

## Chapter 2 - Approaching the Study of Autism

### 1. Levels of Approach

Before we can attempt to explain autism, there is much preliminary work that must be done. Needless to say, it is first necessary to get as precise an idea as possible of what autism is. Less obvious is the need to decide how to approach it. Autism can be studied on three different levels, *genetic*, *physiological* and *functional*. The lowest is the genetic level, identifying genes or combinations of genes that are associated with autism. A clear hereditary factor was already evident in early population studies. The incidence of autism was found to be higher among relatives, increasing with closeness of relationship, and highest in monozygotic twins. There was also found to be a higher incidence of mild autistic traits among relatives who were not autistic. Even among monozygotic twins, however, concurrence is not absolute. Sometimes one twin is autistic but not the other. Heredity has therefore long been known to be a factor, but not the only one. It could be hypothesised that there might be certain genetic compositions that invariably produce autism while others that produce only a disposition requiring other factors to actualise it. More recently, genetic studies have succeeded in identifying several markers associated with autism, and continued research promises to provide valuable information about the relative roles of heredity and development.

Above this is the physiological level, analysing abnormalities in structure and activity of the autistic brain. At one time it was believed that autism was caused by a specific physical anomaly. Years of research, however, failed to find one. In most cases the structure of the brain is normal, and the abnormalities that have been found have not been the same in all cases, nor have they been unique to autism. Furthermore, it is generally in cases where there is also mental handicap that structural abnormalities are found. It seems therefore that certain kinds of brain structure, in particular those that interfere with normal intelligence, may sometimes also cause autism, but that in most cases the cause is not structural.

However, even when brain structure is normal, brain activity may not be. It has been found that patterns of neural activity elicited by socially related stimuli such as looking at a human face tend to be different in autistic than in normal subjects. Such differences are found in both normal intelligence and mental handicap. These findings are not surprising. On the physiological level, *thought is brain activity*. To every thought or behaviour there corresponds a neural activity, and with the appropriate techniques some of those neural activities can be observed. When differences in behaviour indicate that a situation is experienced differently by different individuals, neural activity must differ too. Thus the brain patterns of a trained musician when playing or listening to a piece of music are not the same as those of an amateur. Since autistic people experience certain situations differently from normal ones, there must be differences in what their brains are doing.

The significance of these differences, however, is ambiguous. In particular, they cannot necessarily be taken as a support for the claim that abnormal thought or behaviour in autism is caused by an underlying innate neurological abnormality. It may well be, on the contrary, that the causal relationship is just the opposite. The observed abnormalities, whether in structure or activity, may have been caused by earlier thought and behaviour whose source was in the complex interaction of internal and external factors. The brain is a living organ and is therefore dynamic and plastic. Every thought and every action has an effect on the physical structure and chemistry of the brain. Although many of those effects are only

temporary, some, especially the effects of prolonged patterns of behaviour, produce permanent changes. So features such as size of areas of the brain and connections between them, as well as patterns of chemical activity, cannot be assumed to have preceded autistic behaviour.

It must be remembered that examinations of the brain are never performed until autistic traits have been present in behaviour long enough and at sufficiently serious levels for parents, teachers and physicians to consider such examinations necessary. By then the child has already been living in an autistic mode for some time, which has certainly altered the brain in certain ways. It is therefore possible that both physical structure and patterns of neural activity were originally normal, and that it was the autistic pattern of behaviour that caused abnormal development resulting in the abnormalities that are now observed. So, while understanding the physiological level can be very valuable, care must be taken in interpreting physiological evidence.

Above these is the functional level, analysing thought and behaviour. This level has a special position relative to the others, because this is the level at which autism was originally identified, at which it is diagnosed, and indeed, at which it is defined. A person is autistic not because he has a particular gene or brain anomaly, but because he behaves and thinks a certain way. Had a unique genetic or physiological cause been found, as was once hoped, it might have replaced the original definition by providing a simpler and more precise one. The situation would then have been similar to that of an infectious disease, which is first defined by symptoms, and later, when the microorganism or virus which causes it is found, is redefined in terms of its presence. After that, even if the symptoms in a particular case are not entirely typical, a definite diagnosis can be made. In autism, however, no such redefinition is possible. Autism is not comparable to measles, which is caused by a unique virus, but to blindness and paralysis, for which there are a variety of causes, all having nonetheless the same results. It is therefore ultimately to the functional level, the level of behaviour and thought, that all research must turn. Even though the functional level is the most complex and confusing, it is this level that provides the context for all other research. All research must begin on this level and ultimately return to it. Studies of genetic markers and brain activity must begin with the identification, by means of characteristic behaviour, of some subjects as autistic and others as not, and the significance of subsequent discoveries on those levels lies in the explanations they provide for autistic behaviour and thought. Our analysis will therefore concentrate on the functional level, especially seeking to understand the relationships between the various traits both in the dynamics of the syndrome and in its development. Into the framework thus constructed, research on the other levels can then be integrated.

## 2. Defining Autism

Formulating a good definition can be critical for solving a problem. The right definition alone can sometimes solve the problem by casting it in such a way that leads one effortlessly to the solution, while the wrong definition can obscure the solution and lead farther away from it. One source of difficulty in understanding autism has been the confusion between *definition* and *criteria of diagnosis*. Formulating a definition that identifies the essence of autism is very different from laying down guidelines for determining whether a particular individual is autistic or not. Criteria of diagnosis need not identify the essence of a condition as long as they accurately identify those who have it. The definition, on the other hand, describes the condition itself. Anything that does not belong to the essence of the condition, even if it is invariably associated with it, is not part of the definition. What, then, is the essence of autism? How is

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it possible to determine which of the many diverse qualities and traits associated with autism are essential parts of the syndrome and which are not?

This problem is complicated further by the wide range of subtypes within autism. If all indeed share the same fundamental condition, there must be a unique quality common to all that separates them from those who are not autistic. Before isolating this essential trait, we shall therefore briefly survey the different types of autism by dividing them into four main categories.

Kanner's original cases involved severe autistic traits but apparently normal or near-normal intelligence. They were children who interacted with inanimate objects and were able to develop dexterity and skills in those interactions, but ignored other human beings and seemed not to even be aware of them. Some never acquired language, others only after significant delay. Though some eventually functioned well enough to attend school, all remained aloof and separated from other human beings. Autism was therefore considered to involve feelings and emotions but not mental ability. Even those who did not actually achieve normal intelligence were nonetheless considered potentially capable of it. We shall use the expression "paradigm autism" to refer to this original concept.

As autism became better known after the publication of Kanner's first articles, it was recognised that the syndrome was not limited to those of normal intelligence. There were also some mentally handicapped children who failed to interact normally with other humans. Thus a new category which we shall call "autism with mental handicap" was recognised. Autistic children with mental handicap are a minority within the totality of mentally handicapped children. Most mentally handicapped children do interact socially within the limitations of their intelligence. However, autistic children who are mentally handicapped outnumber those of normal intelligence, so the recognition of this category radically changed the concept of autism. Those with paradigm autism were now seen to be a minority, and some connection between autism and mental handicap, though not an absolute one, was implied.

Within the intersection of autism and mental handicap there are several significant subdivisions. The first, closest to paradigm autism is, "autism with mild or moderate mental handicap". These are children who do acquire language, even if later than normal, and are able to learn both practical skills and academic subjects to varying degrees. Some of Kanner's original subjects were in this category. The autistic traits in this category are similar to those in paradigm autism, as will be discussed in later chapters, so there is no reason to doubt that they are variations of the same syndrome. Together, paradigm autism and autism with mild or moderate mental handicap comprise a continuum in which there is a range of intelligence.

Beyond the extremes of that continuum lie conditions that differ so significantly that it is questionable whether they really belong to the same syndrome. At one end is the category of "autism with severe mental handicap", in which there is little or no language comprehension and learning is, at best, limited to training in simple physical skills such as getting dressed or riding a tricycle. The skilful interaction with physical objects characteristic of the other categories is lacking here, and many of the traits that will be described in the following chapters are necessarily precluded. The strong similarity in their behaviour toward human beings, however, suggests that they are indeed an extension of the continuum. If so, at this extreme autism and mental handicap converge. Children who are severely mentally handicapped cannot interact with other human beings in any meaningful way, so they will necessarily be autistic as well. However, since the range of their activity is more limited, the nature of their autism is different from that of the first two categories.

At the opposite extreme is Asperger Syndrome. In Asperger Syndrome, intelligence ranges from

normal and even superior to mild mental handicap. Autistic traits tend to be less severe. Although there is some disagreement concerning the exact definition of Asperger Syndrome, it is generally agreed that it precludes delay in language acquisition. Nonetheless, while language development is not delayed and indeed sometimes even precocious, it tends to be abnormal in typically autistic ways, as we shall see in later chapters. In most other ways, however, Asperger Syndrome resembles paradigm autism.

These four categories cover the wide range of variety within autism and are sufficient to demonstrate the problem of identifying them all as belonging to the same syndrome. In the next chapter we shall discuss many of the traits of autism, and show how, in spite of their differences, there are several clear fundamental similarities that justify that identification. Now, however, we shall focus on the single most important trait shared by all, on which we shall base our definition.

## 2.1 Autistic Aloneness

Central to autism is *abnormality in relating to other human beings*. Specifically, it is abnormality in the direction of *lack of contact, lack of communication, and lack of understanding*. This last includes both general lack of understanding of the nature of human beings and specific inability to understand other individuals. To a greater or lesser degree, the autistic person is isolated, alone in his own world. The world of those around him is an alien, unknown territory. Throughout the many different varieties of autism, this isolation is consistently present, even though it varies both in intensity and in the way it is manifest. In severe autism it is part of a broader isolation from everything outside of themselves, an inability to interact meaningfully even with the physical world. In moderate autism, such as paradigm autism and autism with mild mental handicap, it is limited to isolation from other human beings. Specific human modes of interaction are impaired, but not purely physical interaction. In mild autism, even ability to interact with human beings is not entirely lacking but only partially compromised. Nonetheless, in some ways even those who are only mildly autistic remain profoundly isolated. They lack the sense of togetherness, of being connected to other human beings, the recognition that “I understand you and you understand me; I know that you understand me, and you know that I understand you.” Even when they cooperate and participate in activities together with others they lack this mutual understanding. Though they may be doing the same thing at the same time, they are not coordinated with them. They may or may not be aware of this separation, but even when they themselves are not, it is generally obvious to the others.

This isolation is sometimes referred to as “autistic aloneness”, a term already found in the earliest descriptions of autism. To anyone familiar with autism the meaning of this term is immediately clear, so there is rarely any attempt to define it precisely. Here, however, we shall make no such assumption. Even the most obvious must be explicitly analysed and defined. The essence of autistic aloneness is that the autistic individual’s actions are not *coordinated* with those of other human beings. Lack of coordination is most extreme and therefore most obvious in small children and in those who are mentally impaired. They show little or no awareness of other human beings and do not interact with them in any meaningful ways. In intelligent autistic adults and in older children who are only mildly autistic, on the other hand, it may not be readily apparent. In most day-to-day situations they are able to get along normally with other people, behave more or less as others do, and seem to be part of the social group. Only those familiar with autism are able to detect subtle manifestations of lack of normal coordination. It is in new and unusual situations that their lack of coordination becomes evident. While most people are able to transfer and

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modify the social skills they already have in familiar situations to the new one, the autistic person may find himself completely lost. Such unexpected lapses reveal that despite otherwise normal behaviour, a certain underlying coordination is still lacking.

Coordination plays a particularly important role in providing a foundation for communication. When in common speech we refer to people as being “in tune” with one another, we mean that they are coordinated with others in their social group. They share certain basic attitudes, views of the world, and modes of conduct. They are therefore able to understand one another even when they do not express themselves clearly and precisely. To the extent that an autistic person is not coordinated with others, he may fail to understand them or to make himself understood by them. He lacks these extra-linguistic factors of communication, so even if his comprehension and use of language are normal, there are occasional misunderstandings of sorts that normal people would never commit.

Among the most prevalent and obvious indications of lack of coordination in intelligent autistic adults is failure to maintain normal eye contact. After language, eye contact is one of the main ways that human beings coordinate with one another. By looking at another person’s eyes one can tell whether or not that person is looking at him. When he is, both know that they are looking at each other and each knows that the other knows that too. Eye signals are therefore a natural way of achieving basic coordination of action. They can be used in conversation to show that one person has understood the other or that he invites the other to speak. But expression of the eyes has developed to serve much more complex functions than regulating turn-taking. It has become a powerful mode of communication of feeling and attitude toward one another, including, though not limited to, coordination of moment-to-moment behaviour during social interactions by enabling each participant to finely adjust his own actions to the changing feelings of the other. When an autistic person fails to look at the other person’s eyes, or looks at them but does not respond to the other person’s eye-expressions and eye-messages with his own, it is clear that this dimension of coordination is missing.

Failure to modulate voice appropriately, which is also common in autism, has similar implications, because tone of voice, too, is an important vehicle for communicating emotion and therefore for emotional coordination.

Another way in which autistic aloneness is often manifest is lack of desire for the company of others. Some autistic people are aware of others and understand them, but prefer to be by themselves. They do not derive pleasure from the company of others or from sharing their feelings with them. Some find it uncomfortable to be in the presence of other human beings or to have to interact with them in any way. Others, while not finding social interaction disagreeable, prefer their own private interests. Eccentricity, which is characteristic of intelligent autistic adults, is a form of autistic aloneness. Sharing the interests and preferences of the group is in itself a kind of coordination. To the extent that the eccentric person, whether autistic or not, does not, he lacks a certain coordination with the others around him. Normally this is confined to limited areas, but in autistic aloneness it is part of a general lack of coordination.

Autistic aloneness is recognisably different from normal shyness. There are people who are shy or uncomfortable with others, yet are not autistic. Though, like those who are autistic, they do not develop normal peer relationships and do not engage normally in social interactions, when they do interact, their actions are coordinated with those of the others. They have the normal sort of understanding of human nature and of the culture within which they live, and know and understand the individuals in their lives the way most other people do. And, unlike those who are autistic, their own behaviour, other than their shyness, is similar to others in their social group. They are rarely eccentric, and their likes and dislikes are

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similar to those of others. Shyness and autistic aloneness are therefore separate and independent of one another. Indeed, some who are autistic are not shy at all. They crave human contact and want to interact with others, yet when they do, they are unable to coordinate with them, and therefore to establish a relationship of mutual understanding.

Autistic aloneness is not a superficial trait. It is a deep, fundamental aspect of an individual's personality, the effects of which are felt throughout his thought and life activities. That this characteristic is shared by all the diverse kinds of autism, including those in which autistic characteristics are too mild to produce any appreciable handicap, is extremely significant. It is this similarity and, by contrast, the dissimilarity from other syndromes, that makes autism a distinct condition. We shall therefore use autistic aloneness as the definition of autism.

For those who are familiar with autism and have worked with a broad autistic population, it is clear that this definition captures the essence of the syndrome. Most current definitions, however, make little mention of autistic aloneness. That is because they have been formulated for the purpose of providing diagnostic criteria, so they concentrate instead on more readily observable and quantifiable traits. But here, since our goal is not to diagnose autism but to understand it, autistic aloneness is presented first and its special significance emphasised. This definition will then serve as a context into which to put the many other associated traits that we shall discuss in the next chapter.

The identification of autistic aloneness as the defining characteristic of autism, and the further identification of lack of coordination with other human beings as the essence of autistic aloneness, should not, however, be mistaken for an explanation of autism. In itself, it is only an observation. It tells what autism is, but explains neither its cause nor the correlation of the various traits. It is the essence of the observed syndrome, not of the underlying condition.

### 2.2 Dimensions within the Definition

In this and the preceding chapter, we have begun to see three axes within autism. The first is *severity*. At one extreme are those who are unquestionably severely autistic, who do not interact at all with other human beings. At the other are those who, while they lack the normal degree of coordination with others, are sufficiently coordinated to be able to function in society. Between these extremes is a continuum. The continuum of severity involves two closely related factors, what *part of the external world* is affected, and what *kinds of interaction* are impaired. The most severe autism involves interaction not only with human beings but with the entire physical world, and affects all kinds of interaction. The mildest involves only human beings, and the kinds of interaction involved and the extent to which they are impaired is limited. We shall refrain from attempting to impose precise divisions on this continuum, which would imply clear distinctions that do not really exist, and instead use vague yet meaningful terms such as “mild”, “moderate” and “severe”.

The second axis is *intelligence*. Intelligence is evaluated by ability in areas other than social interaction. Here too there is a continuum ranging from severe mental handicap to genius. Like severity of autism, we shall divide severity of mental handicap into “mild”, “moderate” and “severe”, above which we shall speak of “normal” and “superior” intelligence. Here too, although there are no clear borderlines, we shall see that differences in intelligence give rise to significant qualitative differences in the nature of autistic traits.

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Third is the axis of *language*. Unlike the others, this is not a continuum. We can identify at least four distinct categories: Asperger Syndrome, in which language development is more or less normal, delayed language acquisition culminating in normal language, delayed language acquisition culminating in imperfect language, and complete lack of functional language. Though there is some correlation between this axis and the other two, it is nonetheless independent.

It has become a common practice to divide autism into two categories, “high-functioning” and “low-functioning”. For several reasons we shall avoid using these terms. First, they confuse severity of autism with intelligence. While they appear to refer to severity, they are in fact defined by IQ, the division between them being at about 70. Second, each includes a wide range both of intelligence and severity of autism, within which there are highly significant qualitative divisions that should not be overlooked. An intelligent autistic scientist (IQ 150) and a mildly retarded autistic dishwasher (IQ 75) are both “high-functioning”, although they are radically different from one another. A classification that places both in the same category tells us very little. Third, the word “functioning” implies that the underlying conditions are the same, and that the difference is only how they actually function. Such an expression would be appropriate in comparing two totally blind people, one of whom is a lawyer and the other a beggar, but that is not the case here. Different kinds of autism are fundamentally different conditions, and some involve more severe handicaps than others. Their inclusion as belonging to the same syndrome is based not on the similarity of the underlying conditions, but the deep similarity of autistic aloneness.

### **3. Questions**

There have been several pivotal questions in the study of autism. Decades of research have already answered two of them. The first was whether all cases of autism are derived from the same underlying cause, or whether there is more than one underlying condition that can cause autism. It has now been established that the cause is not the same in all cases. The second was whether autism is a psychological or biological condition. It has long been established that in all cases, the primary cause is in some way biological, never an emotional disturbance. As we saw in the end of the preceding chapter, the questions that divide current theories of autism involve whether the primary cause is cognitive or affective, and whether it is global or domain-specific.

In the coming chapters we shall present a different explanation. To arrive at it, we shall begin by identifying and analysing the behavioural and cognitive characteristics that comprise the syndrome. Then we shall consider possible relationships between them, including the question of which are primary and which secondary. We shall try to understand how the autistic person thinks, how his thought processes develop, and how these processes and their development differ from those of normal children and adults. This will bring us to a re-examination of the concept of intelligence itself and of its development, to which we shall devote several chapters. The explanation we shall eventually construct will contribute to our understanding not only of autism, but of normal cognition as well.