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## CHAPTER 4

### *Infantile Autism: Status and Research*

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The scientific and medical literature on the childhood psychoses is confusing and contradictory in numerous respects. There is hardly a topic within the field about which the various authors agree. Some books and articles are written from the psychogenic point of view, as though it were quite well-established that faulty mother-child relations were the sole cause, or at least a major contributing cause, of psychosis in childhood (e.g., Bettelheim, 1967; Ekstein, 1971; Szurek & Berlin, 1973; Tustin, 1972). Other authors concern themselves with biological approaches, and pay scant, if any, attention to the convictions of the psychogenecists (e.g., Boullin, Coleman, & O'Brien, 1970; Himwich, Jenkins, Fujimori, Narasimhacari, & Ebersole, 1972; Ritvo, Yuwiler, Geller, Ornitz, Saeger, & Plotkin, 1970). Actually, the disagreement as to cause of psychosis in children is beginning to be dispelled, since as I noted a decade ago (Rimland, 1964), so much evidence is accumulating against the psychogenic viewpoint that the ranks of the adherents of this viewpoint are thinning rapidly.

Another area of major disagreement relates to the matter of diagnosis. The problem is not so much one of distinguishing the psychotic child from the retarded or the learning-disabled child, although some confusion exists on this point, but instead involves differentiating one type of childhood psychotic from the others. The terms childhood schizophrenia, psychotic child, autistic child, and child with infantile autism have been used so often interchangeably, even by authors who would be expected to know better, that some researchers entering the field with a serious interest in the subject have found the topic so muddled that they have given up in despair. Scientific progress is impeded severely by this chaotic situation. I have devoted a good deal of my attention to an attempt to clarify the diagnostic problem. While I cannot claim to have achieved more than partial success, a good deal has been accomplished, as seen later in this chapter.

The following pages are addressed to several of the more important sources

#### 138 Infantile Autism: Status and Research

of confusion in the literature on the childhood psychoses. In particular, because of its unusual significance from both the theoretical and practical standpoints, the major focus of attention is upon the small and unique subgroup of psychotic children afflicted with infantile autism.

#### THE DIAGNOSIS OF INFANTILE AUTISM

Several large-scale intensive surveys in the United States and England have established that the incidence of psychosis in children is about five cases per 10,000 births (Lotter, 1967; Treffert, 1970). The incidence of five children per 10,000 pertains to all forms of psychoses, that is, to the group which is often labelled childhood schizophrenia. The term childhood schizophrenia is not meant to imply a direct relationship to adult schizophrenia, which is different in its manifestations, and very much more common, but only to suggest by analogy that the childhood disorder also produces disorientation and bizarre inappropriate behavior, and is totally or nearly totally disabling.\*

In 1943, Leo Kanner, who was then professor of child psychiatry at Johns Hopkins Medical School, published a paper (Kanner, 1943) in which he described in detail 11 psychotic children he had seen over the preceding years. These 11 children were similar in many respects to the children described by many other writers as childhood schizophrenics; Kanner insisted, however, and has continued to insist (e.g., Kanner, 1943, 1958, 1973), that despite the superficial resemblance between those children and the others, there was a remarkable homogeneity of behavior in these 11, and some important differences between them and the previously described children who had been called childhood schizophrenics.

The following year Kanner (1944) described several more children who closely resembled his first group, and this time he named the new category of childhood psychosis—he titled his paper “Early Infantile Autism.”

The words early infantile referred to the fact that the disorder was usually present at birth, and was, in his opinion “inborn.” The word autistic was used to describe one of the most striking characteristics of the children, their remote, inaccessible personalities, which in some ways made them resemble autistic (daydreaming) adults. The word autism proved to be a poor choice, as Kanner has recently (1973) emphasized, because it led many psychologists and psychiatrists (e.g., Bettelheim, 1967) to conclude, incorrectly, that since autism in

\*In my book *Infantile Autism*, I referred to nonautistic psychotic children as “childhood schizophrenics,” making it clear that the latter term was felt to encompass a number of disorders rather than being a unitary disease. I now prefer to use the term autistic-type children rather than childhood schizophrenics because the latter term implies that we have information that we actually lack. The terms autistic, infantile autism, and classically autistic are used interchangeably.

adults was essentially voluntary, the "autistic" children too were biologically normal individuals who had voluntarily chosen to disassociate themselves from reality, because their dream life was more satisfactory to them than was reality. There is in fact no evidence whatever that infantile autism is voluntary.

When I first met Leo Kanner in 1962 I asked him what proportion of the psychotic children, loosely called autistic by others, were in fact afflicted with infantile autism, as *he* used the term. After a long, thoughtful puff on his ever-present cigar he told me, "Only about 10 percent of the children who have childhood schizophrenia and have therefore been carelessly labelled as "autistic" are really cases of infantile autism." I dutifully recorded his estimate in my book *Infantile Autism* (1964, p. 18). Ten years later, having collected detailed case history material for well over 4000 psychotic children from all over the world, I found Kanner to have been remarkably accurate in his estimate: out of every 100 children showing the bizarre and profound behaviors characteristic of the so-called autistic child, only 10 will, after careful investigation, prove to be bona fide cases of early infantile autism. Thus the incidence of true or classical autism is about five per 100,000, or one birth in 20,000.

Kanner has protested repeatedly against the loose and indiscriminate use of the diagnosis "autistic" and "infantile autism." He has deplored "the dilution of the concept of early infantile autism," and observed that "the diagnosis has been made much too prodigiously." He quite correctly argued:

There is, of course, no denying that overlapping symptomatology creates problems in trying to distinguish between different illnesses which have a number of features in common. But the problem is definitely not solved by the decree that the sharing of symptoms makes the diseases identical or that, because of the partial resemblance, a differentiation is unnecessary [1958, p. 142]."

Both in my book *Infantile Autism*, and in my article (1968) written to commemorate the 25th anniversary of Kanner's first article on autism, I have added my voice to Kanner's, protesting that much of the published literature on the topic was virtually useless because so many authors lumped together heterogeneous subgroups of psychotic children, calling them all autistic. Many authors cite Kanner's classic papers on autism, then blithely proceed to claim that their single case, or all five or all 20 of the children in their sample, were cases of classical autism. Such claims are easily dismissed, in most cases, by careful reading of the case history of the single cases, or, where there are multiple cases, by noting that the authors usually make no mention of the natural control group of nine or so nonautistic psychotic children they had to examine to find each true autistic case.

The concern that Kanner and I have expressed about the loose use of the term autism does not stem from petulance, pedantry, or semantic nitpicking. The history of medicine makes it clear that "nosology precedes etiology." As Kanner

has pointed out, little progress could be made toward defeating "the fevers," until the fevers could be separated and treated in terms of the component individual diseases, such as malaria, cholera, diphtheria, and tuberculosis.

An example much closer at hand may be found in the remarkable progress made in recent years on the problem of mental retardation. Well over 100 syndromes are now recognizable, and as each has been isolated from the others, it becomes the target for researchers dedicated to finding effective means for remediation or prevention. There is no doubt in my mind but that progress on prevention and remediation of the childhood psychoses has been impeded—I would even go so far as to say halted—by the virtual stalemate that exists in the area of diagnosis. It is certain that there are a *number* of causes of the childhood psychoses, and that the various causes lead to different syndromes. Little progress can be expected until these syndromes can be identified.

In view of the importance of the matter of diagnosis, and the dismal state of diagnostic practice in the area of the childhood psychoses, it is distressing to see the careless and indiscriminate neglect of the one breakthrough that has occurred in this area—Kanner's incisive delineation of infantile autism.

The first part of this chapter is devoted to a brief overview of the syndrome of autism and of Kanner's finding of unusual intelligence in the parents of cases of true autism. Little documentation is provided for these topics, since my book *Infantile Autism* provides the needed references. Following the review a report of recent findings that relate to the areas of controversy is presented.

## THE SYNDROME OF AUTISM

At birth the child who later turns out to be a case of classical early infantile autism (Kanner's syndrome) seems to be an unusually healthy and attractive baby. In some instances, the baby seems to be exceedingly alert, almost precociously intelligent in appearance. These hyperalert children tend, by and large, to be those who develop early speech, although their speech is of the peculiarly noncommunicative, autistic variety. Another subgroup of the children who later turn out to be classically autistic tend to be quite passive and inattentive soon after birth.\* The parents tend to regard these passive children as particularly "good" babies. This latter subgroup of babies tends to develop into the mute form of autism, in which speech does not occur in early life at all, and in many instances the mute autistic child goes into adolescence and through adulthood without ever uttering a word.

Although Kanner's early papers refer to the fact that some of the children

\*It is possible that these subgroups among autistic children represent variants in the same sense in which there are at least three types of mongolism and four of PKU.

did develop speech and some did not, the finding that the speaking variety of autism tends to be different in appearance and personality at birth from the non-speaking children is an outgrowth of my own research on my Diagnostic Check List, Form E-2, which is described later.

If the mother has had children before or is used to children, she may notice immediately that the child with autism does not adapt itself to her body and cuddle the way a normal infant does. However, since all babies are different, even experienced parents usually do not become concerned until perhaps the fourth month, which typically finds the normal baby reaching out for its mother when she approaches. The child with autism fails to show any sign of awareness of his mother, or of other people in the environment for that matter. Head-banging is a frequent complaint seen in the case histories of autistic children. Sometimes the child will bang his head against the crib or other objects. Sometimes the head-banging will take place against the body or face of the adult who is holding the infant. The head-banging is often accompanied by vigorous crib-rocking, and parents have repeatedly reported that the child would rock in his crib so vigorously that the crib would have to be fixed solidly in place to keep it from banging into the furniture and walls in the child's room.

The parents have typically become quite worried between the fourth and 18th months because by this time most infants have begun to socialize in a number of ways, whereas their child seems to be completely preoccupied with head-banging or fixated upon small toys or other inanimate objects. Ritualistic play with certain objects is a very common symptom and the toys that are given to the child are rarely used in the normal manner. Instead, toys are handled in ways which show that the child has no concept of the true function of the toy. For example, an autistic child, rather than running a toy truck along the ground as normal children do, will hold it in his hand while spinning the wheels for long periods, sometimes for hours. Or the truck may be turned on its top and spun on the floor. The child also spins various other objects, such as pot lids, bottles, ashtrays, and whatever else he can lay his hands on. It is not uncommon for parents to report that their child will spend many hours a day spinning various objects, sometimes keeping several objects spinning in one room while he runs to the next room to spin some more, then rushes back to the first room to keep the first group in motion.

Perhaps the most disturbing of the symptoms of autism that occur in early life is what Kanner has called autistic aloneness. It is this symptom that gave the disorder its name. The child will sit and stare into space for extended periods of time, seemingly in a remote dreamworld. Calling his name or trying to attract his attention in any way is unsuccessful. The child seems very much as though he is lost in thought, although as indicated earlier, this impression is a very misleading consequence of the child's facial resemblance to the adult who is lost in thought. Some of the parents describe their child as being

"locked in a glass ball." A Swedish psychologist, Karin Junker, has written a book titled *The Child in the Glass Ball*, which is a biographical account of the life of her own daughter (Junker, 1964).

Most of the children seem to be unaware of or uninterested in people, although there are a number of children who clearly have an aversion to other people rather than being merely uninterested in them.

Feeding problems are almost invariably found in children with autism. Some children will insist on eating only certain foods and will have nothing to do with any other food or drink. One child, who had learned to drink from a transparent container, went without taking liquids for several days until it was discovered that he would drink only from a transparent container. Frequently children with classical autism are extremely neat and tidy in their habits and become very upset at any untidiness. One such child began eating with a spoon at nine months and from that point never spilled food on the table or himself. When his clothes did become soiled in any way, he would scream and fuss until they were changed for clean ones.

A striking characteristic of children with autism is the high frequency of repetitive behavior and fetishlike preoccupation with mechanical objects. It is typical of such children to become very engrossed with certain appliances around the house, such as vacuum cleaners, stoves, or refrigerators. Light switches seem to hold a special attraction for them, as do faucets. The children typically react with a violent temper tantrum when any attempt is made to divert them from these preoccupations.

One of the strongest and most characteristic symptoms of classical infantile autism is what Kanner has termed obsessive insistence upon the preservation of sameness in the environment. This is one of the two symptoms that Kanner has reported as being completely necessary for a diagnosis of autism to be reached. The other symptom is the self-imposed isolation—the "autistic aloneness"—described earlier. Insistence on the preservation of sameness is seen in a multitude of ways in these children. In some cases, the child has been known to scream uncontrollably until it was discovered that an article of furniture had been moved from its usual position and that this was distressing to the child. In other cases, the removal of a picture from a wall has brought on a temper tantrum. Rituals, such as the order in which the child's bedclothes are put on him in the evening prior to his bed time, are also a frequent source of temper tantrums when the sameness of the environment, that is, the ritual, is violated. Another way in which this symptom is manifested might be in the child's insistence that the path taken between his home and another point, for example, a store or a relative's house, be invariably followed when going between those two points. If the mother decides to cross the street to look into a shop window or makes some other diversion from the usual path, the child screams and shows signs of distress until the usual route is again taken.

It is almost universal for parents of autistic children to report their strong suspicion of deafness in the child's first year or two of life. Even though they suspected the child might be deaf, they usually also had good reason to believe the child was not deaf, because he showed many indications of exceedingly acute hearing. For example, he might run to the window to look out after hearing a car door slam that no one else in the room had heard. On the other hand, one might call his name loudly and repeatedly or try to gain his attention in other ways with no success. (Similar instances of apparently "selective" attention are seen in laboratory animals with experimentally induced cerebral lesions.)

Many of the parents, having reported that their early suspicion of deafness had been disconfirmed, have next reported a strong suspicion that the child was mentally retarded. Certainly the children are retarded from the standpoint of being unable to do very many of the things that their age-mates can do, such as speaking meaningfully or following instructions. However, the children with classical autism are readily differentiable from the typical retarded child in many ways. For one, facial appearance is almost invariably that of a very intelligent and attractive child. The ordinary retardate whose retardation is so severe that it is detected in the early years of life is usually afflicted with physical stigmata and/or the dull expression which is so characteristic of the individuals with markedly low IQs.

The children with autism typically have a number of rather striking abilities which distinguish them quite clearly from the retardate. Early use of language is one of these skills, although, as it turns out, the language is not meaningfully employed even though it may be articulated very clearly. Additionally, the child frequently shows great skill at remembering tunes and being able to hum or sing them with perfect pitch. Moreover, the child can frequently do various kinds of puzzles, particularly jigsaw puzzles, with great speed and skill. Surprisingly often, the parents have reported their amazement at finding the child assembling a jigsaw puzzle face down by looking only at the shape of the pieces and paying no attention to the picture. As might be expected from the child's characteristic trait of obsessive insistence upon the preservation of sameness, children with autism tend to have remarkably good memories. Kanner has reported an incident in which a child who was shown a roomful of toys, including a jumble of blocks spread all over the floor, screamed vigorously when one of the blocks on the floor was turned in the several days that elapsed between the child's first and second visit.

The motor and manual ability of autistic children is another striking characteristic. Children with classical autism have been described who have been able to climb to great heights, walk along the top boards of very narrow fences, and perform other feats requiring cat-like agility without ever falling or getting hurt. Manual dexterity is also characteristically good in such children. A number of writers have described cases of autism who at the early age of three were able

to balance a dime on edge. One 12-year-old boy who had been taught the numbers on the typewriter was able to type the series to 1000 without making an error at an estimated speed of 60 words per minute.

As is evident from the foregoing description, many children with autism would seem to fall into the realm of idiot savant, about which a great deal has been written in psychological literature. I have made a special study of idiot savant abilities in autistic children (as yet unpublished) and find that indeed idiot savant characteristics of a remarkable sort are far more typical in children with infantile autism than in any other population. On the other hand, there are many cases of idiots savant reported in the literature who are clearly not cases of autism.

Calendar calculation is an ability of the idiot savant sort found in a number of classical cases of autism. Children with this ability are able to answer instantly such questions as, "In which months during the year 1958 did the eighth of the month fall on a Wednesday?" Another such question might be, "In the year 1984, what date will the second Friday in August fall on?" A number of investigators have attempted, with very little success, to understand the mental operations that lead to instant and almost invariably accurate answers to these kinds of questions.

The speech abilities of autistic children are quite remarkable in many ways, although as noted earlier, only about half of all children with Kanner's syndrome are able to use speech. Many parents report that they thought their child was a "budding genius" because of his early use of words. It is not uncommon for a child to begin the use of sentences before his first birthday. Between his seventh and 12th months, one autistic boy exhibited the following vocabulary: mamma, dada, bear, spoon, hungry, done, ball, and "C'mon let's play ball." Sometimes a child who has been speaking for several years will cease to speak for a period of a year or more and then resume speech. In some instances, speech is discontinued and never resumed. Again, it should be understood that when speech is used, it is of a peculiar, uncommunicative sort that in some ways is almost more frustrating to the listener than would be the complete absence of speech.

Kanner has published a number of papers devoted specifically to the children's speaking characteristics, and has given names to a number of these unusual characteristics. One of the most striking speech characteristics of children with classical autism is their failure to use the pronoun "I" until their eighth year or beyond. Instead, they use the word "you." For example a child who wants a cookie might approach his mother and say, "You want a cookie," or "Do you want a cookie?" The substitution of you for I is known as pronominal reversal.

Another word which is absent from the vocabulary of the speaking autistic children until perhaps their eighth year or beyond is the simple word "yes." When an autistic child wants to say "yes," he will typically respond by repeating the

question. If you offer a child with Kanner's syndrome a cookie and say, "Do you want a cookie?" he will repeat the question after you, "Do you want a cookie?" thus signifying yes. This characteristic is known as affirmation by repetition. Saying "no" is usually accomplished by merely saying no or by the child using some signal such as grunting and waving his hands.

Another one of the speech characteristics is extreme literalness. An example of extreme literalness given by Kanner is the boy whose father attempted to teach him to say the word yes by carrying the boy on his shoulders. The boy loved to be carried on the father's shoulders and the father naturally enough used this as a reward for teaching the child to speak properly. The child did learn to use the word yes, but only to mean "Yes, I want to be carried on your shoulders." To an autistic child who has learned the word "down" in the context of putting something down on the floor, there is great difficulty in appreciating that you can also put something down on a chair or a table.

Metaphorical use of language is also frequently seen in the speaking autistic child. One boy always used the sentence, "Don't throw the dog off the balcony," to indicate "no." His mother had long before said, "Don't throw the dog off the balcony," to him when she saw him about to throw a toy dog off the balcony in a railroad station. Another example of metaphorical use of language was seen in a seven-year-old boy who used the phrase, "He knocked me down," to indicate any blow, pat, spank, or bump inflicted by a person of either sex, accidentally or deliberately.

Part-whole confusion was another of the speech characteristics identified by Kanner in his original series of papers on autism. One three-year-old autistic boy used the expression, "Do you want some catsup. Honey?" to ask for his favorite food, which was hamburger patty with a small amount of catsup on it. The same child used the expression "Bumped the head," whenever he was hurt, even though it might be an elbow or a knee that had been injured.

One of the most noteworthy speech characteristics of autism is delayed echolalia. In delayed echolalia, the child will simply repeat a phrase or sentence, often out of context and with no apparent purpose. For example, one child for months repeated the sentence, "It's all dark outside," even on bright and sunny days. It is frequently reported that autistic children repeat radio and TV commercials endlessly. The speech tone of the autistic child when engaged in delayed echolalia is very unusual. The voice is described as being a hollow, high-pitched monotone, almost as though a robot were speaking. Many parents of autistic children report that their child will print brand names, slogans, and other things he has seen on TV commercials, in a sort of graphic version of delayed echolalia.

Prognosis in autism has been found to be closely linked to the speaking ability of the children. The follow-up study of the first 63 autistic children seen by Kanner reported that 32 had developed speech that was at least somewhat

useful and communicative by the age of five. Of these 32 children, 16 were able to achieve *fair* to *good* social adjustment. Of the remaining 31 nonspeaking children, only one even reached a *fair* level. All three of the children whose outcome was described as *good*, as well as 16 of those 46 described as *poor*, came from the speaking group. Of the first 63 children, 34 had been institutionalized at the time of this follow-up study, which was conducted when the median age of the children was 15. The long-term prognosis of children with classical autism has not been good, even though it is somewhat better for the speaking than for the nonspeaking children. Among Kanner's earliest cases, a few seemed to have recovered completely or almost completely and were getting along rather well. One recovered autistic child, for example, became a mathematician, having completed his undergraduate training in mathematics in three years at one of the nation's foremost universities. Another became a meteorologist and composer. However, such favorable outcomes have been reported in only the minority of cases. A fascinating parents-eye report of near-recovery appears in the book *For The Love of Ann* (Copeland, 1973).

## THE PARENTS OF AUTISTIC CHILDREN

One of the major controversies surrounding Kanner's original reports on autism concerned his finding extraordinarily high levels of intellectual ability and achievement among the parents of the children who fit the unique symptom pattern he had termed early infantile autism. In his original article, Kanner provided the following description of the parents of his first eleven cases:

Four fathers are psychiatrists, one is a brilliant lawyer, one a chemist and law school graduate employed in the Government Patent Office, one a plant pathologist, one a professor of forestry, one an advertising copy writer who has a degree in law and has studied in three universities, one is a mining engineer and one a successful business man.

Nine of the eleven mothers are college graduates. Of the two who have only a high school education, one was a secretary in a pathology laboratory, and the other ran a theatrical booking office in New York City before marriage. Among the others, there was a free lance writer, a physician, a psychologist, a graduate nurse, and Frederick's mother was successively a purchasing agent, the director of secretarial studies in a girls school, and a teacher of history.

Among the grandparents and collaterals there are many physicians, scientists, writers, journalists and students of art. All but three of the families are represented either in *Who's Who in America* or in *American Men of Science* or in both [1943, p. 248].

A few years later, in 1949, Kanner was able to report his findings on the parents of the first 55 autistic children he had seen. He noted that his "search for unsophisticated parents of autistic children had remained unsuccessful to date." In 1954 he reported on the first 100 sets of parents:

Fathers: Ninety-six were high school graduates, (two of the non-graduates were immigrants). Eighty-seven entered college, 74 graduated college, 38 did postgraduate work. Thirty-one were business men, 12 engineers, 11 physicians (including five psychiatrists), 10 lawyers, 8 tradesmen, 5 chemists, 5 military officers, 4 writers, 3 Ph.D.'s in science, 2 Ph.D.'s in humanities, 2 teachers, 2 rabbis, and one each: psychologist, dentist, publisher, professor of forestry, and photographer.

Mothers: Ninety-two high school graduates, 70 of whom entered college; 49 graduated; 11 did postgraduate work. Seventeen were secretaries, 16 teachers, 6 business women, 6 librarians, 4 artists, 4 social workers, 3 writers, 3 nurses, 3 telephone operators, 2 psychologists; and one each: physician, lawyer, chemist, Ph.D. in humanities, physiotherapist and laboratory technician.

In addition to observing the very high levels of educational achievement of the parents, Kanner also noted that they had as a group a rather distinctive personality pattern. They were described as cold, bookish, formal, introverted, rather humorless and detached, and even excessively rational and objective:

Nevertheless, aside from the indisputably high level of intelligence, the vast majority of the parents of autistic children have features in common which it would be impossible to disregard. . . .

Most of the parents declare outright that they are not comfortable in the company of people; they prefer reading, writing, painting, making music, or just "thinking." Those who speak of themselves as sociable tend to qualify this by explaining that they have no use for ordinary chatter. They are, on the whole, polite and dignified people who are impressed by seriousness and disdainful of anything that smacks of frivolity [Kanner, 1949, p. 421].

The rate of mental illness among the parents and blood relatives of Kanner's first 100 autistic cases was strikingly low, being only 13 out of 973 parents, grandparents, aunts and uncles. This is about one-third the rate of mental illness in the general population.

Needless to say, these findings set off a great deal of controversy. In the first place, many people preferred to believe that the high intellectual level reported by Kanner was merely a result of the selective referral of well-to-do people to Kanner's clinic, in the mistaken impression that Kanner tended to see only a relatively high socioeconomic level clientele. Adding to the controversy were the reports of investigators who claimed that they had done research on the intellectual and socioeconomic status of parents of children whom *they* called autistic, and their reports supposedly did not confirm Kanner's findings. For the most part, these contradictory findings were based on groups of children who did not meet Kanner's criteria for autism. My book *Infantile Autism* presents a thorough review of this topic. I took the position, based on a comprehensive study of the world literature, including reports of cases of true autism published prior to 1943 and unknown to Kanner, that Kanner's findings on parent intellec-

tuality were valid. Subsequent research, by myself and others, has borne out this position. These findings are discussed later in the present paper.

Perhaps the most far-reaching controversy that erupted as a result of Kanner's papers on autism was concerned with the possibility that the parents' cold, distant "refrigerator-type" personality may have caused the children's disorder, which was at the time widely thought to be functional. Kanner himself stated that he believed the parents' distant personalities had only an indirect bearing on the child's disorder. He was, however, widely misquoted on this point. Again, this part of the controversy is taken up in the next section, dealing with recent research on autism.

The foregoing presentation of the syndrome of autism and of information on parental intelligence and personality is a highly condensed version of this material from Chapters 1 and 2 of my book (Rimland, 1964). The book covers a great deal of information which is quite impossible to deal with in the limited space available here. The topics covered include a cognitive theory of autism, the differentiation of autism from schizophrenia, a neurophysiological theory of cognition and personality in both autism and normals, and a great deal more.

Let us now turn to some of the recent empirical research findings that relate to the topics already mentioned.

## RECENT RESEARCH ON AUTISM

### Diagnostic Check List Forms E-1 and E-2

The first printing of my book *Infantile Autism* included a diagnostic questionnaire titled Form E-1. Form E-1 consisted of 76 questions on such topics as the child's birth history, symptomatology, speech characteristics, and age of onset of disorder. It was designed to be answered by the parents, and for the responses to be readily entered on punched cards for analysis. Within a week of the publication date I began receiving completed copies of Form E-1. Analyses of the forms and the letters accompanying them made it clear that some revisions were needed. This was expected and desired—it was why I had titled the form *E*, for Experimental.

I made the needed changes and called the revised version Form E-2. Like Form E-1, Form E-2 was intended to provide a quantifiable, *objective* means of diagnosing infantile autism. My publisher was kind enough to let me substitute Form E-2 for Form E-1 in the second and all subsequent printings of *Infantile Autism*. Form E-2 has been reproduced by the thousands and widely distributed. The remainder of this paper deals primarily with findings from Form E-2.

The most serious deficiency of the earlier version Form E-1 is worth noting,

however. The instructions indicated the form was intended for children up to about age seven, but the replies from parents made it very clear that seven was too late—dramatic and sudden behavioral changes had occurred long before this, and the changes were clearly such as to obscure the diagnosis. Study of the E-1 forms and case histories then at hand led me to conclude that psychotic children very commonly showed striking changes in their behavior patterns at age five and a half. The changes came about quite suddenly and were entirely unexpected. Many of the symptoms of autism faded away before the sixth birthday. Form E-2 was therefore written to obtain information about the child's behavior *prior* to age five.

While I regard these large and fortuitously discovered behavioral changes at age five and a half as being of considerable theoretical importance, I cannot go into the matter in any detail here. I have discussed the matter elsewhere (Rimland, 1968) and am still investigating it. My main reason for bringing up the matter of age five and a half now is to point out that I believe the failure to appreciate the discontinuity of behavior in autistic and autistic-type children after age five has contributed greatly to the present confusion regarding the diagnosis of these children.

There are two other matters I would like to discuss briefly before going on to the analysis of Form E-2.

### Autistic Children Versus Autistic-Type Children

The discussion below deals largely with the use of Form E-2 as a means of identifying classical infantile autism. There are good reasons for singling out true autism as the first target of research, but it should not be thought that children with nonautistic childhood psychoses are any less important or are being neglected. As seen below, our research is also aimed at clarifying the murky diagnostic picture as it pertains to these other children as well.

### Validity of Parent Reports

The use of a parent-completed questionnaire has been criticized by some, because earlier studies have tended to show that retrospective reports by parents were rather unreliable. Instead, it is suggested, one must actually see the child in one's own office to be confident of a diagnosis. There are many reasons for disagreeing with this position. For one, since diagnosis depends at least in part on retrospective information (e.g., age of onset and behavior in infancy or before age five), there is no way of circumventing parental reports in any case. Even behaviors the child may be manifesting currently may not be seen in the diagnosticians's office or at any other predetermined time and place of observation. Additionally, the studies to be reported below show that Form E-2 does

in fact yield highly useful information consistent with laboratory and other types of data. This may be in part a result of the atypicality of the children assessed with Form E-2—because these are sick children, the parents tend to pay close attention to them, and to have repeated their stories again and again to various professionals. Finally, the record of diagnostic reliability and validity in psychiatry, even when the diagnostician has had ample opportunity to see the patient first hand, is anything but encouraging. Given my choice between having a completed Form E-2 or an opportunity to see the child and talk to the parents, I would, so far as research diagnosis is concerned, vastly prefer to have Form E-2.

### THE FORM E-2 DATA BANK

Since 1965, when the Diagnostic Check List for Behavior-Disturbed Children, Form E-2, became available, completed forms have been sent to me by parents and professionals from around the world. As of this writing, our files contain over 4000 completed E-2 forms. We have forms from every state in the United States and from 30 foreign countries, including not only the large countries such as England, Germany and Italy, but also Finland, Israel, Kenya, New Zealand, Lebanon, and Switzerland. We also have cases from several Communist Bloc countries: Yugoslavia, Poland, and Czechoslovakia.

Most of our cases have been submitted directly by the parents, but many others have been sent to us by the several hundred professionals with whom we collaborate.

The most recent analysis of our data covered 2218 cases. Of these 1652 (74.5%) are boys and 566 (25.5%) are girls.

Form E-2 consists of 80 questions to be answered by the parents. These questions provide for a detailed description of the child's case from birth through age five. The questions cover not only all of the speech and behavior symptoms mentioned by Kanner in his descriptions of classical autism, but also most of the characteristics (such as clinging and whirling) mentioned by others such as Despert and Bender in their case studies of "symbiotic psychosis" and "childhood schizophrenia." Also included are questions gleaned from the reading of hundreds of letters and reports from parents.

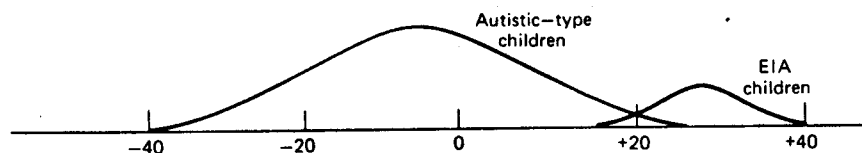
To determine if a child is a true case of autism, Form E-2 is "scored" as though it were a test. One + point is accrued for each question (sign or symptom) characteristic of classical autism, and one - point is scored for each question answered in the nonautistic (schizophrenic?) direction. The child's total "autism" score is the difference between his autism (+) and nonautism (-) scores.

In the absence of a substantial number of cases diagnosed through the use

of laboratory tests, there is no completely adequate technology for developing a perfect scoring key for Form E-2, and thus the keys described below must be considered only approximations. On the other hand, as seen, some very good results have been achieved with the E-2 keys.

The most recently derived scoring key for Form E-2 (March 1971) provides a score range of  $-42$  to  $+45$ , based on the then-available sample of 2218 cases. I regard a score of  $+20$  or higher as highly indicative of classical early infantile autism. A score of  $+20$  means that the child exhibits at least 20 more signs of classical autism than signs of nonautism.

The cutting score of  $+20$  was set in 1965, after careful analysis of all Form E-2 data and all other data available for the total sample of 68 children then available. The cutting score of  $+20$  was set (albeit tentatively) despite the fact that 25 cases of the 68 (37%) had scored higher than  $+20$ , and I was of course well aware from both Kanner's estimate and my own work that a much smaller proportion of the population should be classified as having true autism. I had to assume that classical autism was overrepresented in my early cases. My judgment as to where the cutting score should be set has been supported by later events, as noted below. As the number of E-2 forms at hand grew larger, the present value of 9.7% was reached. This is very close to Kanner's 10% estimate of the occurrence of classical autism in a population of psychotic children.



**Figure 1.** Frequency distribution of total autism scores as derived from Form E-2. Overlapping curves depict hypothetical separation of true autistic cases from distribution of scores of autistic-type children.

Figure 1 shows my representation of the theoretical relationship between the E-2 scores and the actual occurrence of infantile autism. The small curve to the right shows the distribution of E-2 scores I believe would be found in a population diagnosed with great accuracy through the use of a blood, urine, tissue culture, or other laboratory test, if available. A certain proportion of the true cases would be expected to fall below the  $+20$  cutting score (these are false negatives) while a smaller proportion of nontrue cases would be expected to score above a  $+20$  (false positives). The  $+20$  score is thus a conservative cutting score—for purposes of research it is far better to misdiagnose true cases than to misdiagnose false cases. (Better yet would be never to misdiagnose at all, but that is beyond the state of the art, even for such better-understood conditions as tuberculosis and pregnancy.)

In soliciting cases we have emphasized that we are interested in receiving completed E-2 forms for children with severe behavior disorders, especially children who have been or might be diagnosed as "autistic," "childhood schizophrenic," or "severely emotionally disturbed." We have tried to exclude cases of retardation, except where there are definite psychotic features. We thus have, intentionally, a wide range of disorders in our sample.

Form E-2 contains a space marked "Diagnosis," where the parent is asked to write in the diagnoses given by the professionals who have seen the child. These write-ins include an enormous range of responses, including "autistic," "psychotic," "atypical," "emotional withdrawal," "mental block," and "hopeless," to cite just a few examples. Table 1 shows the more frequent diagnoses.

How much confidence can one have in the labels assigned? A number of respondents have entered as many as five diagnoses on a single E-2 form, and one parent listed the 10 diagnoses attached to the child by various professionals who had seen him. To see the lack of agreement between diagnosticians who have all seen the same child is to be convinced that the state of the diagnostic art is nothing short of chaotic. To illustrate graphically what is so obvious from inspection of the forms themselves, I have constructed Table 2, using the first 445 E-2 forms on which the eight most common diagnoses were listed twice by the parent. Only the first two diagnoses listed have been counted. Where the two diagnosticians agree, the entry appears in the diagonal of the table. These diagonal entries, which appear in boxes for emphasis, should be relatively large if there were substantial agreement between diagnosticians. Inspection of the table shows how arbitrarily these diagnoses have been assigned—the labelling presents an almost random pattern. In only 61 cases did the diagnoses agree. A child called autistic or said to have infantile autism by the first diagnostician has less than one chance in four of being so diagnosed by the second. Clearly, there is a compelling need for a more adequate way of arriving at diagnoses if meaningful scientific work on the cause and cure of the childhood psychoses is to be accomplished. Form E-2 was developed to fill this void.

## THE VALIDITY OF THE FORM E-2 AUTISM SCORE

Since clinical diagnoses of children with severe behavior disorders clearly have little value, what reasons are there for believing that Form E-2 can improve the situation? There are several reasons.

### Construct Validity

By comparing the responses of true cases of autism (having E-2 scores above  $+20$ ) with those of children who are psychotic but not autistic (autistic-type



**Table 1. Diagnoses Reported for 2,218 Psychotic Children**

Diagnosis	N	Percent
Autistic	651	29.4
Infantile autism or early infantile autism	168	7.6
Childhood schizophrenia	119	5.4
Emotionally disturbed or mentally ill	134	6.0
Brain damaged or neurologically damaged	163	7.3
Retarded	189	8.5
Psychotic or symbiotic psychosis	43	1.9
Deaf or partly deaf	16	.7
Miscellaneous	735	33.2
<b>Total</b>	<b>2218</b>	<b>100.0</b>

children), it is evident that the high-scoring children manifest the syndrome that Kanner described. This is illustrated in Table 3 by means of data from several sample items taken from an item analysis of Form E-2. The item analysis was performed to ensure that all the items in the scoring key were discriminating properly between the autistic and autistic-type children. To maximize the discriminating power of the key, only a small group of 118 especially high-scoring autistic cases was used, and these were divided into speaking ( $N = 65$ ) and essentially nonspeaking ( $N = 53$ ) subgroups. For comparison purposes a large group ( $N = 230$ ) of autistic-type children was chosen from the middle of the E-2 range (scores of  $-10$  to  $+5$ ).

While some of the nonautistic children present a number of symptoms of autism, the true cases always show a marked preponderance of the key symptoms. The items most descriptive of autism, as delineated by Kanner, show very large percentage differences favoring the true autistic group.\*

**Agreement with Diagnoses of Some of Kanner's Patients**

Among the first 2218 cases analyzed were 31 children whose parents indicated that their child had been diagnosed by Leo Kanner. Twenty-two of the 31 reported the diagnosis to have been "autism" or "infantile autism," while eight reported such nonautistic diagnoses as "retarded," and "schizophrenic." One child, with an E-2 score of  $+33$ , was said to have been diagnosed as "autistically remote." This child was deleted from the analysis.

It must be recognized at the outset that there might very well be inaccuracies in these records. Nevertheless, as a matter of interest, the mean E-2 autism score was computed for each group and the significance of the difference deter-

\*There is a minor statistical artifact here in that the items themselves were used in defining the key development groups, but the differences observed are so large that correcting the percentages for redundancy would clearly have little or no effect on the findings reported.

**Table 2. Agreement between Pairs of Diagnosticians on the Diagnoses Assigned to 445 Children Showing Severe Behavior Disorders**

First Diagnosis	Second Diagnosis										Total
	Autistic	Infantile Autism or Early Infantile Autism	Childhood Schizophrenia	Emotionally Disturbed or Mentally Ill	Brain Damaged, Neurologically Damaged	Psychotic (Symbiotic Psychosis), etc.	Deaf or Partly Deaf	Retarded	Psychotic (Symbiotic Psychosis), etc.	Deaf or Partly Deaf	
Autistic	33	5	53	18	23	10	7	51	10	7	200
Infantile autism or early infantile autism	1	10	6	-	4	-	2	6	-	2	29
Childhood schizophrenia	17	3	1	2	8	-	-	1	-	-	32
Emotionally disturbed or mentally ill	12	2	4	2	9	3	-	13	3	-	45
Brain damaged or neurologically damaged	14	3	2	5	4	-	1	15	-	1	44
Retarded	21	2	6	18	16	2	2	5	2	2	72
Psychotic (symbiotic psychosis), etc.	4	-	1	1	2	-	-	2	-	-	10
Deaf or partly deaf	4	1	-	2	-	1	-	5	1	-	13
<b>Total</b>	<b>106</b>	<b>26</b>	<b>73</b>	<b>48</b>	<b>66</b>	<b>16</b>	<b>12</b>	<b>98</b>	<b>16</b>	<b>12</b>	<b>445</b>

