

## EDITOR'S NOTE:

The Autism Society of America (ASA) is aware that the topic of vaccines and autism is both sensitive and controversial. The opinions of the Centers for Disease Control (CDC) and SafeMinds on the issue do not necessarily represent those of ASA. We feel, however, that given the increased media attention to the issue, ASA members deserve to hear both sides and form their own opinions. Please refer to ASA's Panel of Professional Advisors' Guidelines for Theories and Practices, published here and on our Web site ([www.autism-society.org](http://www.autism-society.org)), when considering this subject. Below is ASA's current stance on vaccines and autism:

ASA has consistently asked agencies to undertake more research, specifically with clinically-based subjects rather than large-scale epidemiological studies that do not address the possible subsets of those who may be more prone to injury by vaccines and their additives; has insisted that those who have been injured by vaccines be fairly compensated and receive the services and interventions that are appropriate and necessary; and has supported legislation that calls for the removal of thimerosal from all vaccines. ASA feels that the federal agencies have had opportunities to address the lack of appropriate services for individuals with autism across the lifespan; the woefully inadequate funding for research; and the steps they would take to address this national health crisis and therefore build a trusting relationship and dialog with the autism community, but have not directly addressed these concerns.

A step in the right direction for the autism community is the bipartisan Mercury-Free Vaccine Act of 2005 (HR. 881), introduced by Congressman Dave Weldon, MD (R, FL-15) and Congresswoman Carolyn Maloney (D, NY-14), and the Senate version, S. 1422, introduced by Senator Chuck Hagel (R-NB), both of which ASA staunchly supports. The bills ensure, through law, that thimerosal will be phased out, and kept out, of vaccines. ASA wholeheartedly endorses both bills, and applauds legislative efforts to protect our nation's future.

### SPECIAL REPORT PROLOGUE

## GUIDELINES FOR THEORIES AND PRACTICES

*Prepared on behalf of ASA's Panel of Professional Advisors by David Holmes, Ed.D., Former Chair, PPA*

Throughout the history of the Autism Society of America (ASA), parents and professionals have been confounded by conflicting messages regarding what are, versus what are not, appropriate remedial methodologies for children and adults with autism.

In 1995, the Panel of Professional Advisors (PPA) for the Autism Society of America unanimously agreed to develop a series of guidelines on theories and practices so that consumers of such matters, both parents and professionals, can be forearmed with a set of parameters under which they can better determine associated threats and opportunities and, therefore, make informed decisions. Further, a better educated consumer, the panel felt, would also help control the embracing of unproven notions that may distract the field from developing effective courses of treatment for individuals with autism. The education of consumers notwithstanding, the PPA also felt an obligation to abate the promotion of sometimes harmful and expensive treatments that have no foundation in scientific evidence.

The panel observed a relatively consistent series of events that frequently emerge relative to unsubstantiated theories and/or practices. Those events include initial excitement;

interest generated in the popular media; non-replication under controlled conditions; excuses proffered by proponents for non-replication; accusations by proponents against those who voice concern regarding these matters; development of an ardent group of true believers in the matter; and the inevitable distraction of the development of effective treatment(s).

Forearmed with these viewpoints, the panel agreed to establish guidelines for theories and practices, not to discourage the development of new theories or practices, but rather to encourage the professional community to disclose the nature of the theory or practice relative to its history, prospects for the future, and their interest in it.

The ultimate objective of these guidelines is to help consumers assess theories and practices in order to make thoughtful decisions when it comes to services for their child(ren) and adult offspring and/or students. The PPA and, in turn, the board of the Autism Society of America, hope that these guidelines for theories and practices are beneficial to all who employ them.

# GUIDELINES FOR THEORY AND PRACTICE

Developed by the Panel of Professional Advisors and approved by the Autism Society of America Board on January 17, 1997. The following guidelines were developed to assist people with autism, parents/guardians, practitioners, and advocates in evaluating theories and practices related to autism. The guidelines will provide such consumers with a set of parameters under which they can better determine the threats and opportunities associated with theories and practices.

## GUIDELINES

In assessing theories and practices, consumers need to ask professionals the following questions.

- Do you adhere to the Priorities of Professional Conduct promulgated by ASA? (See *Autism Society of America Priorities of Professional Conduct*.)
- What is the purpose of this theory/practice?
- What do I have to do to benefit from the theory/practice, and what are its lasting effects?
- What is the status of this theory/practice relative to controlled (scientific) investigation, and is there a reference list of publications?
- How long must my child be involved in this theory/practice to gain benefit?
- Are there any physical or psychological harms which might come to my child as a function of participating in this theory/practice?
- What are the personal costs of time and money that I will have to endure, and will I be able to be reimbursed for these expenses?
- How do I know that the costs for the implementation of this theory/practice are fair and reasonable?
- Are the theoreticians or practitioners competently and appropriately trained and prepared to implement the provisions of the theory or practice, and how is this competence assured?
- What steps will be taken to protect my privacy?
- Are there any legal actions, current or past, against promoters, consumers, or practitioners of the theory/practice?
- How will the effects of this theory/practice be evaluated for my child?
- By choosing this theory/practice, what alternatives (proven/unproven) are not being pursued?
- Does this approach exclude other alternative approaches and does it mesh with my child's total program?
- Which individuals with autism has this theory positively benefited, and under what conditions?

## GENERAL CONDITIONS

Proponents of theories and practices must inform participants that they are free to participate, free to decline to participate, or withdraw from the treatment; they must explain the foreseeable consequences of declining or withdrawing; they must inform participants of significant factors that may be expected to influence their willingness to participate, such as risks, discomfort, adverse effects or limitations, confidentiality; they must explain other aspects of which the prospective participants inquire (*see guidelines to the left*); and they must protect the prospective participants from adverse consequences of declining or withdrawing from participation.

For persons who are legally incapable of giving informed consent, the proponents of theories and practices must provide an appropriate explanation to a guardian and obtain assent from the guardian if substitute consent is permitted by law.

In offering inducements to participate in the theory or practice, proponents must make clear to each participant the nature of the services as well as the risks, obligations, and limitations. Proponents must not offer excessive or inappropriate financial or other such inducements to obtain participation. Proponents must not coerce participation. Proponents must never deceive participants regarding significant aspects that would affect their willingness to engage in or make use of the theory or practice, such as physical risks, discomfort, unpleasant emotional experiences, and/or financial demands. Theories and practices must not be presented in a misleading or fraudulent manner; either because of what is stated, conveyed or suggested, or because of what is omitted concerning research or practice.

## IMMEDIATE PRESENTATIONS

Proponents of theories and practices in public lectures, demonstrations, radio or television programs, prerecorded tapes, printed articles, mailed material, or other media forms must ensure that statements are consistent with the ASA Priorities of Professional Conduct Statement (July 15, 1993).

## TESTIMONIALS

Proponents of theories and practices must not solicit testimonials from current consumers or persons who, because of their particular circumstances, are vulnerable to undue influence.