

## EDITOR'S NOTEBOOK/Bernard Rimland, Ph.D.

### Save the children from their saviors

"Hell is paved with good intentions."—  
Samuel Johnson

As these words are written in late November, the TV screens, newspapers and magazines abound with images of joyous people savoring the fresh air of freedom. Germans dance atop the Berlin Wall and stroll happily through gates newly torn through the wall—Czechs numbering half a million shout down and demand resignations from their oppressive Communist rulers. Those of us in the U.S. who treasure our freedom join the people in Eastern Europe in rejoicing at their liberation from tyranny. But are we Americans really free?

What the East Europeans demand is the right to decide *for themselves* what is best for them and their children. They want freedom from the dictates of government officials whose decisions are based on self-interest or on ideology rather than on empirical evidence and rational and humane considerations.

"Fine," you may be saying, "but how is all this related to autism?" In fact, it is quite related to autism, as you'll see. But first let me point out an interesting paradox: the officials whose actions so enraged their countrymen were supposedly, and probably believed themselves to be, acting in the *best interests* of those who now despise them. Unlike most tyrants of bygone years, these 20th century despots did not merely represent exploitation of those weaker than themselves. The Communist governments had imposed their ideology as a means of *doing good*, as *saviors* of their fellow men. It didn't work! People have the need and the right to decide for themselves. They do not want "Big Brother" riding their backs, telling them how to live their lives.

#### Fudenberg treatment: who should decide?

The two cover stories in this issue of the ARRI have much to do with people's right to make their own decisions. The story about the parents of Dr. Fudenberg's autistic patients battling the Medical University of South Carolina and the Federal Food and Drug Administration on behalf of their children is a sad and familiar one. I first learned of the very good results Dr. Fudenberg was getting in some autistic patients in a phone call from Dr. Mary Coleman, a preeminent authority on autism, several years ago. "Several of my patients who have visited Dr. Fudenberg are showing remarkable improvement," she said. I could hear the excitement in her voice. Others, of course, have not improved. All families have the right, in my opinion, and I hope in the opinion of the courts, to try Dr. Fudenberg's approach if they think it may help. It is their lives, their money, their risk, their decision. Like the Poles, East Germans, Czechs and other oppressed people,

they, and not officious officials, should decide what is best for themselves and their children. *That is freedom.*

In his new book, *Medical Mavericks*, Dr. Hugh Riordan provides account after account of the rejection, ridicule, and persecution that medical innovators have suffered at the hands of their benighted peers. Semmelweis was destroyed by his fellow physicians

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*Parents of autistic children have the right to try treatments which may hold promise. It is their lives, their risk, their money, their decision.*

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for claiming that their habit of going from the bedside of diseased patients to the delivery room without *washing their hands* was an important cause of infant mortality. Harvey was reviled for claiming that the heart was a pump that caused the blood to circulate throughout the body. There is an endless succession of such stories; *Medical Mavericks* is but the first of a three-volume series. The fact that Semmelweis and Harvey were right does not of course prove that Fudenberg is also right, but it does prove that those in authority can be wrong and can inflict great suffering through arrogant exercise of power.

The actions by the FDA and the MUSC are deplorable and not befitting a democracy whose citizens are deemed to have the right to make decisions for themselves, if those decisions do not place others at risk. The officials should be entitled to *state their opinions*, as they do in the warnings about cigarettes and liquor, but they should not be allowed to override the judgment of those they are hired to *serve*.

I applaud Dr. Fudenberg's patients for fighting the bureaucrats in the courts, and I applaud Judge Blatt for his temporary restraining order prohibiting the FDA and the Medical University of South Carolina from interfering with Dr. Fudenberg's efforts. I hope Dr. Fudenberg will be allowed to continue his important work.

#### NIH: recommendations, not edicts

Our other cover story, the NIH Conference on Self-Destructive Behavior in the Developmentally Disabled, presents an entirely different and much more favorable picture. It is a beautiful example of how a government agency *should* behave. Dr. Duane Alexander, Director of the National Institute of Child Health and Human Development,

concerned about the plight of self-injurious autistic and retarded persons, and aware of the ongoing bitter controversy between the "anti-aversives" faction on the one hand and the "right to effective treatment" faction on the other (ARRI 2/3), wisely decided that some solid information and common sense might be in order.

Dr. Alexander called together a very carefully selected panel of scientists who had not previously taken a position on either side of this controversy, in order to consider the facts in a careful and reasoned way, and come out with recommendations that would be accepted by both sides of the dispute. The process took several years of careful, intelligent staff work. All organizations known to have an interest in the topic were invited to submit written material and to speak to the panel. The process was, all in all, an outstanding display of impartial preparation for rational policy-making.

The panel's final report will not be issued for several months, but the draft report is precisely on target, in my view. As the parent of an autistic adult, and as a researcher who has investigated the subject for over a quarter of a century, I can agree with the panel in all respects. In particular, there are cases where the use of judiciously applied aversives, specifically including the new SIBIS device (ARRI 2/3) are needed to protect the person from severe self-injury and to allow time for positive reinforcement interventions to be employed.

To Dr. Alexander and his staff, and to the NIH panel, a hearty "Well done!" (Legislators take note: we appreciate a government which issues *recommendations*, not edicts.)

#### Families fighting for treatment

The NIH panel report is especially timely and welcome. Excessively zealous anti-aversive advocates, not content merely to argue their case, have managed to persuade some state and local governments to prohibit the use of aversives, thus compelling compliance from people who do not themselves agree with the fallacious position that aversives can always be dispensed with. Cases in point: as we go to press, two families in Michigan are battling local bureaucrats for the right to send their handicapped children to school wearing the SIBIS device. Both children are severely self-injurious, and nothing tried earlier has prevented these children from inflicting severe injuries upon themselves, such as skull fractures and permanent eye and ear damage. One mother, the parent of an incredibly self-injurious boy on whom positive reinforcement methods have failed completely, said she had prayed for 15 years for a treatment for her son's self-injury; she called the SIBIS device "a gift from God." More on these parents' struggle for their children's right to effective treatment, in the next issue of the ARRI.