thought to be responsive to stimulant medication.

Two chapters focus on the schools. Dr. Patricia Tanner-Halverson describes techniques developed for early intervention within the classroom setting over the past six years when she ran a demonstration classroom for young children with FAS/FAE which began with a small pilot program from the Arizona State Department of Education. Dr. Thomas Wentz presents the shocking findings from his 1995 national survey of state directors of special education in which he found, for example, that only three of the 50 states surveyed had taken any action on FAS, based on a discussion of this problem.

Two chapters discuss case management solutions for people with FAS/FAE. Claire Anita Schmucker gives specific tips on how a privately paid case manager and independent living instructor can assist patients with FAS/FAE. Therese Grant and colleagues describe how a successful model developed for the highest risk mothers in the community who are abusing alcohol and drugs during pregnancy and getting little or no prenatal care (Birth to 3: The Seattle Advocacy Model) can be adapted to meet the needs of mothers who themselves have FAS/FAE, as they face pregnancy and parenting challenges with adolescence and adulthood.

Three chapters are by two lawyers and a judge who have successfully advocated for young adults with FAS. Peter McKee, in plain language, describes the ins and outs of the social security system from the standpoint of an FAS client. Jeanice Dagher-Margosian describes her defense of a client with FAS in a criminal case and the relevance of the FAS diagnosis to each phase of the criminal investigation. The Honorable C. C. Barnett, whose powerful utilization of FAS as a sentencing factor in *Regina vs. Rose Abou* inspired the work of Dagher-Margosian in her sentencing appeal, describes how he reached his decision that it is "simply obscene to suggest that a court can properly warn other potential offenders by inflicting a form of punishment upon a handicapped person who has, indeed, committed an offense for which some sanction must follow." He describes how he used sentencing to focus on some measure of protection for others and to provide a realistic framework for rehabilitation for the offender herself.

Two chapters are written by psychologists involved in various ways with adolescents and adults with FAS and FAE. Dr. Robin LaDue and Tom Dunne, M.S.W. review FAS evaluations for legal determination of competency, capacity, diminished capacity, decline/remand, and highlight problems in making each determination. Dr. Natalie Novick describes treatment issues with sexual offenders diagnosed with FAS, and offers advice to parents on coping strategies at home to prevent inappropriate sexual behaviors from reaching the level of a criminal offense.

In two chapters, parents describe their special contributions to preventing and overcoming secondary disabilities in FAS/FAE. Jocie DeVries and Ann Waller describe their effective efforts for public policy change for increased services for people with FAS/FAE in Washington state, and their successful mobilization of a parent support network for political action. Jan Lutke, with 20 years' experience raising children with FAS/FAE, describes how she has learned from her children the practical meaning of problems with memory, motivation, and time — "spider web walking" as her daughter describes it.

Finally, three administrators approach FAS from a more global perspective. Joseph Hess M.S.W., M.B.A., and Dr. George Nieman describe residential programs needed in the community to meet the continuum of care and comprehensive service needs of people with FAS/FAE. Richard Jackson, M.D., Director of CDC's National Center for Environmental Health, approaches FAS from a public health standpoint. He reviews other toxicants, such as lead, that damage developing brains, which have seen a dramatic decline over the past

two decades as a result of changes in general knowledge and public policy, and compares these problems to FAS. From a public health standpoint, the best intervention is prevention.

In the final chapter, Fred Bookstein, who took copious notes throughout the three days of the conference, presents in his "Rapporteur's Report" pithy summaries of the presentations of thirty additional speakers.

As it goes to press, this book is dedicated with great admiration and sorrow to Michael Dorris, whose untimely death on 11 April 1997 stilled our most passionate voice for FAS.

Ann Streissguth
April 1997
Seattle, Washington

Acknowledgments

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Thanks are due to many who made the conference on "Overcoming and Preventing Secondary Disabilities in Fetal Alcohol Syndrome and Fetal Alcohol Effects" such a success: Pam Phipps, Research Manager of our Fetal Alcohol & Drug Unit (FADU) was the mainstay of organization and innovation; Jonathan Kanter, M.A., with exquisite attention to detail, was the Conference Coordinator. A Community Steering Committee, made up of local colleagues passionate about FAS education (Jocie DeVries, Co-Director of the FAS Family Resource Institute; Therese Grant, Ph.C., FADU; Louise Harper, M.A., Bellevue; Robin LaDue, Ph.D., FADU and Private Practice, Seattle; Sandra Randels, M.S.N., past Washington State FAS Coordinator; and Marceil TenEyck, M.C., C.C.D.C., Private Practice, Seattle) and our research consultants (Fred Bookstein, Ph.D., Distinguished Research Scientist, Institute of Gerontology, University of Michigan; Heather Carmichael Olson, Ph.D., FADU; and Sterling Clarren, FAS Diagnostic Clinic, Aldrich Professor of Pediatrics, University of Washington School of Medicine) who worked together to plan and carry out both the research and the conference.

A National Scientific Advisory consisted of Dr. Oakley; Dr. Bookstein; Dr. Clarren; Dr. Lewis Holmes, Chief, Genetics and Teratology Unit, Massachusetts General Hospital; and Dr. Kenneth Warren, Director, Office of Scientific Affairs, National Institute of Alcoholism and Alcohol Abuse.

Preparation of the present book was facilitated by a Review Committee who reviewed and critiqued the manuscripts invited for this volume, which derived from selected papers presented at the conference. This committee included Susan Astley, Ph.D., Heather Carmichael Olson, Ph.D., and Nancy White, then of the Western Washington March of Dimes. Additional reviewers included Fred Bookstein, Ph.D., Sterling Clarren, Ph.D., Paul Sampson, Ph.D., and Kieran O'Malley, M.D. The contributions of this committee in enhancing this volume are gratefully acknowledged.

Acknowledgment is also due to Sharalyn Jackson, dedicated work-study student from Seattle Pacific University who typeset the manuscript, and to the staff at FADU for clerical help and support services.

Naomi Pascal, Associate Director and Editor-in-Chief of the University of Washington Press, was an unfailing source of support and encouragement. Co-Editor Jonathan Kanter, M.A. assumed the bulk of the technical responsibility for editing the manuscripts, sandwiched gracefully between his duties as a Research Assistant and graduate student in the Psychology Department of the University of Washington.

Jonathan and I thank Martin, Zelma, and Laura Kanter, Antoinette Giedzinska, and Daniel Streissguth for their continuing support, confidence, and encouragement.

Finally, we thank the 36 authors who graciously contributed their time and expertise to this volume, including Fred Bookstein, who not only condensed three days of talks into his Rapporteur's Report, but was an active consultant on all stages of the manuscript preparation. This volume is the first to bring together the research and writings of professionals and families working to overcome secondary disabilities in people with Fetal Alcohol Syndrome and Fetal Alcohol Effects. May it not be the last.

All proceeds from the sale of this volume will be used for further applied research on alcohol-related birth defects, through the Fetal Alcohol Research Fund of the University of Washington School of Medicine.

Introduction

Michael Dorris

Eight years ago at the Research Society on Alcoholism meetings in South Carolina I was generally perceived to be the worst kind of pest — a parent with issues. Since then, since *The Broken Cord* was published and then made into a film and translated into languages from Korean to Polish, I have heard from more than four thousand parents much like I was then — desperate and terrified. I have tried to respond to each of them — not with a message of hope for cure, which I cannot offer, but with information and, more importantly, with compassion.

Each parent's tale of their child with Fetal Alcohol Syndrome or Fetal Alcohol Effects is an original script, never before spoken in the light of day, and yet each one of us, almost as if we are compelled to do so, recounts certain basic and similar events, the same disappointments, the same guilts and regrets. All we can wish for from a fellow traveler is understanding, a nod of recognition, a hand on the arm. Empathy — and its more complicated cousin, probably, diagnosis — doesn't solve our problems, or our children's, but it is healing, it is affirming, it is a candle in a long dark corridor.

I am honored to have been asked to introduce this vitally important book, and I do so with the realization that it's not me you're honoring, but Abel, my late, and inspiring son, who should have been nearly thirty years old now, should have been a father, a husband, somebody's wonderful lover, should have contributed to this world by his original acts and not by his sad example. Let me tell you the most remarkable thing about Abel: He lived for 23 years, endured daily loneliness and confusion and hardship and frustration, and in all that time never once did anything that was intentionally cruel or hurtful to another living creature. He was maddening in his inability to learn from experience, to grasp a larger picture, but he was also sweetness distilled. When he visits me in dreams he is always smiling, always forgiving, always advising me not to take everything so seriously. Those graceful qualities made him irresistible, were what shone through the book, were what continue to provoke indignation on his behalf.

If only he had been able to learn how to cross the street in accordance with a green light.

My thoughts here are full of beginnings, pregnant with questions, loaded with stories I want to tell you so that you who are not parents of an alcohol-damaged child will understand what we as a society and as individuals are losing by not solving this preventable scourge.

I was recently in Rangiroa, in the South Pacific and two events there stood out to me as examples I might share.

The first occurred my last night there. A Polynesian family — mother, father, two daughters and a son — invited me for dinner. Afterward we sat on the verandah under a half-full moon and read, passing the book around, the French translation of my young adult book, *Morning Girl*. That two hours was, to me, the epitome of family: sharing, gentle, patient, involved. It was a moment perfectly ordinary to that remote and protected place, where never once in two weeks did I hear a child cry. It was a moment impossible to conceive if one placed within its cast of characters a child or adult afflicted with FAS or FAE. It is *not* a utopian fantasy, I thought as I walked home that night, to imagine that we could, as human beings, learn to be live like that again. It is not crazy to know what to hope for.

The other example from Rangiroa casts me in the role of any of my three adopted alcohol-impaired children. The magazine assignment that sent me to the Tuamotus was to learn to scuba dive in order to write about the adventure. Initially, I pictured myself as Lloyd Bridges in "Sea Hunt." The problem was, all the instruction I received was in French.

"*Tu comprends?*" Manu, my teacher asked solicitously at every stage of the process.

I could sense I was slow, a bit annoying, and so I dutifully answered "*oui*," even as the truth escalated from "not exactly" to "no way."

Did I actually *comprends*, in the life-and-death sense? Did my children *comprennent* when their learning disabilities specialists or the police or their parole officers explained to them the basic operating instructions for survival in a world in which they had no bearings? Did they *comprennent* the meaning of limits, the necessity of thought before action?

No. Like me, they depended at first on one-on-one guidance, which worked for a little while. And when that stopped, when they or I were expected to have learned the rules, mastered the game, be independent and be left solo, did we truly know what to do?

No, again. I was actually swept out to sea in a strong undercurrent that, though I was later assured it had been explained to me, was one

of those features that I didn't sufficiently comprehend. I was barely saved. My older children similarly were swept into the chaos of a demanding society — and they were lost. When you don't understand how things work, your chances for success are slim.

Another beginning. The other day I was in a toy store in Pioneer Square in Seattle with my three healthy, normal, younger daughters. The first thing that caught my eye was a novelty toy called "The Incredible Brain." There it was, this little plastic fist of potential — and the directions seemed so simple.

How To Make Your Brain Grow!

Fill a large container (jar, bottle, sink or tub) with water. Place your new brain in the container. Stand back! Just kidding. Actually, it takes up to 48 hours for your brain to reach it's full growing potential. Show it to your friends, they'll be amazed!

But what if one screwed up, put the new brain into ethanol rather than water and it didn't grow. Instead, its convolutions smoothed out, stayed small, did not fill its cranial container. The moral is: It's not enough to follow the directions. You have to employ the right ingredients to start with.

FAS is the last thing on earth I ever wanted to be "expert" on. We fall into our fates, or leap unknowingly into them, and then we try to figure them out as best we can. Albert Camus once said that it was the writer's job to speak for those without a voice. Perhaps the job of a parent of a child with FAS or FAE is purely to rage and howl for his children — or for those who entrust to him or her their anonymous tragedies. For seven years I have opened nearly every day the letters of strangers, letters demanding to be contradicted. Letters about cosmic unfairness, waste, broken marriages, crime, far reaching consequences, good intentions turned into bitter cynicism. Their authors call out to you today through me. "If you can't help our children," they cry, "make sure this never happens again. Our hands are full, so we depend on you, those not directly involved. *Do the impossible.*" I join their plea: *end* this cycle of woe. Let the beginning of its eradication start here, today. A quarter of a century ago scholars at the University of Washington first had the imagination to identify the culprit, first made the logical leap, put two and two together and came up with four: Whatever goes into the mother's body becomes the consuming environment for the fetus she harbors.

What have I learned from these chronicles? Certainly, that ordinary people can rise to courage and perseverance, can remain loyal to their ideals. But also, in chorus, they alert me to the relatively small

effect of environment on changing the inevitable. One can surely make a bad condition worse by abuse or neglect or denial or failure to obtain an early explanatory diagnosis, but one can't create *ex post facto* what was inhibited from natural development. Whether my letters come from Malaysia or Miami, from India or Indiana, there is a chilling uniformity in the appearance of defining symptoms. 'Predestination' is too mild a word to describe the steady march from "small, cute and so affectionate," to an individual's struggle to learn how to tell time, to retain the multiplication tables, to not shoplift. There is a typical FAS/FAE trajectory — *dejectory* is probably the better term — with which parents and professionals responsible for these brain- and body-damaged people are all too familiar: Things almost always get worse with the passage of time.

As those of us in the field know well, once involved it's hard to quit. FAS engages our emotions, our sense that justice has been violated, our impulse to put out the fire before the forest is ablaze. It regularly challenges our politics because its hypothetical solutions sometimes go against the grain of our allegiance to universal and absolute human rights. It sets up profoundly agonizing conflicts of interest that go to the core of our ethical beings: What takes precedence, the right of a woman to decide what to ingest into her own body or the right to wholeness of the child she has elected to carry to term? Do protocols protecting client or community confidentiality or privacy *always* supersede the public need for every scrap of useful data, even if it's only evidence of the magnitude and scope of the problem? In matters of life and death, some armchair principles seem less than immutable, some rules may need to be humanely bent. One thing is sure: Bureaucracies positively impede progress and obscure the truth.

But who's going to blow *that* whistle and never receive another dime of funding, plus risk the censure of the purists, the disapprobation of those lucky enough not to have to face the issues head-on, daily, hourly? Who's going to tell the hard truths: We need a new Australia, where many victims of the so-called "gin epidemic" two hundred years ago were exiled and, deprived of alcohol, bore healthy offspring? We may well need to create a set of mandatory farms or protected rural living environments which stress repetitive tasks and are permanently tuned in to the cartoon channel. We need oversight for those who can't or don't foresee enough to protect themselves.

In reviewing reports of FAS-related projects around the country sponsored by the Centers for Disease Control, I was struck by a fact that is rarely mentioned — perhaps because it is so overwhelming in its implications. The vast majority of people afflicted with FAS or FAE

in this world are not children, but adults. Unless some of them become — as often they do — mothers of a next generation of FAS-impaired infants, they rarely get diagnosed or counted. In my experience, their life-long brain and motor damage is not even tentatively identified until a court sentencing hearing in which a savvy public defender of a seemingly remorseless criminal gets the bright idea of an FAE-mitigating strategy.

It's a facile but short-sighted policy to act as though FAS is an issue confined to children under twelve years old, or to women. There is no logical cutoff point in the population because innate disability — physical or mental — interacts with social environments and shifting expectations in different ways throughout a person's lifetime. Behaviors that are tolerable though worrisome at eleven become unacceptable and criminal at fifteen, prosecutable at eighteen, thuggish at forty. Unless we are willing to accept a Brave New World scenario with a constantly increasing percentage of middle-aged "gammas" — some of them dangerous to themselves and others, all of them permanently confused and requiring the enactment of generalized laws that are more and more restrictive (for all of us) to replace the normal cultural ability to interact with common assumptions, to learn from example or experience — we must redefine FAS as an issue that cuts in varying but real ways across every sector and age group of the population, both genders, all social and economic demographics.

I can't demonstrate this to you with color transparencies, statistical analyses or cautious peer-reviewed conclusions. I am in many respects today what I was eight years ago — an implacable, desperate parent with issues, knocking, pounding on the door. One of my children is dead, one has been diagnosed by a court-ordered psychiatrist as homicidal, violent and obsessive, the last is selling crank — and herself — on the streets of a western city, when she isn't practicing her own wacky brand of Satanism. This is in spite of hundreds of thousands of dollars expended on "special" schools, counseling, rehabilitation, in spite of Covenant House, Boys Town and Casey Family Services, in spite of prison and boot camp and the Job Corps. In spite of the fact that though they will always be my children and hence I will always love them as such I must, for the safety of myself and my family, strictly maintain a physical and emotional distance from them — possibly forever.

Let me conclude with more stories to illustrate how far we have yet to go.

For a while I believed my wife and I had done our little part — and Abel his big one — with *The Broken Cord*. I thought it had

reached a lot of people, a critical mass, and had made some dent of difference. I thought I could go back to doing what I love to do: writing fiction.

It's not that easy. I've reluctantly embarked on a new book titled *Matter of Conscience* about that ephemeral collection of otherwise inexplicable symptoms heretofore known as Fetal Alcohol Effects. I don't look forward to doing it; I thought I was done.

I made the decision to do this book, however, because of three incidents of the past year that demonstrated to me in how much trouble we as a society still find ourselves.

The first two involve smart, highly educated, powerful professional women whom I met in New York last spring. One had given birth to a son two years before and told me how her Park Avenue obstetrician greeted her with a martini at her standing Friday 5:15 appointment — to calm her down after a stressful work week. Sometimes the exam concluded with a second round. She had no idea he was potentially feeding her baby poison.

The second woman, equally impressive in her career, had recently been a week late in delivering her baby. Her Park Avenue obstetrician/gynecologist advised, "Oh, relax and take the Italian solution": In other words, go home, drink a *bottle* of Chianti, and have great sex.

"I did it for four nights," she confided to me, "but after all I still had to be induced."

Four bottles of Chianti, one after another, during one of the most critical periods of fetal brain development. Doctor's orders. Paid for, no doubt, by a corporate HMO.

Finally, I knew I had to do this book when I received a call from an Indian Health hospital in the Pacific Northwest. The nurse had read *The Broken Cord* some years ago, and just hours before she had delivered from my 38-year-old unmarried alcoholic cousin a full FAS-diagnosed neonate.

"I thought you'd like to know," this anonymous voiced woman told me over the phone. "She named him after you. Michael Dorris."

I don't just owe my continuing efforts to faceless infants and adults, I owe it to my namesake, I owe it to my children, I owe it to me.

Let me end by offering the first paragraph of what I hope will become *Matter of Conscience*, to be published in the fall of 1998.

I am society, and my life is in threat. I believed I could alter fate. I tried and failed, in process with lapses of patience and with anger, and ultimately because I had no choice but not to

give up. I intended nothing but good, though I expected to be rewarded with gratitude and love, and I wound up the center of a target. I imagined myself powerful, but now I awake every night consumed by dread, by fear. I was foolhardy, a fool. I was driven temporarily mad and may never fully recover enough to completely recall the person I think I used to be. I tried to save three lives: Maybe I didn't try hard enough. Maybe they were unstable. One is gone. One is lost. One is a danger to anyone within his line of sight. I wish I had reconciled earlier to the impossibility of my goal. I wish the conclusion that faces me was avoidable. I wish I could return to do it again, so as perhaps not to do it again, at least not as blindly as I did it the first time. I want my life back. I want my peaceful sleep. I want to fear once again only those natural human fears. I wish my adopted children to achieve amnesia or, better, to remember the entirety of their lives with me. I want them to be well. I want justice. I want reasonable hope for a future untainted by preventable tragedy. I want my and my children's experience to spare just one life, for all of the sorrow to balance a single redemption. I want my children's lives to have mattered.

Fetal Alcohol Syndrome can be eliminated, but it's a slow and painstaking process. Progress moves slowly, one rescued human life at a time.