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# The Autistic Syndrome: Proceedings of the Sandoz Working Party on Definition, Nomenclature, and Classification, Held in the University of Queensland, August 1969

edited by JOHN RENDLE-SHORT and HELEN CLANCY

FACULTY OF MEDICINE

Volume I

Number 3



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UNIVERSITY OF QUEENSLAND PRESS St. Lucia

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This publication consists of the proceedings of a working party on childhood autism organized by the Department of Child Health within the University of Queensland and held on 27 and 28 August 1969.

The working party, whose proceedings occupied two days, was supported financially by Messrs. Sandoz Proprietary Limited and we would like to express our gratitude for their generous assistance. The purpose of the Sandoz working party was to bring together, by invitation, professional people actively engaged in diagnosing and treating autistic children in Australia and New Zealand, with a view to achieving some agreement on the nomenclature and diagnostic criteria for autism. It was followed by a seminar which was open to all professional people interested in the problems of autistic children, and provided an opportunity for workers of varying disciplines to present current research and clinical practices, and for the audience to share in the interchange of ideas. The proceedings of the seminar have been published separately.\*

Our particular thanks go to the University of Queensland Press for all their help in arranging for the publication of these proceedings, and to Mrs. J. Moy for her excellent secretarial assistance.

<sup>\*</sup>Obtainable from the Department of Child Health, University of Queensland, Royal Children's Hospital, Herston, Queensland.

# THE AUTISTIC SYNDROME: PROCEEDINGS OF THE SANDOZ WORKING PARTY ON DEFINITION, NOMENCLATURE, AND CLASSIF-ICATION, HELD IN THE UNIVERSITY OF QUEENSLAND, AUGUST 1969

# I. INTRODUCTION

There is increasing interest throughout the scientific world in childhood autism, and this is no less true in Australia. The condition represents one of the challenging areas of investigation in medicine today because the questions raised have implicatons for human growth and development in the widest terms. We have few answers to the questions as yet, although there is no dearth of theories and speculations all reflecting the particular orientations and prejudices of their exponents.

Neither are the basic problems entirely clear, for it is evident that children manifesting the autistic syndrome do not comprise a homogeneous group. The major defect that the children do appear to have in common is a disordered ability to form bonds with other human beings, and without bonds there can be no socialization, so that, whatever the aetiology of the autistic behaviour, there are repercussions in all aspects of development, and the problems are multiplied.

Many of the problems in investigation stem from lack of understanding of the aetiology or aetiologies. Because the child is affected so early in life, almost invariably we are working on the basis of retrospective information which is not available to confirmation by clinical observation. Consequently people have tended to interpret Kanner's original symptomatic picture in many ways, and without prior definition of terms, it is no longer possible to be sure that when we talk of "autism" we are meaning the same condition. Research, and consequently effective understanding and management of the problems of autistic children, will be impeded while this state of affairs continues.

In the Department of Child Health at the University of Queensland, we have long argued for study of the very young autistic child, i.e. under three years of age, and for early treatment intervention, It was gratifying to find that others shared this view and the emphasis of the working party was therefore very much toward young children.

The absolute necessity of an interdisciplinary approach to autism was also stressed, and it is therefore hoped that this report will be of value to all interested in autism whatever their basic discipline.

# II. EDITORIAL COMMENT

In editing the verbatim proceedings recorded on tape I have endeavoured to give the sense of the working party, often reporting the actual words used. However in a free-flowing discussion which was minimally structured it was inevitable that some members' protests might be drowned, or the flow of the verbal interchange might have moved too rapidly for them to have been recorded. Thus the finished report must not be regarded as fully representing the views of each working party member. No votes were taken, but if they had been it is very possible that there might have been several minority reports. I take full responsibility therefore for the proceedings as recorded but would like to state that I too do not necessarily agree with everything stated here.

It soon became apparent that a philosophical difference of approach separated the psychiatrists in the working party from the non-psychiatrists.

The paediatric viewpoint is that a diagnostic syndrome must be delineated in order that a specific approach can be made to it aetiologically, therapeutically, and prognostically. Whenever a new disease or syndrome is discovered, people find examples of it and the concept is widened to include a wide variety of conditions. At this stage it is valuable to reconsider the original syndrome. Is it a separate entity? What are its essential diagnostic features? What is the nuclear condition? Are we for instance all describing essentially the same condition when we talk of infantile autism? Until this stage is reached it is not possible to compare the effect of treatment on prognosis between two series of cases because we are never sure that in fact we are considering the same condition. To the paediatricians this seemed to be the stage which we had reached and it thus seemed that the aim should be to define and classify. This was the purpose of the working party.

The psychiatrist on the other hand almost regards the diagnosis as a "red herring" in psychological medicine. He tends to see the whole spectrum of children brought to him as a continuum, at one end of which might be the autistic syndrome and at the other children who show isolated autistic symptoms.

All agreed that to attach the label "autistic" to a child is potentially dangerous. If a child is labelled as having tuberculosis or epilepsy this is a stigma which may have far-reaching implications in later life. Nevertheless there is obviously value in labelling a child autistic for the purpose of research into aetiology, or to develop a therapeutic programme, or for prognostic purposes. In short, it is essential if we are to communicate to another person what we are talking about.

Labelling was also recognized as having practical advantages in relationship to autistic societies or associations. Undoubtedly through these associations many parents come together and obtain mutual support and funds are gathered for research.

The working party had the task of defining autism, of trying to agree upon a nomenclature and of classifying the disorder. This we attempted to do--whether we have succeeded or not is left to readers to decide. One thing however is certain, and that is that the whole subject of autism is still in a state of flux and will be until more basic research is done on the subject.

I would like to thank all those who participated in this working party for their keen interest, candour, and lack of rancour. Particular thanks go to Miss Helen Clancy, who organized the working party so excellently, and to Messrs. Sandoz, who financed it.

- Miss Y. Atkinson, Child Guidance Clinic, 590 Newcastle Street, Perth, Western Australia
- Dr. K. M. Benn, Psychiatrist Superintendent, Travancore Clinic, Flemington Street, Flemington, Victoria
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- Dr. A. S. Bull, Staff Psychiatrist, Department of Psychiatry and Child Guidance, Royal Alexandra Hospital for Children, Camperdown, New South Wales
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- Dr. S. Williams, Psychiatrist, The Psychiatric Centre, Cox's Road, North Ryde, New South Wales

# IV. REPORT AND RECOMMENDATIONS OF THE SANDOZ WORKING PARTY

# Definition

The working party looked first at Bleuler's original use of the word "autism". Although of historical value it was considered that the whole concept of autism had been widened since that time by Kanner and others. Bleuler originally used the term in the context of schizophrenia, but it was felt that this word was best reserved for children and adults with a later onset of psychosis.

The concept of primary infantile autism, a nuclear autism, or Kanner syndrome, is still somewhat conjectural. The data relating to the child's development in early infancy are crucial to the elucidation of this point. Unfortunately such data are at present rarely available except in a retrospective fashion.

Several different wordings for a definition of "autism" were suggested, considered, and modified. Considerable discussion centred round the concept of "selfinvolvement". It was pointed out that from the clinical point of view these children were not involved with us as outside people. Were we justified therefore in assuming that they were involved with themselves? They might be absent mentally or in a limbo. The word "autism" with its connotation of self might in fact be a misnomer. For this reason some members of the working party wished to toss out the word "autism" altogether!

Other current definitions given in the literature were discussed. Some of these emphasized that "autism" is a descriptive term to describe a disturbance of interpersonal relationships. This failure to make relationships was discussed. Certainly this is the first and probably the most significant observable feature of the condition. However there is a sense in which these children do involve themselves with others: they have their own method of communication even though this may be by withdrawal or blankness.

Eventually the following definition was agreed upon: "AUTISM IS A CLINI-CAL STATE TRANSIENT OR PERSISTENT CHARACTERIZED BY A FAILURE TO DEVELOP OR SUSTAIN NORMAL RELATIONSHIPS WITH HUMAN BEINGS, AND ASSOCIATED WITH AN EXCEPTIONAL DEGREE OF SELF-INVOLVEMENT".

Having defined autism as a disorder, the working party next considered the condition of infantile autism, or the autistic syndrome as it applied to children.

It was agreed that the condition commenced in "infancy", which for this purpose was defined as under thirty months of age. The working party felt that with regard to the autistic syndrome the essential feature to emphasize was the partial or complete blockage in the child's normal developmental processes, resulting in permanent psychological damage even though the autistic state might have been short-lived. Such a permanent state could be called the autistic syndrome. Obviously therefore the syndrome would differ with the age of onset, or rather with the developmental age of the child at onset.

Further it could happen that the cause of the autistic process might be quite short-lived and soon over for the child, but having dropped into the state of autism he is not able to get out of it, and thus the condition becomes self-perpetuating.

Persistent autism occurring before the age of thirty months creates a clinical condition of partial or complete disruption in the developmental process, and the fully developed autistic syndrome develops from this clinical state.

The working party considered how long infantile autism lasted. Some members felt that the term should only include cases which were long-lasting. Others, referring to the autistic syndrome, stated that "if the behaviour is the same as the autistic syndrome, it's autism". Thus the concept was born of transient autism lasting perhaps for three weeks under stressful circumstances. But it was agreed that these transient cases were different in kind from the long-lasting ones.

#### On classification

The working party considered that the classification proposed by the W.H.O. committee on the psychosis of infancy and early childhood had great merit. This considers the condition under three axes:

- 1. The clinical syndrome
- 2. The intellectual level\*
- 3. Aetiological factors and associated conditions.\*\*

# Axis 1—The clinical syndrome

Early infantile autism is a condition in which there is an "autistic type of disturbance in inter-personal relationships together with delayed or distorted language development, ritualistic or compulsive features with a resistance of change, irregular intellectual developments and often motor stereotypies. The term includes other psychotic disorders developing during the infancy period (regardless of whether or not there is an associated organic brain disorder or mental sub-normality)."

This succinct description is excellent as far as it goes, but what does the child with autism really look like and how can he be recognized?

<sup>\*</sup>Considered on page 79.

<sup>\*\*</sup>Considered on page 80.

Firstly, the question was asked: Is there a pure autistic state—a Kanner syndrome? That is, are there some children who are autistic from birth irrespective of their environment?

The consensus of opinion seemed to be that while such a condition probably existed, the difficulty of retrospective diagnosis was such that it was rarely, if ever, seen.

Secondly, at the other end of the scale, the working party discussed the autistic syndrome as a member of the "isolation syndrome", that is the child who has impaired communication with others, particularly his mother. Other examples of this syndrome are the severely deprived child, the deaf child, and certain types of mental retardation.

#### Diagnosis in the first year of life

It was agreed that it was very difficult, perhaps impossible, to diagnose autism in the first nine months of life. Some reasons for this were:

a) The developing child normally passes through what might be described as an autistic phase of development.

b) Much of the behaviour which we associate with the autistic syndrome, such as failure to talk or tip-toe walking, is just not possible for a baby.

c) The most important reason, however, is that we do not know what to look for at this age. This is because the history of the child's early development is almost always retrospective. The sequence of events is usually that at about the age of two years the child appears to be so abnormal that he is taken to the doctor. A diagnosis of the autistic syndrome is then made (on differing evidence depending on the particular views of the doctor), and the mother is asked to describe, in as much detail as possible, the child's early development. However by this time she may well have read something about autism in the popular press and this influences the story she tells. She therefore tries to squeeze the child into her preconceived ideas of the symptomatology of the disorder.

The mother is, in any case, a highly biased observer as she is one half of the mother/child unit. In addition her level of sophistication as an observer depends on her previous experience of child rearing, particularly as she may have some normal children as well as the abnormal child.

d) We know so little of the norms and range of normal infant behaviour in the first months of life. This is particularly so in relation to the mother/child interaction.

Although the working party fully recognized the above limitations, it nevertheless decided it was worthwhile to collect together all the information we had with regard to the type of appearance and behaviour of infants who were later diagnosed as having the autistic syndrome. In this way it was hoped it would be possible to establish a profile of the sort of child who might later develop the syndrome, in fact of the child "at risk".

## The child at risk of autism

While endeavouring to define the child at risk, the working party was constantly aware of the dangers of this exercise.

a) It was of course realized that many other children would behave in the same sort of way; certainly this would be true of mentally retarded, cerebral palsied, deaf, emotionally deprived, and in fact quite a lot of normal children. However, the list which follows is especially geared toward infantile autism. One thing about the autistic syndrome child that was thought to be of particular distinguishing value was his inconsistency (see p. 79). That is to say there were areas in which he seemed comparatively normal, whereas in other things he was markedly abnormal. b) It was also realized that the observation of the young child would inevitably be at different levels by different people. Particularly it was felt by some members of the working party that casual observation in an unstructured situation by personnel not specifically trained to observe psychologically might be of little value or even positively misleading. The working party wished that more training was given in the field of infant development from the point of view of the child's emotional development and in the family setting.

Nevertheless it hoped that infant welfare sisters and general practitioners would be alerted to realize that something was wrong with the child in a general sort of way, and then a more sophisticated observer, perhaps a paediatrician or psychiatrist, would be able to make a detailed observation and try to come to a definite conclusion as to whether the child was a variant of normal, was mentally retarded, deaf, or possibly autistic. Of these the last was statistically the least probable.

We saw the child "at risk" for the autistic syndrome as having some or all of the following features below the age of six months. The order given here is random; no attempt has been made to try and establish an order of priority.

a) Not cuddly. The working party recognized that this was very difficult to define. The following descriptions were suggested: arching the back, resisting by crying, puckering the face and turning away, baby like a piece of wet blotting paper, or rag doll. It was emphasized that experimental work had shown that quite a number of normal children behave in this way at some time or other. An important point may be that the mothers of normal children are not worried by the child's lack of response, whereas the mother of the autistic child tends to say: "O.K. If you don't like me, I don't like you." It is also worth considering that just as the child is "not cuddly" to the mother, so the mother is "not cuddly" to the child.

b) Slow to smile. By this was meant a smile occurring in response to the visible stimulus of a face appearing. Normally this would be expected to appear under the age of eight weeks. It was recognized that autistic children of over three months might respond by smiling or laughter to auditory or tactile stimulation (e.g. tickling), but not in response to the observer's face.

c) *Cut-off.* The working party was here considering the child who is unaware and apparently unappreciative of *variety* in his environment. Such variety was considered as visual, auditory or tactile; alternatively the variety could be recognized as being external or internal to the child. From the mother's point of view, the child appears unresponsive, implacable; but perhaps from the child's point of view it is that he is resisting the variety.

d) *Lazy sucker*. The working party had some difference of opinion as to whether this item should be included, perhaps because lazy sucking is a non-specific behaviour, known to be associated with several conditions in infancy.

e) Insistence on sameness. An illustration of this was given as the child who is happiest when left on his own in his bassinet.

f) Hypo- or hyper-responsiveness to sound, tactile stimulation, etc. The working party was as much concerned with the child who over-responded as with the one who under-responded when stimulated.

#### The role of the parents

All children can be regarded as "autistic" at birth and it is the responsibility of the parent to bring the child out of this autistic into a normal state. In order for this to happen the mother must appear as a constant, permanent object. But if the mother is only fleetingly present, or has bewildering changes of mood, or on the other hand, if the child's neurological apparatus is damaged from birth or by accident or developmentally, he cannot integrate the different perceptions of his mother in her different states. He does not see her as a constant object. And so secondary symptoms follow and he becomes attached to inanimate objects instead. In fact, it must be quite an intellectual exercise for a baby to recognize the mother who smiles and the mother who is angry, the mother who is in the room and the mother who is absent, all as the same person.

Put another way, the child fails to achieve the initial bond with his mother and thus primary socialization never occurs in a consolidated manner.

In whatever way the autistic process commences, it is obvious that a vicious circle is set up. Either the child is rejected and so rejects the mother, and she in turn rejects the child and so on, or the child first rejects his mother and so she rejects him, etc. However it commences, communication between the two becomes less meaningful and more mechanical. The child becomes isolated and in fact seems actively to work at maintaining his isolation. Some members of the working party thought that this was a particular feature of the autistic syndrome, whereas others considered it was not a distinguishing point but was common to all chronic behaviour problems in childhood.

From the viewpoint of treatment it is essential to undertake case-work not only with the child but also with the mother and the family. Indeed, in many cases, the community--neighbours, kindergarten teachers, even doctors--also need counselling.

## Maternal profile

Throughout its discussion of the child at risk, the working party was constantly reminded of the difficulty of defining the child's behaviour in isolation from that of the mother. The *first smile* for instance—should it be regarded as a purely biological reaction to something seen as a white disc with holes in it, or was it a social response to a social overture?

Thus having considered the child in isolation, the working party tried (not very satisfactorily) to consider the mother in isolation, and then the quality of the mother/child interaction.

To this end the working party attempted to compile a profile of the mother of the young child (less than twelve months) with the autistic syndrome, or rather the child who is later considered to have the autistic syndrome. It was realized that this approach had potential dangers as in fact a full range of personalities might be found.

a) It was recognized that initially both the mother and child might appear quite normal, but that as the child's disorder became apparent the mother would react by becoming increasingly anxious and might then show some of the profile characteristics given below. She might for instance respond as in the example given on page 76 (not cuddly).

b) The essential component seemed to be that there was an interruption of the normal mother/child relationship.

c) The age of the child was of particular importance. The six-year-old child can cope with his mother's anxiety or depression, but the six-months-old child cannot.

A maternal profile was compiled although the potential inaccuracies were fully recognized. It was also realized that, in fact, it is not possible to differentiate between abnormalities in the mother, and abnormalities in the child. Which is the egg and which the chicken? Two particular aspects of maternal behaviour were recognized.

a) *The mother's abnormal emotional state*. This may commence before or after the birth of the child and be one or a combination of all of the following:

i) Depression

ii) Preoccupation with other pressing material activities

iii) *Inappropriate anxiety*. This may be general or particularly related to this child. Thus there is undue anxiety where it would not ordinarily be expected, or no anxiety where it might be expected. It was incidentally agreed that mothers of autistic children tend to be prolific letter writers. Maybe this is because of inappropriately meagre medical anxiety.

b) Abnormal attitude to the child. The mother often has an inadequate awareness of the child's needs, physical, material and emotional, for instance the child's need for love and security.

The mother may also give inappropriate responses to the child's needs. This may be partly due to wrong instruction. For example she may have been told not to pick the child up when he cries, and this may have been interpreted too rigidly.

The working party considered that more research was needed in this field and particularly assessment against appropriate scales and observation under structured situations. This would help to bring the profile given above out of the realm of the anecdotal.

The working party held the view that at present we do not have sufficient information to say whether the child was abnormal because the mother was, or whether the mother was abnormal because of her child, or perhaps that both are true.

The essential question to be asked is: What sort of experiences is this child having in relationship with this mother? Many mothers are abnormal but the experience for the child may not be disabling.

#### The father

The working party also discussed the father, while again realizing the dangers of describing rigid profiles.

a) It was recognized that the father tends to remain in the background from the doctor's point of view. For this reason, he is often difficult to interview. Mainly we see him as he is described by his wife.

b) From the father's point of view, it seems that often the child just isn't there. He is not prepared to be emotionally involved with his child. He is thus not available to act as a replacement for the mother if she is depressed or sick. He too is not cuddly to the child—he is not there to be cuddled.

c) Sometimes the father is absent because he has a demanding profession or is too busy making things in the garage. Sometimes he is edged out by an overefficient mum. Rarely is he psychotic.

# Diagnosis in the older baby----6-18 months

The division of time from naught to six months and from six to eighteen months was made after considerable discussion. We felt that the normal child alters in his responsiveness to the outside world and to strangers at about the age of six to seven months, and then again around the age of eighteen months.

a) Absence or delay in development of social games. In normal children the earliest type of social interaction is probably the child rubbing his mother's face. Later more sophisticated games develop, such as peek-a-boo, clapping hands, waving bye-bye, etc. These pastimes are late or poorly developed in the autistic child.

b) Absence or delay in the development of communicable speech. This was regarded as a most important indication of a child at risk. The working party were uncertain as to whether there was any evidence that pre-speech babbling did not occur in autistic children. This was considered to be an important area requiring further research. Certainly it is well known that formal speech is usually greatly delayed. c) Hypo- or hyper-reactivity to sound. Some autistic children appear deaf. Others scream when a noise suddenly occurs such as a vacuum cleaner or motor mower being started. Sometimes both reactions may appear in the same child inconsistently.

d) Delay in responding to language. This can probably be regarded as a particular example of hypo-reactivity to sound.

e) Absence of or exaggerated stranger response. About the age of seven months the normal baby is able to distinguish his mother, or other well-known adult, from strangers. The child with the autistic syndrome may well go to anyone indiscriminately.

f) *Hypo- or hyper-activity*. Mothers commonly say that the child is "so good you don't know he is in the house". Alternatively other children may kick a hole in the blanket or rock the cot across the room. The observation was made that all of the child's behaviour seemed designed to achieve and maintain isolation.

g) Inconsistent appearance. The working party was impressed by the fact that whereas the mentally retarded child usually has physical stigmata which immediately set him apart from the normal, the child with the autistic syndrome appears normal, even beautiful.

h) Inconsistent behaviour. Similarly in the functional field a scatter is often observed in the visual, auditory, language, and social areas. Thus the child may function in some ways as though he was mentally retarded, but show average or above average development in other fields. In addition the lines of development may become kinked so that a particular skill may appear, disappear, and appear again. This may also occur in normal children, but is seen in an exaggerated fashion in the autistic.

Because of this inconsistency, the autistic child is sometimes referred to as having "islets of normal behaviour". It would perhaps be more accurate to consider that he has "lakes of abnormal behaviour" and that as successful treatment continues these "lakes" are slowly obliterated. When it is remembered that during early development the normal baby has to store in his brain millions of memories, instincts, habits, abilities, loves, fears, hates, desires, colours, textures, tastes, faces, shades, sounds, subtleties of behaviour, it is no wonder that the disintegrated development of the autistic child is missing in large areas. So the "lakes" are present which have to be laboriously filled in by active therapy later.

#### Diagnosis of the older child—18 months and above

The working party had before it the manuscript of a paper entitled "The Diagnosis of Infantile Autism" by Helen Clancy, Alan Dugdale and John Rendle-Short, which was subsequently published in *Developmental Medicine and Child Neurology* (11 [August 1969]: 432-42). At the seminar which followed the working party, this paper and a film\* to illustrate it were discussed. Very condensed reports of the discussions of both the working party report and the seminar paper are given in Appendix 1 and Appendix 3, on pages 84 and 86.

# Axis 2-The intellectual level

As is well known, it is always difficult to assess intelligence accurately in autistic children. Two factors were regarded as important in this regard:

Firstly, we can hypothesize that the child would have had a certain I.Q., which

<sup>\*</sup>Obtainable from Messrs. Sandoz Drug Co., 620 Harris St., Ultimo, New South Wales.

would come somewhere on the continuum from subnormal through average to very high, if he had not been afflicted by the autistic process. This is his theoretical basic I.Q. But, secondly, because he developed the autistic syndrome and because this disrupts development in the vital early years, his I.Q. will be depressed. Here the factors of age of onset and of treatment are vital.

#### Axis 3—Aetiological factors and associated conditions

The W.H.O. classification states that the autistic syndrome may occur in association with other conditions such as:

- a) organic disorders: genetic, infective, toxic, metabolic, neoplastic, degenerative, convulsive, traumatic;
- b) sensory and perceptual disorders;
- c) developmental deviations;
- d) environmental factors, either emotional or social.

The working party underlined the fact that autism might be *associated with* one of the above. It was anxious to get rid of the concept that autism was synonymous with mental retardation, developmental deviations, etc. Other aetiological factors considered were:

#### Hereditary factors

It was agreed that there was no evidence of genetic inheritance in the sense of major psychotic breakdown, severe depression, or other known physical illness in the parents or near relations. There are, however, several recorded cases of autism occurring in siblings, or with one child autistic and another severely mentally retarded. Identical twins have been reported both with infantile autism, but also one with and the other without infantile autism. On the whole therefore it was considered that the evidence was against any specific hereditary factors.

The importance of the high male incidence of the disorder (approximately four to one, male to female), was discussed. Points which were considered were: that the young male child is always at greater risk, that developmental deviations are more common in boys, and that the Y chromosome might be the cause of a biological difference.

The incidence of infantile autism in non-European families was also considered. Cases were recalled by members of the working party in a West Indian child, a Thai child, and Chinese and Japanese children.

# Environmental factors

It was agreed that there was a significantly reduced incidence of the autistic syndrome in children coming from a low socio-economic environment. (This was here taken in the W.H.O. sense of overcrowding, poverty, and cultural deprivation.) The reason for this is not known. Elucidation of this problem might go far to unlock the whole aetiological enigma of autism. Some suggestions made were:

a) In the lower socio-economic groups, behaviour which is unacceptable to the mother is dealt with in an entirely different way from that of the higher groups. The example was given of a mother who said, "I cracked him out of his blinks." A more intellectual type of woman might have brought the child for detailed medical investigation.

b) The rejected child in the low socio-economic level tends to become sick and die rather than stay alive and become autistic.

c) In primitive cultures there is usually such constant mother/child interaction, at any rate on the physical level, that this might preclude the development of autism.

### Physical factors

The working party considered that children with the autistic syndrome could be physically normal or might have "hard" or "soft" neurological abnormalities.

"Hard" neurological abnormalities included definite lesions such as hemiplegia, deafness, blindness, Down's syndrome, phenylketonuria, tuberose sclerosis, encephalitis, or undoubted E.E.G. dysrythmias. Some children have fits, but these are usually the ones with obvious neurological damage. There is also evidence that fits sometimes commence in adolescence.

The working party observed with interest that all the medical lesions noted to occur in combination with autism had a neurological component. There was no mention for instance of urinary tract or orthopaedic abnormalities. Congenital heart lesions did occur in association with autism, but in each case there could well have been neurological damage—for instance in rubella embryopathy or Fallots tetralogy (in which there is an intense, long lasting cyanosis and sometimes an associated brain abscess).

"Soft" neurological abnormalities or minimal cerebral dysfunction include such disorders as minor E.E.G. changes, minor abnormalities of psychological functioning, clumsiness, incoordination, perceptual difficulties, receptive aphasia. It is however doubtful whether children with these lesions are more at risk for autism than others. Certainly such minor abnormalities would be difficult to demonstrate in a child with the autistic syndrome.

There was some difference of opinion as to how neurological abnormalities were associated with the autistic syndrome. Possibilities advanced included:

a) That there was an anatomical abnormality of the reticular system. This, however, was regarded as pure hypothesis. A pathologist was quoted as saying that he had never been able to identify damage to this area.

b) That autism resulted from some direct electrical or biochemical alteration of brain physiology attributable in some unknown way to an organic lesion. This also is in the realm of conjecture.

c) That there is an intervening variable, e.g. the brain damage leads to a disturbed mother/child relationship and thus to the autistic syndrome.

#### The role of precipitating causes

Whenever parents are confronted with sickness in their child, be it physical or psychological, they look for causes. Some notable event is singled out and is said to be the reason for the child's disability. This is more likely to occur when

a) The parents have not realized the child was abnormal before.

b) The parents, unperceived by themselves, because of their own personality traits, are heavily involved in the aetiology of the disorder.

c) A child has grown older before being investigated. Then factors leading to the child's illness must have occurred years before, and time tends to highlight some events and obliterate others.

Nevertheless it was recognized that the history of a definite precipitating event was very commonly obtained from parents. Often the parents can show photographs or films of the child before and after the event which demonstrate the difference in his appearance and behaviour. Considerable discussion centred on which of the following possibilities was the most likely:

a) The child was normal before, then a sudden event occurred from which time onward he was autistic. Presumably in this case the event would have to be of great severity. b) The child was vulnerable for some reason and therefore a comparatively minor event commenced the process.

c) A number of events occurred of which one retrospectively sticks out in the mind of the parents as being of particular significance to themselves, but this is not necessarily true for the child at the time.

In general it may be stated that an event of great significance to the child may be misunderstood or not noticed by the parents. Therefore it is important that when considering trauma as an aetiological factor, it should have occurred in a situation and to objects to which the child was intimately related.

The working party felt that a field of research would be to record and analyse events which appeared to precipitate the autistic syndrome to discover whether there are any common factors. For example precipitating factors may be

a) Purely psychological. The advent of a new baby or some frightening experience such as watching the birth of a baby were given as examples.

b) There may be some organic component. For example severe gastro-enteritis with dehydration, an anaesthetic, or whooping cough. It is of interest that if the precipitating event is mainly physical it always seems to be one in which there could well have been a neurological component.

c) The common factor may lie in the way the child reacted to the event. For instance there might be a traumatic disruption in the mother/child relationship due to a multiplicity of possible causes, actual separation being the commonest. But other factors might amount to a de facto separation even though the mother and child were together physically.

Consideration was given to the children who were presented to the doctor without there being a dramatic precipitating event. It was thought that possibly in some of these cases the "event" might be that an obsessional mother could not stand the child now that he was starting to walk around and obtrude himself. Previously when he had spent most of his time in his cot she could tolerate him. And so the "event" at about the age of twelve months might be a disturbance in the mother / child relationship because of the biological factor of development. This would be all the more psychologically damaging to the child as at this age, above all, he should be leaving the cot and learning to investigate for himself.

Finally, the working party believed that the syndrome of autism might vary from child to child in relation to time and mode of onset, duration and severity. Variables which determine this are:

The child's vulnerability to stress. Vulnerability is manifested by an exaggerated or inappropriate response to stimuli.

Whether the child has any neurological deficit, dysfunction, or disintegration of whatever cause. Examples which might be given are minimal cerebral dysfunction, cerebral palsy, tuberose sclerosis, and phenylketonuria.

Whether the child has any sensory or perceptual disorder. This may be with regard to any of the sensory modalities, e.g. visual, auditory, tactile, etc.

Whether the child has any sensory deficit or deficiency. Here the working party was considering particularly deafness and blindness.

Whether the child has intellectual retardation of a primary or secondary nature. Secondary retardation may be suspected if there is a scatter in the child's abilities as demonstrated for example by intelligence tests.

Whether the process is primary. For lack of certain evidence the Kanner syndrome was regarded as a hypothetical concept.

Whether the process is reactive. The reactivity is seen particularly in terms of response to abnormalities in the mother/child relationship, or in situational events which have a potential for disrupting the mother/child relationship. Examples of this could be:

a) A child has an organic neurological defect which brings out an excessively abnormal response from the mother.

b) A "normal" baby has a disturbed, distressed mother for whom this child has some particular significance.

c) A vulnerable, hypersensitive child has exceedingly gifted but vulnerable parents.

d) Or a vulnerable child is paired to a "normal", but to him devastatingly abnormal type of maternal personality.

# Severity of the syndrome

The working party discussed the idea of "severity" as applied to the autistic syndrome. It was felt that factors of importance with regard to this were:

a) The child's basic, pre-autistic I.Q. potential.

b) The length of time the process had persisted unmodified by treatment.

c) The way in which the autistic process had eroded his development. In this context the commonly reported islets of normality are of considerable significance.

d) Some members felt that the syndrome could be considered as a spectrum with "mild" at one end and "severe" at the other. This would perhaps be best seen with regard to the child's "relationship" to other people. If some degree of "relationship" was present the child could be regarded as being mildly affected whereas if he was completely cut off, as severe. An obvious difficulty lies in measuring "relationship".

e) Some members felt that the absence of speech in the older child indicated a severe involvement irrespective of his other behaviour.

# Summary

Some important aspects of the working party deliberations were:

- 1. The realization that autism is a "clinical state" which is essentially linked with, and therefore to a large extent determined by, the young age of the child. An illustration can be taken from vitamin D deficiency. A lack of vitamin D in an adult causes osteomalacia, or softening of the bones; but in children, because the vitamin is particularly required by the growing bone ends, deficiency leads to rickets—a specific disease of children. In the same way stress which might be resisted or pass unnoticed in an older child results in autism in the still developing infant.
- 2. The probability that this "clinical state" can occur from birth (Kanner syndrome), but it may also develop up till the age of thirty months (the developing period) in association with other conditions, and following various precipitating causes.
- 3. The difficulty of early diagnosis.
- 4. The importance of the mother/child relationship and indeed of the total family dynamics in the origin and continuation of the autistic state.
- 5. The importance of the intellectual level, particularly from the point of view of treatment and eventual prognosis, but the realization that it is an incidental background feature on a different "axis".
- 6. The fact that although in many ways all autistic children resemble each other, thus constituting a syndrome or group, yet in other respects they differ in many significant particulars.
- 7. The vital importance of early treatment while the child is still developing.

#### APPENDIX 1

# COMMENTS AND QUESTIONS ABOUT THE WORKING PARTY REPORT FROM THE SEMINAR AUDIENCE

A summarized version of the proceedings of the Sandoz working party was given by Professor Katz for the benefit of the seminar audience, most of whom had not participated in the working party. Some of the comments and questions from the seminar audience which followed this are included in this appendix.

#### Comment

Autistic children are children with multiple handicaps, and in my view one of their handicaps is that of being regarded primarily as a psychiatric problem. I mean no disrespect to individual psychiatrists who are often doing a wonderful job with autistic children, but many of the psychiatric problems of autism are secondary ones arising from neglect of autism, rather than problems of a primary condition. If we can detect these children at a much younger age, then they may more appropriately come within the role of the paediatrician and the educational psychologist. Information desperately needs to be disseminated in the community, to the infant welfare sisters, the general practitioners, and paediatricians. If this is done it may be that many of these children perhaps will not need to reach psychiatrists at all in the future.

#### Answering comment

Certainly there must be more dissemination of information amongst nurses, as well as physicians and paediatricians, because nurses are now much more equipped to pick up this condition than most general practitioners or paediatricans. Assessing what is going on in a family system is another aspect and this is where your psychiatrist should come in. I think the desirable situation is one in which people work as a team, in terms of training and talent.

#### Question

Was there any discussion in the working party about the relationship between mental retardation, whether primary or secondary, and early childhood psychosis?

### Answer

Yes, a good deal was discussed as to the relevance of "scatter", and of significant intellectual difficulties in these children. The question of "primary" and "secondary" retardation was one about which we reached no conclusion. I think it was accepted that there may be a core of psychotic children who show oscillations in intellectual capacity, and this may be up as well as down, but mostly down, and there would be areas of specific intellectual achievement in psychotic children who otherwise show mental retardation.

#### Question

Did the working party throw out the idea of a primary "Kanner syndrome"?

#### Answer

It depends on whether you are looking at individual symptoms and rating them, or whether you are looking at the patterns of symptoms which exist in these children, and I think that this seems to be a very critical area of future research. Perhaps if we could get the patterns as well as the ratings of different symptoms then we might indeed find that a Kanner syndrome does exist, and that other more global syndromes also exist. But in order to answer this question there is a need for increased interdisciplinary cooperation and particularly a biochemical approach to the study.

# Comment

Very intensive study should be undertaken not only on the mother/child interaction in normal development, but on the perceptual responsiveness and motor behaviour of normal children. We could then compare the normal children with other children. The child "at risk" is at risk for a lot of things.

# Question

Do autistic children babble in the first year?

# Answer

The child, in the first twelve months, does not appear to go through the normal stage of pre-speech development.

# Question

It has been observed that some abnormality of histidine metabolism may produce non-talking children. Have any biochemical investigations been done with autistic children? If so, have there been any significant results?

# Answer

Routine biochemical tests are all normal in autistic children except for the occasional association with P.K.U. It has been found that extracts from serum of psychotic children produce convulsions in rats whereas the same extracts from the serum of normal children did not do so. I think the significance of this is highly doubtful. Most of the studies, and also the biochemical studies of schizophrenia, are very open to question. The environmental variables, such as long institutionalization, or the kind of diet the individual is on, may be factors influencing the results. One thing that we do know is that the chromosomes are normal in autistic children.

# APPENDIX 2

# UNIVERSITY OF QUEENSLAND DEPARTMENT OF CHILD HEALTH: MAJOR MANIFESTATIONS OF INFANTILE AUTISM

# Note:---

- 1. For the diagnosis of Infantile Autism or Autistic symptoms to be considered, a child should have at least 7/14 of these manifestations.
- 2. The child's original symptoms should have presented within the first three years of life.
- 3. Normal children do all the things listed here at certain stages of development; autistic children do them constantly and at an inappropriate age.
- 4. This is a screening test only and should be used in conjunction with clinical and family history, full examination including I.Q. assessment, E.E.G., and urine aminoacids.

- 1. Great difficulty in mixing and playing with other children.
- 2. Acts as deaf. No reaction to speech or noise.
- 3. Strong resistance to any learning, either new behaviour or new skills.
- 4. Lack of fear about realistic dangers, e.g. may play with fire, climb dangerous heights, run into busy road or into the sea.
- 5. Resists change in routine. Change in the smallest thing may result in acute, excessive or seemingly illogical anxiety, e.g. child rejects new or all but a few foods.
- 6. Prefers to indicate needs by gestures. Speech may or may not be present.
- 7. Laughing and giggling for no apparent reason.
- 8. Not cuddly as a baby. Either holds himself still or clings limply.
- 9. Marked physical overactivity. Child may wake and play for hours in the night and yet be full of energy the next day.
- 10. No eye contact. Persistent tendency to look past or turn away from people especially when spoken to.
- 11. Unusual attachment to a particular object or objects. Easily preoccupied with details or special features of this object, and has no regard for its real use.
- 12. *Spins objects* especially round ones. Can become totally absorbed in this activity and distressed if interrupted.
- 13. Repetitive and sustained odd play, e.g. flicking pieces of string, rattling stones in a tin, tearing paper.
- 14. *Standoffish manner*. Communicates very little with other people. Uses them as objects rather than people.

# APPENDIX 3

# DISCUSSION ON PAPER ENTITLED "THE DIAGNOSIS OF INFANTILE AUTISM"\*

# Question

This original pro forma was used by mothers; my problem is understanding how the resulting 14 point major manifestations [Appendix 2] can be translated into an instrument for use by a skilled observer. It seems to me to be uncommonly useful as a screening instrument at perhaps the first level with the mother herself, but there seems perhaps to be a major fallacy in a doctor or a nurse using this as a diagnostic instrument.

#### Answer

We were initially only interested in getting the mother's perception of the child, and that is why we used mothers as the source of data collection in all of the groups. But I think it can be taken a bit further. As long as the doctor—a G.P. for instance is aware that this is only a rough screening test I think it can be used to make an original, presumptive diagnosis, to alert the doctor to the possibility that this is not, on the one hand, merely a case of mental retardation, or on the other hand, a child who "will grow out of it". If the child does not score seven points this obviously does not mean he is sent home with a pat on the head. Other conditions need to be considered.

<sup>\*</sup>Subsequently published in Developmental Medicine and Child Neurology 2 (August 1969): 432-42.

## Question

Was there any provision made for scaling these questions in terms of the degree of reaction, for example not cuddly sometimes, not cuddly always, always cuddly?

## Answer

We kept to the very crude yes or no answers, meaning that we just wanted to know whether the child showed that behaviour at all, to discover whether there is an autistic behaviour pattern which is separate from other disease entities. We realized then that the next step would be to do a cumulative analysis of it, but we didn't attempt that at this stage.

#### Question

Has the order of the fourteen points any significance?

#### Answer

No, almost certainly not with regard to frequency in a population of autistic children. For example, the last point, "standoffish manner", is probably the most significant. The order did however have significance with regard to the original computer analysis and it was for this reason it had to be recorded as such.

#### Question

Have you found that the way that children score on the fourteen points changes with time?

#### Answer

Yes, particularly in relation to treatment—the child scores fewer and fewer points. Take the "acts as deaf" point for example. Children who are well treated, in time, don't act as deaf in the slightest degree. But using the pro forma as a continuing checklist is something to be cautioned against. It was intended to be the primary screening test that got the child to a specialist for further investigation and nothing more than that, so that it is only really diagnostically significant in relation to the behaviour at the time when it's being queried.