Autism Research Review

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NIH panel: aversives needed, drugs overused

A federal panel of experts, convened by the National Institutes of Health (NIH), has issued a statement in favor of using aversives when other methods of treating severe behavior problems fail.

After listening to testimony from researchers, educators, and parents, and studying extensive scientific evidence, panel members participating in the NIH Consensus Development Conference on the Treatment of Destructive Behaviors concluded that aversives including SIBIS (which uses brief, uncomfortable electrical stimulation to stop severe head-banging) are sometimes necessary to stop severe self-injury and aggression. They added, however, that aversives should be used only after appropriate review; that they should be used only as a temporary measure; and that aversives should be used in conjunction with positive reinforcement.

The panel also stressed that all behavioral treatments should be preceded by a "functional analysis" of the factors that may be causing behavior problems.

"Treatments should be based on an analysis of medical and psychiatric conditions, environmental situations, consequences, and skill deficits," they noted.

In addition, the panel concluded that psychiatric medications are used too frequently and carelessly as a means of controlling behavior problems, and that these medications often do more harm than good. Panel members recommended that such medications be used only to calm individuals for short periods in order to institute behavioral or educational treatments, or to treat specific disorders such as depression

A number of organizations including the International Association for the Right to Ef-

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fective Treatment (IARET), a group of professionals and parents, supported the resolution. Other groups, including the Autism Society of America, have protested the NIH panel's conclusions, claiming that the panel report is "biased and unscientific."

The panel found that aversives, including SIBIS, are sometimes necessary to stop severe behavior problems safely.

They question the evaluation of treatment effectiveness "in isolation from concerns about legal and ethical problems that aversives raise," and claim that the report "does not accurately reflect the current state of scientific knowledge about aversive and non-aversive treatments." In addition, the groups charge that they were not allowed sufficient input at the conference.

NIH conference participants reply that "the consensus panel consisted of professionals representing a variety of scientific disciplines and included parents of children with developmental disabilities." They note that panel members were carefully selected on the basis of both their expertise and their lack of bias.

"NIH made a broad effort to involve the greatest number of interested participants," they add, noting that more than 13,000 amnouncements inviting participation were mailed to groups and individuals. "No individual or organization requesting to speak was denied the opportunity. All material received from respondents was [given] to panel members."

The NIH panel, chaired by Dr. R. Rodney Howell of the University of Miami, included psychiatrists, psychologists, and experts in special education. Such conferences have historically been convened, according to NIH official David Gray, "whenever [a] controversy reached a point that resolution did not appear possible and when the health of a group of the population was at risk."

The panel issued a draft report following the conference. Their final report will be issued in January 1990.

Controversial autism therapy reinstated by judge's order

A federal judge has ordered the Food and Drug Administration and the Medical University of South Carolina to allow Dr. Hugh Fudenberg, an immunologist at the university, to resume a controversial treatment for people with autism and other disorders. Fudenberg's treatment involves injecting material (Dialyzable Leucocyte Extract) from the white blood cells of healthy individuals (usually relatives) into patients, in order to bolster their immune systems.

FDA and university officials ordered Fudenberg to stop the treatments last August, claiming that there is no documentation of the treatment's effectiveness, and that there is a potential risk of blood-carried diseases such as AIDS and hepatitis.

Pediatric neurologist Mary Coleman, author of The Biology of the Autistic

Syndromes, argues that many of her patients treated by Fudenberg have shown "dramatic improvement," adding that "[Fudenberg's] work may become a major breakthrough in autism, and today there is no other medical treatment. He is one of the founders of clinical immunology."

Fudenberg, Coleman and colleagues recently reported that immunologic studies of 24 patients with autism revealed that 18 of the individuals had histories of severe or recurrent viral infections following immunization with live virus vaccines. A number of their subjects, they say, showed antibodies to NAFP (Neuron-Axon Filament Proteins), "suggesting the role of a 'slow virus'" in these cases of autism. Antibodies to NAFP, Fudenberg and colleagues note,

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