New! The Autism Treatment Evaluation Checklist (ATEC)

A major obstacle in autism research has been the lack of a valid means of measuring the effectiveness of various treatments. Over the years, researchers have published hundreds of studies attempting to evaluate different biomedical and psychoeducational interventions intended to benefit autistic children. Much of this research has produced inconclusive or, worse, misleading results, because there are no useful tests or scales designed to measure treatment effectiveness. Lacking such a scale, researchers have resorted to using scales such as the Childhood Autism Rating Scale (CARS), the Gilliam Autism Rating Scale (GARS), or the Autism Behavior Checklist (ABC), all of which were designed to *diagnose* autism—to tell whether or not a child is autistic—and not to measure treatment effectiveness.

Two recent reviews have commented on the problem: "Often, investigators have attempted to use diagnostic instruments to measure changes in response to treatment... this approach has not been very successful... because most diagnostic instruments... are not sufficiently sensitive to changes within an individual."[1] "...[M]easures of clinical improvement to validate treatment outcomes are even more seriously deficient."[2]

The Autism Treatment Evaluation Checklist (ATEC) was developed by Bernard Rimland and Stephen M. Edelson of the Autism Research Institute to fill this need, which is especially urgent right now because of the 20 or more studies starting soon to evaluate secretin.

The ATEC is a one-page form designed to be completed by parents, teachers, or caretakers. It consists of four subtests: I. Speech/Language/Communication (14 items); II. Sociability (20 items); III. Sensory/Cognitive Awareness (18 items); and IV. Health/Physical/Behavior (25 items).

Unlike most of the scales, it is not copyrighted and may be used free of charge by any researcher. Copies are available on request from the Autism Research Institute or at the ARI website, www.autism.com/atec.

Users of the ATEC may have it scored (4 subscores and a total score) by entering the responses via computer to the ATEC form on the website for immediate and free-of-cost scoring.

Results of research using the ATEC will appear in future issues of the ARRI (only with the express permission of the researchers who use the ATEC, of course).

References:

1. Lord, C., in: *Handbook of Autism and Pervasive Developmental Disorders* (1997). D. J. Cohen and F. R. Volkmar, Eds.,Wiley, New York (p.477).

2. Accordo, P., and Bostwick, H., "Zebras in the living room: The changing faces of autism," *Journal of Pediatrics*, Vol. 135, No. 5, November 1999, p. 533.

Researchers identify Rett syndrome defect

Researchers in the United States have pinpointed the gene defect that causes Rett syndrome, a progressive disorder that can resemble autism in its early stages. R. E. Amir, Huda Zoghbi, and colleagues announced that a mutation of the gene that makes the protein MECP2 is responsible for the disorder.

MECP2 is a critical link in a network of proteins whose job is to "silence" other genes. When this genetic switch fails to function, genes that should shut down instead remain active, and excessive amounts of certain proteins are manufactured.

Amir et al.'s discovery explains why Rett syndrome is diagnosed almost exclusively in females. Females have two X chromosomes, but only need one functioning X chromosome, so the body randomly switches off half of females' X chromosomes. Males, however, have only one X chromosome, so a serious X-linked defect is generally fatal.

Officials at the National Institute of Child Health and Human Development have announced plans to promote research into the possibility of manipulating the MECP2 gene. in the hope of ameliorating or even preventing Rett syndrome.

Girls with Rett syndrome generally develop normally until they are around one to two years old, and then begin to lose language, social, and motor skills. A classic characteristic of Rett syndrome is a constant "hand-washing" or hand-wringing motion.

—

"Rett syndrome is caused by mutations in X-linked MECP2, encoding methyl-CpG-binding protein 2," R. E. Amir et al., p. 185-188. Address: R. E. Amir, Dept. of Pediatrics, Baylor College of Medicine, Houston, TX 77030.

More on the "autism epidemic"

Recently (see ARRI 13/1), researchers reported a huge upsurge in the number of autistic individuals in the state of California. The report, based on an analysis of data from the state's 21 Regional Centers, revealed that the state's population of autistic clients rose from 3,864 in 1987 to 11,995 in 1998. In 1998, 1,685 cases were recorded, and in 1999, almost 2,000 new cases are projected.

Researchers also report that, according to the 1998 Maryland Special Education Census data, the number of autistic pupils in that state has jumped as well, increasing by 513 percent between 1993 and 1998. (Baltimore, for instance, had only 54 autistic students in 1993, but reported 306 in 1998.) In contrast, the number of retarded individuals increased by only 13 percent and the number of learning disabled students by only 7 percent since 1993, and the general population grew by only 7 percent between 1990 and 1998.

Data from other states indicate that they too are experiencing exponential increases in the number of reported cases of autism (e.g., Florida reports a 563 percent increase in five years). Says parent advocate Rick Rollens, "How much more evidence is necessary for policy makers to wake up and declare what we all know is happening: this country from coast to coast is in the middle of a growing autism epidemic?"

Death rates higher in the community

(continued from page 1)

semi-independent settings. Deaths due to homicides were three times as common in the community, and of the 28 deaths due to drug or medication overdoses, 79 percent occurred in supported living settings or small group homes.

Strauss and Shavelle say, "There is... no reason to believe that problems we have reported are confined to California." They suggest that the change from the "medical model" of institutions to the "behavioral/social/legal" model of community homes, while beneficial in some respects, "seems to have resulted in a dramatic reduction in attention to health issues."

The researchers say different conclusions can be drawn from their data, but conclude, "In our view... the main conclusion is this: When policymakers and advocates assure us that their programs are working just fine, they should be asked: Where are your data? Where are your peer-reviewed studies?"

—

"Mortality of persons with developmental disabilities after transfer into community care: A 1996 update," Robert Shavelle and David Strauss, *American Journal on Mental Retardation*, Vol. 104, No. 2, March 1999, pp. 143-147.

—and—

"What can we learn from the California mortality studies?" David Strauss and Robert Shavelle, *Mental Retardation*, October 1998, p. 406.

Address for both: Robert Shavelle or David Strauss, Department of Statistics, University of California at Riverside, Riverside, CA 92521-0138.