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Follow-up Study of Eleven Autistic Children Originally Reported in 1943

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The June 1943 issue of the now extinct journal *The Nervous Child* carried a paper entitled "Autistic disturbances of affective contact"; the first 24 pages told about 11 children who had in common a pattern of behavior not previously considered in its startling uniqueness; this was followed by 9 pages of discussion and comment. An introductory paragraph concluded with the sentence: "Since none of the children of this group has as yet attained an age beyond 11 years, this must be considered a preliminary report, to be enlarged upon as the patients grow older and further observation of their development is made."

Twenty-eight years have elapsed since then. The periodical in which the article was printed has been out of circulation for a long time.

The patients were between 2 and 8 years old when first seen at the Children's Psychiatric Clinic of the Johns Hopkins Hospital. What has become of them? What is their present status?

Under the auspices of Dr. Alejandro Rodriguez, the present director of the Clinic, Miss Barbara Ashenden, head social worker since 1931, undertook the task of learning about their whereabouts, functioning levels, and interim destinies. The results will be presented in the sequence of the original presentation. . . .

Case 1: Donald T.

In 1942, his parents placed him on a tenant farm about 10 miles from their home. When I visited there in May 1945, I was amazed at the wisdom of the couple who took care of him. They managed to give him goals for his stereotypes. They made him use his preoccupation with measurements by

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having him dig a well and report on its depth. When he kept collecting dead birds and bugs, they gave him a spot for a "graveyard" and had him put up markers; on each he wrote a first name, the type of animal as a middle name, and the farmer's last name, e.g.: "John Snail Lewis. Born, date unknown. Died, (date on which he found the animal)." When he kept counting rows of corn over and over, they had him count the rows while plowing them. On my visit, he plowed six long rows; it was remarkable how well he handled the horse and plow and turned the horse around. It was obvious that Mr. and Mrs. Lewis were very fond of him and just as obvious that they were gently firm. He attended a country school where his peculiarities were accepted and where he made good scholastic progress.

The rest of the story is contained in a letter from the mother, dated April 6, 1970:

"Don is now 36 years old, a bachelor living at home with us. He had an acute attack of rheumatoid arthritis in 1955. Fortunately, this lasted only a few weeks. Physically, since that time, he has been in perfect health. . . . Since receiving his A.B. degree in 1958, he has worked in the local bank as a teller. He is satisfied to remain a teller, having no real desire for promotion. He meets the public there real well. His chief hobby is golf, playing four or five times a week at the local country club. While he is no pro, he has six trophies won in local competition. . . . Other interests are Kiwanis Club (served as president one term), Jaycees, Investment Club, Secretary of Presbyterian Sunday School. He is dependable, accurate, shows originality in editing the Jaycee program information, is even-tempered but has a mind of his own. . . . He owns his second car, likes his independence. His room includes his own TV, record player, and many books. In College his major was French and he showed a particular aptitude for languages. Don is a fair bridge player but never initiates a game. Lack of initiative seems to be his most serious drawback. He takes very little part in social conversation and shows no interest in the opposite sex.

"While Don is not completely normal, he has taken his place in society very well, so much better than we ever hoped for. If he can maintain status quo, I think he has adjusted sufficiently to take care of himself. For this much progress, we are truly grateful. . . . Please give Dr. Kanner our kindest regards. Tell him the couple Don lived with for 4 years, Mr. and Mrs. Lewis, are still our friends. We see them quite often. Don has never had any medication for his emotional trouble. I wish I knew what his inner feelings really are. As long as he continues as he is now, we can continue to be thankful."

Case 2: Frederick W.

In September 1942, he was enrolled at the Devereux Schools, where he remained until August 1965. A close contact was maintained between the

Schools and our Clinic. In 1962, a report from Devereux stated: "He is, at 26 years, a passive, likeable boy whose chief interest is music. He is able to follow the routine and, though he lives chiefly within his own world, he enjoys those group activities which are of particular interest to him." He was a member of the chorus in the Parents' Day program and was in charge of the loud speaker at the annual carnival. He went on weekend trips to town unaccompanied and made necessary purchases independently.

Wicky, now addressed as Creighton, has been with his parents for the past 5 years. He is now 34 years old. After leaving Devereux, the family spent a year in Puerto Rico where "he picked up a lot of Spanish and worked out a schedule of studying language lessons on records at 4 o'clock every afternoon." The family then moved to Raleigh. The parents report: "We settled into a new home and he did his part in it. He has become acquainted with the neighbors and sometimes makes calls on them. We tried him out in the County Sheltered Workshop and Vocational Training Center. He took right to it, made friends with the teachers, and helped with some of the trainees. Through his relationship there, he took up bowling and he does pretty well. . . . Creighton was suggested by the Workshop for a routine job in connection with running duplicating machines. Since November 25, 1969, he has been working in the office of the National Air Pollution Administration (HEW) every day, and all day." A letter from the Acting Director, dated April 29, 1970, says, "Creighton is an outstanding employee by any standard. Outstanding to me means dependability, reliability, thoroughness, and thoughtfulness toward fellow workers. In each case Creighton is notable."

Case 3: Richard M.

The mother felt that she was no longer capable of handling him, and he was placed in a foster home with a woman who had shown a remarkable talent for dealing with difficult children. After two changes of foster homes, he was placed at a State School for Exceptional Children in his home State in May 1946. A report, dated June 23, 1954, said: "The institution accepted him as essentially a custodial problem; therefore, he was placed with a group of similar charges."

Richard is now 33 years old. In 1965, he was transferred to another institution in the same State. The Superintendent wrote on September 19, 1970: "At the time of admission, tranquilizers were pushed to the point of toxicity. After about 3 months, he showed some awareness of his environment and began feeding himself and going to the toilet. He is now being maintained on Compazine, 45 milligrams t.i.d. . . . He now resides in a cottage for older residents who can meet their own personal needs. He responds to his name and to simple commands and there is some non-verbal communication with the cottage staff. He continues to be withdrawn and cannot be involved in any structured activities."

Case 4: Paul G.

When the mother came to this country, she deposited Paul with a lady who ran a small home for retarded children. She removed him some time at the end of 1941, wrote friendly sounding letters to the Clinic but did not keep return appointments. She consulted Dr. Walter Klingman in 1941, Dr. Samuel Orton in 1943, applied for Paul's admission to the Devereux Schools in 1945 but decided that this was not the proper place for him. This is where the trail ends. Mother and child could not be located since then.

Case 5: Barbara K.

Barbara was placed at the Devereux Schools in the summer of 1942 and remained there until June 1952, when she was admitted to the Springfield State Hospital (Maryland) where she is still residing. She is now 37 years old. A note written by her ward physician October 8, 1970, has this to say: "She still has the stereotyped smile, the little girl-like facial expression with a placid grin, the child-like voice when uttering her parrot-like repetitions. Whenever I pass the ward, she greets me as follows: 'Doctor, do you know I socked you once?' She then usually gets very close to the writer following her to the office. . . . She still shows a total absence of spontaneous sentence production; the same phrases are used over and over again with the same intonation. Her mind is fixed to the same subjects, which vary to some degree with the person she is communicating with. Besides all of this she is childish, impulsive, subject to temper outbursts with stamping her feet, crying loudly and upsetting other patients. Her memory is completely intact. She likes to hum some melodies monotonously; whenever she feels like it she bangs the piano with well-known songs."

Case 6: Virginia S.

Virginia will be 40 years old next September. She has been transferred to the Henryton State Hospital. "She is," the report from there, dated November 2, 1970, says, "in a program for adult retardates, with her primary rehabilitation center being the Home Economics Section. She can hear and is able to follow instructions and directions. She can identify colors and can tell time. She can care for her basic needs, but has to be told to do so. Virginia likes to work jigsaw puzzles and does so very well, preferring to do this alone. She can iron clothes. She does not talk, uses noises and gestures, but seems to understand when related to. She desires to keep to herself rather than associate with other residents."

Case 7: Herbert B.

After a short stay at the Emma Pendleton Bradley Home in Rhode Island, and another at Twin Maples ("a school of adjustment for the problem child") in Baltimore, he was placed by his mother with Mr. and Mrs. Moreland who had a farm in Maryland. He seemed happy there from the beginning. He followed the farmer around on his chores and helped him "making things in the barn." Mrs. Moreland reported in October 1950: "He knows his way around the area near the farm and can go for miles and come back without getting lost. He had learned to cut wood, uses the power mower, rakes the lawn, sets the table perfectly, and in his spare time works jigsaw puzzles. He is a manageable and nice child. Occasionally he get upset if there is a sudden change in plans. . . . When his mother comes to visit, he gets himself absorbed and does not come toward her." After Mr. Moreland's death, the widow opened a nursing home for elderly people. Herbert remained with her, took the old ladies out for walks, brought them their trays to their rooms but never talked.

His mother, after serving as a public health officer in Maryland, spent several years (1953-1958) abroad—in Iraq and in Greece. On her return, she took a position in Atlanta, Georgia. She died in 1965.

Herbert is now 33 years old. His father wrote on January 5, 1971: "He is still with the people in Maryland. It is several years since I have seen him but I have word that he is essentially unchanged. More than anything else, he seems to enjoy doing jigsaw puzzles which he can do with the utmost skill."

A letter from his mother, written shortly before her death, contained this lament: "Our marriage seems to have produced three emotionally crippled children. Dorothy, after a disastrous marriage, is at home with her little baby girl and is trying to get on her feet working part time as a nurse in a local hospital. Dave is on the West Coast and has cost me \$450.00 monthly as he gets intensive psychiatric treatment."

Dorothy is Herbert's legally appointed guardian.

Case 8: Alfred L.

This ended the Clinic's contact with Alfred. The mother started him out on a tour of schools and hospitals, not informing them about preceding evaluations and taking him out after a time, not disclosing the next step she planned to take. We do know that he was at the V. V. Anderson School in Stratsburg-on-Hudson, N. Y. (1948-1950); the Taylor Manor in Ellicott City, Md. (July to October 1954); and the Philadelphia Hospital Department for Mental and Nervous Diseases (March 3 to April 20, 1955). Some time be-

tween the last two, he was for a time on Thorazine; then at a "school for brain damaged children" founded by his mother in October 1954.

Alfred is now 38 years old. So far as can be determined, he is at his mother's "school." Both at Sheppard-Pratt and Philadelphia Hospitals he was interested in the occupational therapy materials and did well with them. When this was brought to the mother's attention, she decided to take him out.

Case 9: Charles N.

Charles N. was brought by his mother on February 2, 1943, with the chief complaint: "The thing that upsets me most is that I can't reach my baby."

Charles was placed at the Devereux Schools on February 10, 1943. Early in 1944, he was removed, spent 3 months (from March to June) at Bellevue Hospital; was admitted on June 22, 1944, to New Jersey State Hospital at Marlboro; transferred to Arthur Brisbane Child Treatment Center on November 1, 1946; transferred to Atlantic County Hospital, February 1, 1951; transferred to the State Hospital at Ancora on October 14, 1955. He is still there, now 32 years old. This means that he has been a State Hospital resident from the age of 5 years and 10 months. Inquiries by the Clinic, if responded to at all, yielded meager general statements about continuing deterioration. One note of December 1953, said something about "intensive psychotherapy." The last note, dated December 23, 1970, said: "This patient is very unpredictable in his behavior. He has a small vocabulary and spends most of the time singing to himself. He is under close observation and is in need of indefinite hospitalization."

Case 10: John F.

After attending a private nursery school, John was at the Devereux Schools (1945-1949), then at the Woods Schools, then at Children's House (June 1950), and attended Town and Country School in Washington, D.C. An inquiry about him came from Georgetown Hospital in 1956.

Dr. Hilde Bruch, who saw him in 1953, remarked on his "exuberant emotional expression with no depth and variation and with immediate turnoff when the other person withdraws the interest."

John died suddenly in 1966 at 29 years of age.

Case 11: Elaine C.

Elaine was placed in a private school. The father reported "rather amazing changes: She is a tall, husky girl with clear eyes that have long since lost

any trace of that wildness they periodically showed in the time you knew her. She speaks well on almost any subject, though with something of an odd intonation. Her conversation is still rambling, frequently with an amusing point, and it is only occasional, deliberate, and announced. She reads very well, jumbling words, not pronouncing clearly, and not making proper emphases. Her range of information is really quite wide, and her memory almost infallible."

On September 7, 1950, Elaine was admitted to Larchworth Village, N.Y. State School. While there, "she was distractible, assaultive, and talked in an irrational manner with a flat affect. She ran through wards without clothing, threw furniture about, banged her head on the wall, had episodes of banging and screaming, and imitated various animal sounds. She showed a good choice of vocabulary but could not maintain a conversation along a given topic. EEG did not show any definite abnormality." She was found to have an IQ of 83.

On February 28, 1951, she was transferred to the Hudson River State Hospital. She is still there. A report, dated September 25, 1970, says: "She is up and about daily, eats and sleeps well and is acting quite independent. She is able to take care of her personal needs and is fairly neat and clean. Her speech is slow and occasionally unintelligible and she is manneristic. She is in only fair contact and fairly well oriented. She cannot participate in a conversation, however, except for the immediate needs. If things do not go her way, she becomes acutely disturbed, yelling, hitting her chest with her fist, and her head against the wall. In her lucid periods, however, she is cooperative, pleasant, childish, and affectionate. She has epileptic seizures occasionally of grand mal type and is receiving antiepileptics and tranquilizers. Her general physical condition is satisfactory." She is now 39 years old.

DISCUSSION

Those were the 11 children who were designated in 1943 as having "autistic disturbances of affective contact." They were reported as representing a "syndrome, rare enough, yet probably more frequent than is indicated by the paucity of observed cases." The outstanding pathognomonic characteristics were viewed as (a) the children's inability from the beginning of life to relate themselves to people and situations in the ordinary way, and (b) an anxiously obsessive desire for the preservation of sameness. A year after the first publication, the term early infantile autism was added to psychiatric nomenclature.

Now, 28 years later, after early infantile autism has become a matter of intensive study, after dozens of books and thousands of articles, after active stimulation by concerned parent groups in many countries, after the crea-

tion of special educational, therapeutic, and research units, it may be of interest to look back and see how these few children have contributed to the introduction of a concept that has since then stirred professional and lay curiosity.

For quite some time, there was considerable preoccupation with the nosological allocation of the syndrome. The 1943 report had this to say: "The combination of extreme autism, obsessiveness, stereotypy, and echolalia brings the total picture into relationship with some of the basic schizophrenic phenomena. Some of the children have indeed been diagnosed as of this type at one time or another. In spite of the remarkable similarities, however, the condition differs in many respects from all known instances of childhood schizophrenia." The "uniqueness" or "unduplicated nature" of autism was emphasized strongly then and in subsequent publications. Nevertheless, it has been just recently that this view has been generally accepted. The ultimate concession has come in 1967 from Russian investigators who had the courage to break through the officially sanctioned "line," according to which autism had been assigned the status of "schizoid psychopathy." The message, however, has not quite percolated to the framers of the 1968 Diagnostic and Statistical Manual of Mental Disorders (DSM II), adapted by the American Psychiatric Association. This is a widely used code system in which autism is not included, and children so afflicted are offered item 295.80 ("Schizophrenia, childhood type") as the only available legitimate port of entry.

As for the all-important matter of etiology, the early development of the 11 children left no other choice than the assumption that they had "come into the world with an *innate* disability to form the usual, biologically provided contact with people." The concluding sentence of the 1943 article said, "here we seem to have pure-culture examples of *inborn* autistic disturbances of affective contact." One can say now unhesitatingly that this assumption has become a certainty. Some people seem to have completely overlooked this statement, however, as well as the passages leading up to it and have referred to the author erroneously as an advocate of postnatal "psychogenicity."

This is largely to be ascribed to the observation, duly incorporated in the report, that all 11 children had come from highly intelligent parents. Attention was called to the fact that there was a great deal of obsessiveness in the family background. The very detailed diaries and the recall, after several years, that the children had learned to recite 25 questions and answers of the Presbyterian catechism, to sing 37 nursery songs, or to discriminate between 18 symphonies, furnish a telling illustration. It was noticed that many of the parents, grandparents, and collateral relatives were persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature and limited in genuine interest in people. But at no time was this undeniable and

repeatedly confirmed phenomenon oversimplified as warranting the postulate of a direct cause-and-effect connection. To the contrary, it was stated expressly that the aloneness from the beginning of life makes it difficult to attribute the whole picture one-sidedly to the manner of early parent-child relationship.

The one thing that the 1943 paper could neither acquire nor offer was a hint about the future. Everywhere in medicine, prognosis can be arrived at only through retrognosis. No empirical data were available at the time; the whole syndrome as such was a novelty as far as anybody was aware. Now we have information about the fate of the 11 children in the ensuing three decades.

We must keep in mind that they were studied before the days when a variety of therapeutic methods were inaugurated, based on a variety of theoretical premises: psychoanalytically oriented, based on operant conditioning, psychopharmacological, educational, via psychotherapy of parents, and combinations of some of them. Sufficient time has not elapsed to allow meaningful long-range followup evaluations. At any rate, no accounts are as yet available that would afford a reasonably reliable idea about the more than temporary or fragmentary effects of any of these procedures intended for amelioration.

Of the 11 children, 8 were boys and 3 (Cases 5, 6, and 11) were girls. It was, of course, impossible at the time to say whether or not this was merely a chance occurrence. A later review of the first 100 autistic children seen at the Johns Hopkins Hospital showed a ratio of 4 boys to 1 girl. The predominance of boys has indeed been affirmed by all authors since then. It may be added that the boys were brought to the Clinic at an earlier age (between 2 and 6 years) than the girls (between 6 and 8 years).

Nine of the children were Anglo-Saxon descent, two (Cases 9 and 10) were Jewish. Three were only children, 5 were the first-born of two, one was the oldest of three, one the younger of two, and one the youngest of three. Order of birth was therefore not regarded as being of major significance *per se*.

On clinical pediatric examination, all 11 children were found to be in satisfactory health physically. Two had large tonsils and adenoids, which were soon removed. Five had relatively large head circumferences. Several of the children were somewhat clumsy in gait and gross motor performances but all were remarkably skillful with regard to finer muscular coordination. Electroencephalograms were normal in all except John (Case 10), whose anterior fontanelle had not closed until he was 2½ years old and who, 3 years after his first visit to the Clinic, began having predominantly right-sided convulsions. Frederick (Case 2) had a supernumerary nipple in the left axilla. There were in the group no other instances of congenital somatic anomalies. All had intelligent physiognomies, giving at times—especially in the

presence of others—the impression of serious-mindedness or anxious tenseness, at other times, when left alone with objects and with no anticipation of being interfered with, a picture of beatific serenity.

While there were, as is to be expected, individual nuances in the manifestation of some of the specific features, the degree of the disturbance, and in the step-by-step succession of incidental occurrences, it is evident that in the first 4 or 5 years of life the overall behavioral pattern was astoundingly similar, almost to the point of identity in terms of the two cardinal characteristics of aloneness and stereotype. Now, after 30 or more years, it is also evident that from then on, notwithstanding the basic retention of these two features, major differences have developed in the shaping of the children's destinies.

We do not know about the present status of Paul G. (Case 4) and of Alfred I. (Case 8). Paul's mother went shopping around to a number of specialists, dropping out each time after one or two appointments, and could not be located since 1945, despite many efforts worthy of a competent detective agency. Alfred's mother had him at first in rapid succession in 11 different public and private schools and then in several residential settings. He responded well to occupational therapy but the mother, not considering this adequate, took him out and kept him with her in a "school" founded and run by herself.

Two of the children, John and Elaine (Cases 10 and 11) developed epileptic seizures. John's began about 3 years after his first visit to the Clinic; after sojourns in several residential places, he died in 1966. Elaine's convulsions started in her middle to late twenties and she is now, at 39 years, still "on anti-epileptics and tranquilizers"; her EEG was reported normal in 1950, when she was admitted to the Latchworth Village, N.Y. State School. She was later transferred to the Hudson River, N.Y. State Hospital, where she still resides.

Richard M., Barbara K., Virginia S., and Charles N. (Cases 3, 5, 6, and 9), who spent most of their lives in institutional care, have all lost their lustre early after their admission. Originally fighting for their aloneness and basking in the contentment that it gave them, originally alert to unwelcome changes and, in their own way, struggling for the status quo, originally astounding the observer with their phenomenal feats of memory, they yielded readily to the uninterrupted self-isolation and soon settled down in a life not too remote from a nirvana-like existence. If at all responsive to psychological testing, their IQ's dropped down to figures usually referred to as low-grade moron or imbecile.

This fortunately did not happen to the remaining three children. Herbert B. (Case 7), still mute, has not attained a mode of living that one can be jubilant about but has reached a state of limited but positive usefulness. He was placed on a farm, where, following the farmer around on his chores,

he learned to participate in some of them. When the farmer died and the widow established a nursing home for elderly people, he learned to perform the functions of a kind, helpful, competent orderly, using his routine-consciousness in a goal-directed, dependable manner.

Donald T. (Case 1) and Frederick W. (Case 2) represent the two real success stories. Donald, because of the intuitive wisdom of a tenant farmer couple, who knew how to make him utilize his futile preoccupations for practical purposes and at the same time helped him to maintain contact with his family, is a regularly employed bank teller; while living at home, he takes part in a variety of community activities and has the respect of his fellow townspeople. Frederick had the benefit of a similarly oriented arrangement in the framework of the Devereux Schools, where he slowly was introduced to socialized pursuits via his aptitude for music and photography. In 1966, his parents took over. He was enrolled in a sheltered workshop and received vocational training, learning to run duplicating machines. He has now a regular job and is reported by his chief as "outstandingly dependable, reliable, thorough, and thoughtful toward fellow workers."

COMMENT

Such was the fate of the 11 children whose behavior pattern in preschool age was so very much alike as to suggest the delineation of a specific syndrome. The results of the followup after about 30 years do not lend themselves for statistical considerations because of the small number involved. They do, however, invite serious curiosities about the departures from the initial likeness ranging all the way from complete deterioration to a combination of occupational adequacy with limited, though superficially smooth social adjustment.

One cannot help but gain the impression that State Hospital admission was tantamount to a life sentence, with evanescence of the astounding facts of rote memory, abandonment of the earlier pathological yet active struggle for the maintenance of sameness, and loss of the interest in objects added to the basically poor relation to people—in other words, a total retreat to near-nothingness. These children were entered in institutions in which they were herded together with severely retarded coevals or kept in places in which they were housed with psychotic adults; two were eventually transferred from the former to the latter because of their advancing age. One superintendent was realistic enough to state outright that he was accepting the patient "for custodial care." Let it be said, though, that recently a few, very few, State Hospitals have managed to open separate children's units with properly trained and treatment-oriented personnel.

The question arises whether these children might have fared better in a

different setting or whether Donald and Frederick, the able bank teller and the duplicating machine operator, would have shared the dismal fate of Richard and Charles in a State Hospital environment. Even though an affirmative answer would most likely be correct, one cannot get away from wondering whether another element, not as yet determinable, may have an influence on the future of autistic children. It is well known in medicine that any illness may appear in different degrees of severity, all the way from the so-called *forme fruste* to the most fulminant manifestation. Does this possibly apply also to early infantile autism?

After its nearly 30-year history and many bona fide efforts, no one as yet has succeeded in finding a therapeutic setting, drug, method, or technique that has yielded the same or similar ameliorative and lasting results for all children subjected to it. What is it that explains all these differences? Are there any conceivable clues for their eventual predictability?

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. At long last, there is, in addition, an increasing tendency to tackle the whole problem through a multidisciplinary collaboration. Genetic investigations are barely beginning to be conducted. Insights may be gained from ethological experiences. Parents are beginning to be dealt with from the point of view of mutuality, rather than as people standing at one end of a parent-child biopolarity; they have of late been included in the therapeutic efforts, not as etiological culprits, nor merely as recipients of drug prescriptions and of thou-shalt and thou-shalt-not rules, but as actively contributing cotherapists.

This 30-year followup has not indicated too much concrete progress from the time of the original report, beyond the refinement of diagnostic criteria. There has been a hodge-podge of theories, hypotheses, and speculations, and there have been many valiant, well-motivated attempts at alleviation awaiting eventual evaluation. It is expected, with good justification, that a next 30- or 20-year followup of other groups of autistic children will be able to present a report of newly obtained factual knowledge and material for a more hopeful prognosis than the present chronicle has proved to be.