

An Editorial You Should Read

How dare we forget...

The Autism Society of America's founding mission, purpose, and objective can be summarized in one phrase: to discover and promulgate the truth about autism.

The following editorial by Steven M. Edelstein, Ph.D., accurately chronicles autism's challenging odyssey – what "truth about autism" we've learned and what we've done with it. This editorial is a must read for everyone in the autism community.

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Editorial: Stephen M. Edelson, Ph.D.

Leo Kanner and 70 Years of Autism

Reprinted with permission from Autism Research Review International, Vol. 27, No. 4, 2013, pp. 3,6. 2013 marks the 70th anniversary of the first paper to distinguish autism from other developmental disabilities. Autistic Disturbances of Affective Contact was written by Leo Kanner, M.D., in 1943. The director of the first child psychiatry clinic (at Johns Hopkins Hospital), Kanner was considered by many to be the father of child psychiatry. His book Child Psychiatry (1935) was considered the premier textbook on child psychiatry for many years.

In his 1943 article, Kanner eloquently described 11 children who were different from children with other disabilities, most notably those with childhood schizophrenia. He discussed their familial and developmental histories, as well as symptoms and behaviors. Kanner based his descriptions mostly on his in-depth interviews with parents. Leon Eisenberg, M.D., a colleague of Kanner, once wrote, "His interview with parents is remarkable for its capacity to elicit a sequential account of the vicissitudes of development. A sensitive listener, he rarely interrupts. His questions are disarmingly gentle but shrewdly penetrating" (1973).

Kanner's objective was to delineate a new disability, and he truly captured the essence of autism. He used phrases that are still used today, such as "insistence on sameness," "immediate and delayed echolalia," and "pronominal reversal." He also described common behaviors, obsessions with objects such as trains, "limitation of spontaneous activity," inability "to generalize," and fear at the sound of noises such as the vacuum cleaner.

Kanner also mentioned that six of the 11 children suffered from feeding problems, saying that "our patients... anxious to keep the outside world away, indicated this by the refusal of food." One can't help wondering if effective treatment for the gastrointestinal issues faced by many in this community might have arrived years ago if he had not ascribed a psychological genesis to the children's unusual propensity to avoid food and to vomit.

In his 1943 paper and other writings, Kanner expressed the thought that parents might have contributed to their children's autism. After commenting on the parents' preoccupations with science, literacy, and art, as well as a "limited genuine interest in people," Kanner wrote: "The question arises whether or to what extent this fact has contributed to the condition of the children." In 1954, Kanner may have alluded to a possible genetic predisposition to autism by stating, "The parents themselves have escaped the psychotic proportions of their offspring's aloneness and sterile obsessiveness. It is to speak of them as successfully autistic adults." At the first meeting of the Autism Society of America (formerly known as the National Society for Autistic Children), Kanner evidently apologized to a crowd of parents for blaming them. It is important to remember that Kanner was writing during the heyday of Freudian psychotherapy, when parents and early experience were blamed for everything.

As many of you know, Bernard Rimland's 1964 seminal book, Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior, debunked Kanner's suggestion that parents played a role in autism as well as Bettelheim's direct assertions that parents caused their child's autism. (Note: Next year is the 50th anniversary of Rimland's book!)

Kanner and Rimland began corresponding in 1959, and Kanner wrote the foreword to *Infantile Autism*. When Kanner stepped down as editor of the first scientific journal on autism (*Journal of Autism and Developmental Disorders*) in 1974, he asked Rimland to become its editor. Due to a busy schedule working full-time for the Navy, raising a family of three children, and conducting pioneering research on autism in the evenings and on the weekends, Rimland declined Kanner's offer. However, he continued to participate as a member of the journal's Board of Contributing Editors.

Last year I visited the American Psychiatric Association's main office to request a copy of Kanner's file on Rimland. I was pleasantly surprised to find a photograph of Rimland's son, Mark, pasted on the front cover of the folder. Interestingly, in one of his letters to Kanner, dated Nov. 24, 1963, Rimland mentioned Asperger's syndrome and said that it might be "related" to early infantile autism. There had been little discussion of autism and its relationship to Asperger's syndrome prior to the publication of Uta Frith's edited book in 1991.

There are three issues I find particularly interesting on the anniversary of the publication of Dr. Kanner's paper. Here is a look at each one.

Follow-up of the 11 cases

Twenty-eight years after the publication of his monumental paper on autism, Kanner wrote an article in which he described how each child was functioning in adulthood. According to Kanner, only two of the eleven, Donald T. and Frederick W., were described as "real success stories." Recently, two writers, John Donovan and Caren Zucker, located

Donald T. in Forest, Mississippi. Donald, age 77, still has autism, but he is doing quite well. He drives a car, spends mornings drinking coffee with his friends, and loves to play golf. You can read an article and view a five-minute video at www.DonaldT.com.

Kanner's syndrome

Today the term "autism spectrum disorder" is used to describe a wide range of individuals with autism; but for many years, terms such as "classical autism," "PDD," "Asperger syndrome," and simply "autism" were labels commonly used to describe the heterogeneity of the disorder. In retrospect, these terms helped to pinpoint different partitions of the spectrum.

When autism was first discussed within the disability community from the 1940s to the 1960s, much of the discussion centered on classical autism, which was often referred to as "Kanner's syndrome." Dr. Rimland focused much of his early work on those with classical autism, and developed a checklist, *Diagnostic Checklist Form E-2*, to determine whether or not a child had Kanner syndrome. (Note: Research on the validity of the E-2 has been mixed, and the lack of consistent findings is primarily due to the administration of the E-2 to children on the entire spectrum rather than just those with classical autism.)

One of the major projects of the Autism Research Institute is the development of a more efficient way to diagnose autism with respect to the apparent subtypes. It was clear to Dr. Rimland as early as the mid-1960s that there are many forms of autism, and he thought that a careful analysis of the E-2 checklist data might reveal various subgroups. For almost 50 years Dr. Rimland distributed his E-2 checklists to families, collecting data on more than 42,000 cases worldwide. Due to his busy schedule, the data were not analyzed in his lifetime.

A few years ago, a graduate student in computer science approached ARI and asked to analyze the E-2 database for clusters or subgroups. The analyses were quite elaborate, involving numerous factor and cluster analyses, and the results were encouraging. They suggested that based on the E-2 data, there might be 10 to 12 distinct subtypes of autism.

The next step in this research project is to replicate these findings. The survey has been posted at www.AutismResearchSurvey.com, and we encourage families worldwide to complete it. Please

note that additional questions were added to Dr. Rimland's original E-2 checklist. Most of these questions (which were not obvious to Dr. Rimland in the 1960s) inquire about physiological problems, such as GI and immune problems, seizures, and migraines. If we can accurately determine subtypes, we may be able to identify appropriate treatments for each one, shortening the amount of time and money now wasted on trial and error.

Kanner's vision

Although his writings on autism were descriptive rather than experimental, Kanner was a true pioneer with a vision for the future. In his follow-up article on the original 11 cases in 1971, Kanner posed two questions: "What is it that explains all these differences? Are there any conceivable clues for their eventual predictability?" He answered them by writing:

"At long last, there is reason to believe that some answers to these questions seem to be around the corner. Biochemical explorations, pursued vigorously in the very recent past, may open a new vista about the fundamental nature of the autistic syndrome." Yes, Kanner stated the term biochemical, not neurological, over 40 years ago! Much of the research supported by the Autism Research Institute has focused on biochemical abnormalities.

"At long last, there is, in addition, an increasing tendency to tackle the whole problem through a multidisciplinary collaboration." Kanner was well ahead of his time, because even now, the notion of approaching autism by understanding the whole person is relatively new to the autism field. Professionals are just beginning to recognize and integrate biomedical, social, and sensory challenges rather than to view them as independent of one another.

"Genetic investigations are barely beginning to be conducted." This remains true today. Although researchers have spent a great deal of time and money searching for "autism genes," they have just begun to expand their investigation into epigenetics in order to determine how these genes interact with environmental toxins.

Much has happened in the field since Leo Kanner published the first paper on autism 70 years ago, but the underlying causes of this condition are still under investigation. There is little consensus on even one likely cause. And further, there are only a handful of accepted, evidence based interventions. Fortunately, exciting new research on autism is published almost daily; and we truly hope there will be some real answers five years from now, when we celebrate the 75th anniversary of Kanner's paper.