

What's Holding Up "Aversives" Report?

An NIH report on treatments for the developmentally disabled has been delayed for months. Some think politics is to blame

NIH CONSENSUS DEVELOPMENT CONFERENCES are supposed to help clinicians by summing up the scientific evidence on treatments for a specific condition. But sometimes factors other than science intrude.

That seems to be what is happening to the report of a consensus development conference held last September by the National Institute of Child Health and Human Development (NICHD) on treating the developmentally disabled. For 5 months the report has gone nowhere, and many observers suspect a long-running, highly emotional debate over one subject dealt with in the report—"aversive" treatments—is to blame.

The problem surfaced last fall when a preliminary statement was issued in the name of the scientists at the conference saying that aversive, or punitive, methods are sometimes appropriate for an estimated 24,000 retarded people with disorders including autism and cerebral palsy who suffer from chronic, violent, self-injurious behavior—constant head-banging, for example, or attempts to gouge out their own eyes or bite off their fingers.

Examples of the aversive techniques winning qualified acceptance range from rather mild efforts to alter behavior patterns (withdrawing attention at signs of self-destructive behavior, say) to a new electric shock device known as self-injurious behavior-inhibiting system (SIBIS). SIBIS works through a sensor attached to the head. Every time the wearer bangs his head, the sensor sends a message to a unit worn on the arm or leg that delivers an electrical impulse—equivalent to a hard pinch—lasting for 0.08 second.

Even qualified acceptance of any aversive technique is vehemently opposed by some advocacy groups for disabled people. No sooner had the conference closed when several of those groups, including the Autism Society of America (ASA) and the Association for Retarded Citizens (ARC), tried to discredit the verdict. They contended that the conference's scientific panel—headed by pediatrician R. Rodney Howell of the University of Miami School of Medicine—was biased and the conference process was "flawed." The ARC has written several times to Department of Health and Human



Cruel and unusual? SIBIS (self-injurious behavior-inhibiting system), which is at the center of a controversy over "aversive" therapies, is worn by an 11-year-old boy at Children's Hospital in Columbus, Ohio.

Services Secretary Louis Sullivan, urging him to block the final report. And Senator Sam Nunn (D-GA) asked the HHS Inspector General to investigate whether the conference was properly conducted.

The high level of emotion engendered by the aversive component of the conference is no accident. Psychologist Johnny L. Matson of Louisiana State University says aversives have "become perhaps the single most frequently discussed issue in the field of developmental disabilities."

Aversives enter the picture because, although many "positive" (nonpunitive) methods for stopping self-injurious behaviors have been developed, they don't work in all cases. In some instances aversive methods offer the only alternatives to heavy drugging or physical restraints. The most frequently used methods are nonintrusive ones, such as "overcorrection" (making a person clean up the mess he just made) and "time out" (ranging from short periods of isolation to a teacher briefly turning away). Others are more aggressive: mild electric shocks, exposing a person to bad tastes or ammonia, or temporarily blocking vision.

SIBIS is a variation on old shock techniques, one said to be more effective because it provides automatic, instant feedback. De-

veloped at the Johns Hopkins Applied Physics Laboratory and introduced in 1987, the device has been hailed by many professionals as a major breakthrough—in many cases resulting in the immediate suppression of self-injurious behavior while it is worn.

Only about 50 such devices are in use at any given time. But SIBIS, with its high-tech overtones, has become the rallying symbol among those who oppose aversives. "It is a return to the dark past," says lawyer

Thomas Nerney, a prominent anti-aversives spokesman who until recently was executive director of the ASA. "Whatever the rhetoric, what they've done is sanction shock," says psychologist Gary LaVigna, clinical director of the Institute for Applied Behavior Analysis in Los Angeles. He says there is no research demonstrating its effectiveness.

But LaVigna's blanket pronouncement doesn't settle the matter. Psychologist Thomas Linscheid of Ohio State University

published one of the first clinical studies on SIBIS in the spring 1990 issue of *Journal of Applied Behavior Analysis*. Linscheid tested SIBIS on five people who engaged in continual head-banging that had not been cured by years of other interventions. He reported that they needed to wear the device only a few hours a day to drastically diminish the behavior. Linscheid says that, contrary to allegations, there were no bad side effects, and most subjects indicated SIBIS was less unpleasant than tastes, ammonia, overcorrection, or restraint. For some, the effects are permanent, although most must continue their sessions.

Psychologist Matson argues that the scientific evidence favors aversive therapies in general, not just SIBIS. Last year he published a review of 382 treatment studies done between 1967 and 1987, most of which contained "an aversive component." He reports, in *Research in Developmental Disabilities*, that although critics say aversive treatments only yield short-term effects, "all studies reporting follow-up showed significant maintenance of treatment gains."

Those who are opposed don't buy this evidence. The most vocal anti-aversives group, the Association for Persons with Severe Handicaps (TASH), has published

its own monograph by psychologist Edward G. Carr of the State University of New York at Stony Brook. TASH reports that in 96 studies using only positive approaches, the success rate for suppressing undesirable behaviors was nearly 60%. From this, the organization concludes, "positive procedures do work."

The critics say they fear SIBIS and other methods are open to abuse—and that using them will short-circuit the challenge of developing better, nonpunitive, training methods. But psychologist Eric Schopler of the University of North Carolina thinks the conflict isn't so much about methods as about politics. He calls the critics "self-serving ideologues" who drastically oversimplify the issue with emotional arguments and "are making a fortune going around doing workshops on how to never use aversives."

The conference statement issued last fall was by no means a ringing endorsement of aversives. It was cautious, proposing that aversives should be used "only if they are incorporated in the context of a comprehensive and individualized behavior enhancement treatment package." But this was enough to set in motion the protests and some rather unusual actions on the part of HHS.

For example, preliminary statements are usually released immediately after a conference, but this time, NICHD director Duane Alexander and John Ferguson of the National Institutes of Health were first summoned downtown to HHS headquarters to defend the conference proceedings. Then on 20 July, Sullivan (belatedly responding to a letter of concern sent him last fall by the anti-aversives ARC) told ARC he had asked Martin Gerry, HHS assistant secretary for planning and evaluation, "to review our current policy in light of the assessment of current knowledge provided by the consensus statement as well as the concerns of your organization. . . ." According to James Hill, chief of the office of science policy and analysis at NICHD, it is "most unusual" for the assistant secretary for planning and evaluation to be given the job of "assuring someone that the result of any DHHS effort is above board."

Some observers believe it is Gerry who has been responsible for stalling the publication of the conference findings. Gerry is a lawyer who was formerly a consultant to Sullivan. For the past decade he has been a member of TASH and he has done legal work for groups that oppose aversives. Gerry, however, told *Science* he had nothing to do with delaying the statement or the final report. He did say, though, that he was concerned that the consensus development panel's conclusions "not be seen as the de-

partment's policy."

So the consensus development report, which Hill calls a "thorough, scholarly monograph," seems snarled in a maze. Researchers say the report is needed to help counter political efforts to ban aversives. There have been attempts in Congress to withhold federal funding from institutions that use aversives with mentally retarded clients, and several states are considering or already have such laws.

According to psychologist Michael Caldo of the Johns Hopkins University

School of Medicine, the report is eagerly awaited by researchers who would like to stop this political trend in its tracks. But they may not get their wish. The first hurdle will be the report from the investigation requested by Senator Nunn. But even if that report, which is expected soon, finds that the conference was entirely proper, researchers still won't know when the consensus report will see the light of day. Says Hill: "We have not heard a thing. Hill about the report's status: 'We have not heard a thing.'"

■ CONSTANCE HOLDEN

U.K. Science Responds to Terror

Swansea, Wales—Over the past few years, while an escalating campaign of animal rights terrorism has engulfed British science, the scientific establishment here has largely remained silent. Now, at the annual meeting of the British Association for the Advancement of Science, science in the U.K. has issued its first organized response to the terror. In a statement issued on the meeting's last day, a star-studded panoply of individuals and institutions declared that experiments on animals are "important" and "essential" for human health.

The declaration has been signed by half a dozen Nobel laureates and the heads of all the Royal Colleges of Medicine and is now being released to gather even wider support. The statement was prepared by Colin Blakemore, professor of physiology at Oxford University, himself a frequent target for animal rights activists. Blakemore sees it as the first salvo in a campaign to regain public confidence in research.

"We're not speaking to the people who put bombs under cars," Blakemore told *Science*, referring to an incident several weeks ago in which bombs were set off in the cars of two U.K. researchers. "They're not going to be convinced by a declaration no matter how eminent the medical and scientific people who sign it. But all the evidence is that public opinion is being moved on this issue."

So far the movement has been largely in favor of the animal rightists, Blakemore says. He cited recent polls showing that among younger people, 25% support the aims of animal rights extremists and 20% support their methods. The reason, he adds, is that the scientific establishment, in trying to avoid attention, has failed to rebut misleading public relations campaigns. "A quarter of the young people think that cosmetics testing, which has been the subject of many campaigns, is the major use of animals in experiments. In fact, it's less than half a percent."

Blakemore believes that in the absence of effective rebuttal, the claims of the animal rightists have become increasingly extreme. "The latest line," he says, "is to claim that a thorough study of the scientific and clinical literature reveals that not a single medical advance has depended on experiments on animals. That's arrant nonsense. I can't think of a single advance that has not depended on animals at some stage."

Some of the quiescence from the scientific side has been the result of policy on the part of funding agencies trying to protect researchers. Those policies have begun to change, partly in response to arguments like Blakemore's. Dai Rees, secretary of the Medical Research Council (MRC), has reversed that agency's policy, which aimed at concealing the role of animals in MRC-sponsored research.

In future MRC annual reports, he says, the role of animals will be stressed. The same will be true of announcements of research advances, "provided individual scientists are not put at risk," Rees told *Science*. The MRC is also considering ways of providing young people, especially at school, with accurate information to counter extremist campaigns.

Max Headley, a Bristol University veterinarian and one of the two researchers who escaped serious injury in the recent car bombings, expressed pleasure at the recent declaration: "I very much hope that the statement will reassure the public that animal experiments have made a vital contribution in the past and that they must be allowed to do so in future."

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