

Autism Research Review

I N T E R N A T I O N A L

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Reviewing biomedical and educational research in the field of autism and related disorders

Lovaas: original Young Autism Project participants' recoveries are enduring

Twelve years ago, Ivar Lovaas and colleagues rocked the autism world when they reported that nearly half of a group of 19 autistic children undergoing their intensive behavior modification program improved to the point where they had normal IQs and could attend regular school classes. At the time that study was published, the children were adolescents, and Lovaas reported, "If you met them now that they are teenagers, you would never know that anything had been wrong with them."

Now Lovaas et al. report, in preliminary findings from an about-to-be published study,

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that these children—currently in their twenties—continue to function at normal or near-normal levels. Lovaas recently told the American Psychological Association's *Monitor*, "Eight of [the subjects] look indistinguishable from typical individuals, other adults." The ninth one, Lovaas says, "definitely has some personality problems... but he wouldn't be diagnosed as autistic anymore."

The 19 autistic study subjects were around three years old when they entered the Young Autism Project, and had average IQs of 60. One had some some appropriate speech, seven were echolalic, and 11 did not speak. All of the children received 40 hours a week of individual treatment from trained specialists, and parents were trained to continue the program at home.

By the end of the study, nine of the participants (the same subjects being followed up in the new study) were able to enter regular first grade classes, and eight others progressed to the "mildly retarded" range and

were able to enter classes for language-delayed students. In contrast, of forty children in a control group, only one student was able to attend a normal first-grade class, and most remained severely disabled.

Critics of Lovaas' original study note that he excluded subjects with profound retardation. Psychologist Frank Gresham says, "The kids he selected were kids that really had the best probability of doing well to begin with, probably regardless of what you did with them." At the time the study was published, however, even high-functioning autism was considered to be incurable, with almost no cases of recovery reported in the literature.

Lovaas et al. currently are conducting replication studies at 14 sites in the United States and Europe. Preliminary data from some of the sites may be published next year.

"Two autism studies fuel hope—and skepticism," Hugh McIntosh, *American Psychological Association Monitor*, Sept. 1999, p. 28.

DAN! Conference V: Another big success

The fifth Defeat Autism Now! (DAN!) Conference, held in Cherry Hill, New Jersey on October 2-3, was another highly successful event, sold out long in advance. The enthusiastic crowd of parents, physicians, and other professionals heard an array of world-class physicians and scientists presenting up-to-the-minute reports on research on various causes and on effective biomedical treatments for autism.

MARK YOUR CALENDAR: The next Defeat Autism Now! Conference will very probably be held in San Diego, California, September 15-17, at a site considerably larger than the Cherry Hill Hilton, which could accommodate only 1,200 attendees. Negotiations for the San Diego site are underway, and details will be announced in the next ARRI.

New data confirm death rates higher in community settings

Three years ago, David Strauss and Theodore Kastner reported that the death rate of mentally retarded individuals in community settings is dramatically higher than the death rate for institutionalized individuals with comparable disabilities (see ARRI 10/4). Since then, Strauss and colleagues have conducted five more studies comparing mortality rates in community and institutional settings—and all five indicate that a retarded individual is at greatly increased risk of dying when placed in the community.

The newest study, by Strauss and Robert Shavelle, examined the mortality rate, during 1996, in a group of 1,812 individuals with developmental disabilities who transferred from California state developmental centers to community settings between April 1993 and March 1996. The researchers controlled for gender, age, mobility, and level of self-care skills.

Of the subjects moved into the community, 36 died in 1996. "Overall," the researchers say, "the community death rate was 88 percent higher than expected for comparable persons living in institutions." They found that the difference between community and expected institutional deaths was greatest among the highest functioning individuals, who were nearly three times more likely to die in community settings. The researchers compared the number of deaths in institutions with the number predicted by their model, and found that the model was highly accurate.

Additional studies published by Strauss et al. since their original paper have reported similar findings. Among them:

- Also in 1996, Strauss et al. reported a 25 percent higher mortality rate in community settings than in institutions for children with severe mental retardation.

- In 1998, the researchers analyzed accidental deaths and homicide deaths among developmentally disabled individuals and found that these were more common in the community, and particularly in supported and

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