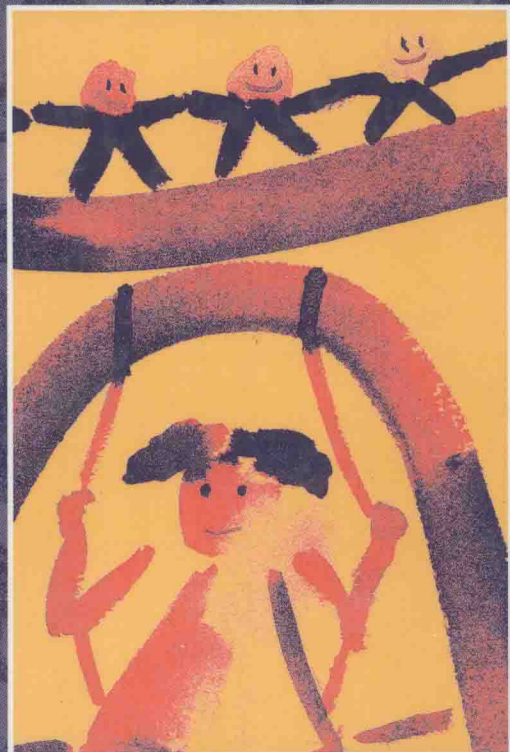




Understanding and Teaching Children with Autism

Rita Jordan
&
Stuart Powell



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RITA JORDAN AND STUART POWELL

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Preface

This book aims to help all those concerned with the education and welfare of children with autism to understand their charges better and thereby to provide more effectively for their education. We talk about ‘children’ but we accept that autism is a lifelong condition that will require special care and consideration into adulthood. Some of the suggestions in this book, then, will be applicable across the age range even though our focus is clearly on children. Early intervention is advantageous but it is never too late to improve quality of life through greater understanding of individuals with autism and more effective ways of meeting their needs.

We are not claiming to offer a ‘miracle cure’ for autism but there is evidence to suggest that education can be effective, not only in ameliorating the symptoms of autism, but in tackling some of the fundamental learning difficulties involved. This book, then, offers hope but makes no false promises. Although this is a very exciting time for research into autism, in terms of understanding both its biology and its psychology, at the time of writing there is no known cure. It is important then to be clear about the sense in which one can ‘accept’ this situation. We think that those working with individuals with autism need to respect the way in which such individuals think and learn. But at the same time it is possible to want to work within the context of the autism to make that thinking and learning more effective.

Autism involves distinctive ways of thinking about the world which lead to particular ways of behaving. Temple Grandin is a very able individual with autism who is very successful as an academic, as a professional designer, and as a business woman; she leads a full life and lectures at conferences around the world.¹⁰ Yet she is still very much aware of thinking and perceiving in a different way to others and says she is glad to be ‘autistic’ because of the strengths as well as the limitations it brings. Most parents and professionals will find it hard to accept this entirely, and indeed for the majority of individuals with autism additional learning difficulties will make the ‘strengths’ of autism less evident and the limitations difficult to overcome. Nevertheless, professionals and parents need to understand those ways of thinking and learning as best they can; they need to work within the context of the autism and work with the autism itself.

It should be noted here that we can only describe autism from our own

non-autistic perspective. We tend to interpret in terms of what it would be like *for us* to be without certain understandings (e.g. the lack of an ability to understand the intentions of others). This is necessarily a limited perspective and remains so in that we cannot experience from the inside how the world appears to the individual with autism. The closest we can get, perhaps, is by listening to the description of those like Temple Grandin who can tell us something of what it is like to be autistic. But even here there is a limitation in that such individuals are exceptional and in any case they learn to use terms in such a way as to make it easier for the non-autistic to understand.

We nevertheless believe that effective education must be based on the understandings that we do have and not on following some prescriptive 'recipe' approach. We cannot say 'Do this and all will be well', but we can show how to make sense of what the child with autism does and how to build a teaching approach based on this understanding. When we talk about children with autism it is important to recognise that there will be a range of individual differences across a range of dimensions. No two children with autism will think or behave in the same way. In short, each child is very much an individual, and will respond to the autism in his/her own way. Nevertheless, there is enough known about the general ways of thinking in autism to allow some generalisations to be made and this book is based on notions of ways of responding to a particular [autistic] kind of thinking and learning.

In coming to the ideas that are presented in this book we have taken on board the work of people such as Simon Baron-Cohen² and Uta Frith³ and their important and far reaching 'discovery' that individuals with autism have particular difficulty in understanding mental states—their own or those of others. It is not just that they do not understand *what* others are thinking and feeling (which is apparent as lack of empathy) but that they do not even understand *that* they themselves, or others, are thinking and feeling at all. This is an important finding in that it helps to make sense of the thread that runs through much of the pattern of autistic thinking, as will be apparent in later chapters. We should stress that we are not claiming that individuals with autism do *not* think or feel, but that they may not be aware of themselves (or others) doing so.

Perhaps it is important to note here that the most fundamental difficulty arising from this 'deficit' is that people in general become unpredictable. Those of us who are not autistic base our understanding of others and what they are likely to do, not so much on what they have done before, which only works for very limited and structured situations, but on what we *think* they are feeling, wanting and believing. It is very much a matter of us continually interpreting the intentions of others, and it is this process which is at the heart of social interactions and which enables us to function more or less successfully within ever changing social environments. Variation in success

for an individual relates substantially to familiarity with social context. One only has to think of how difficult it can be in an unfamiliar social milieu to recognise the social signals, let alone make appropriate responses. Again, to use our non-autistic perspective to interpret the nature of the autistic 'problem', it seems likely that without social understanding, people would appear to be behaving unpredictably and that this would make social contexts and the people within them confusing, possibly stressful, and even frightening. We begin, then, to come closer to an explanation for the social difficulties in autism and it is also possible to see how the theories mentioned above provide more specific predictions of the kinds of difficulties to be found in communication and some of the features of rigidity in thinking and behaviour.

However, even the original research by Baron-Cohen and others showed that a proportion of individuals with autism are able to pass what have been called 'theory of mind' tests, demonstrating some understanding of mental states.² Yet the actual behaviour of such individuals in social situations is still 'autistic' and their generally more effective functioning might be attributable to their higher level of intelligence (for it is usually the more able individuals with autism who pass such tests) rather than their performance on 'theory of mind' tasks. Also, the tests that are used tap into a high level of understanding about mental states demonstrated by understanding of false beliefs and this level of understanding is not apparent in normally developing children until four years of age. Clearly, children with autism develop very differently from normally developing children up to the age of four years so the differences cannot reside fully in a lack of a 'theory of mind'. It may be, as the authors of such theories propose, that the difficulties lie in precursors to the theory of mind but then their theoretical account becomes more like that of others who place the fundamental difficulty as occurring much earlier in development.

The significant 'other' here is Peter Hobson who, while not arguing with the research findings in developmental psychology on 'theory of mind' difficulties in autism, reinterprets those findings in the light of his view that autism is a disturbance in intersubjectivity.¹¹ While this may seem to be a simple reworking of the accepted core deficits in autism, in fact, Hobson locates that disturbance as being at a level of affective relatedness to the world, leading not only to problems in direct social perception but also to problems in categorising and relating to the world in relation to the self. Here there are clear connections with what Frith has identified as a failure to search for coherence and with the notion that we develop in this book that there is, in autism, a failure to develop satisfactorily an 'experiencing self'. In essence, Hobson pushes the explanation of the source of the difficulty in autism beyond the perceptual to the experiential, stressing the importance of what he terms 'perceptually-anchored intersubjective communication'.

We are influenced in our own thoughts by his notion that a kind of affective co-ordination is critical for the sort of interpersonal engagement that is, in turn, so critical for social and intellectual development.

In this book we will argue for the importance of teachers understanding the nature of autism at the psychological level rather than just treating it at a behavioural level. It seems to us that the teacher needs to pay attention to the full range of developmental sequelae that follow from the deficit suggested by Hobson¹¹ and to develop teaching approaches and curricular content that address each of these areas. But the aim of such approaches should not be limited to teaching normal development in the form of an early developmental curriculum, since there is no reason to suppose that the child with autism is able to benefit from such an approach, beyond the mechanical rote learning of skills, which will be unrelated to understanding and therefore difficult to generalise or extend.

Rather, our interpretation of the pedagogy that follows from the ideas that we have put forward in this preface is that teachers of individuals with autism need to remain aware of all the areas of normal development that the child with autism will be unable to access via the normal affective, spontaneous, intuitional route and to use the route to which they *do* have access (i.e. the general cognitive route) to provide explicit teaching in those areas. The central thesis of this book is that when teaching pupils with autism one needs to recognise the real nature of the problem, since it affects understandings that are so much part of our non-autistic biological endowment that we are seldom aware of them as 'achievements' in any sense. This book will help the teacher to identify these teaching goals, and to develop ways of teaching them explicitly. It also recognises that many children with autism, especially those with additional learning difficulties, will not reach these levels of understanding, even with explicit and direct teaching. It will suggest compensatory strategies that can be taught to help the child move forward in his or her development in spite of those problems and to gain access to as full and meaningful a curriculum as possible.

We also suggest ways in which the environment can be structured to enable learning to occur in spite of the difficulties and to enhance the quality of life for the children both now and in the future. Learning to participate in a society that is to a large extent 'alien' to them is bound to be difficult and there are ethical issues about the degree to which education should insist on conformity. Teachers need to confront these issues and to ensure that what is taught is of benefit to the individual and not just to the particular situation (classroom, school, education system) in which the individual is placed. This book is about helping children to claim their rights to be treated with dignity as well as about meeting their special needs as we have defined them.

We would like to acknowledge our debt to the many staff, parents and children with autism with whom we have worked over the years. We cannot

acknowledge them all individually but we would like to make special mention of the staff and pupils of Radlett Lodge School where we have both worked for considerable periods. The book concerns our own interpretations and is largely based on our experiences but we owe much to the special expertise and inspiration of many colleagues and must make mention here of Wendy Brown, Margaret Golding and Katie Thomas.

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Introduction

THE AUTISTIC CONTINUUM AND SPECIAL EDUCATIONAL NEEDS

DIAGNOSTIC CRITERIA

In the early days of the general understanding of autism, there appeared lists of ‘points’ for the diagnosis of the condition, although it was often called ‘childhood schizophrenia’ at this stage. Sometimes these ‘points’ (referring to aspects of abnormal behaviour or development) were merely seen as descriptive, i.e. ‘salient features’, and so there was no clear prescription of which features had to be present in order to make the diagnosis of autism and which were merely features that frequently accompanied autism but were not essential criteria. Apart from misgivings about the nature of some of these points themselves, this also led to the confusing and unacceptable situation whereby two children might be diagnosed as autistic and yet not have a single ‘defining feature’ in common.

THE TRIAD OF IMPAIRMENTS

There are difficulties in defining autism as a syndrome, because of other developmental problems that often accompany it. Kanner had originally supposed that all children with autism were fundamentally intelligent and that apparent delays in development were a direct result of the autistic condition.¹⁷ Sadly, this is one of the ‘facts’ about autism that Kanner got wrong and autistic individuals like ‘Rainman’ (the character in a well-known film) are very rare indeed, even within the population with autism. The majority of individuals with autism have additional learning difficulties, many of them severe. In fact, the more severe the general learning difficulties the more likely the individual is to have autism, although it becomes increasingly difficult to separate out the effects of autism from the effects of severe retardation.

Lorna Wing and Judy Gould, however, found that, even within populations with developmental difficulties, there were a cluster of features that provided diagnostic criteria for autism.³⁵ These are commonly referred to as Wing’s Triad of Impairments in Autism:³⁴

- 1 *Social*. Impaired, deviant and extremely delayed social development—especially interpersonal development.

This is on a continuum from those who might be regarded as classically autistic in that they are solitary and withdrawn, through those who will respond in a passive way when approached by others but will not initiate interaction, to those who appear ‘active but odd’ in that they seek attention but do not know how to deal with it. A child may begin at one end of this continuum as a classically withdrawn toddler and, through the course of development or through positive teaching, end as an ‘active but odd’ teenager.

- 2 *Language and Communication*. Impaired and deviant language and communication—verbal and non-verbal.

The range of spoken language difficulties associated with autism is wide. Again, there are extreme cases, where there are additional language and/or severe learning difficulties, where spoken language never develops. At the other extreme are children who have highly developed language skills in the sense that their grammar and pronunciation are excellent and they may have a special talent for learning foreign languages. Yet, regardless of the level of spoken language competence, there will be problems with all aspects of communication. There will be difficulties in understanding and using facial expressions, expressive gestures, body postures and positionings and (where there is spoken language) some problems with the meaning (semantic aspects) and pragmatic aspects of language. Pragmatics relates to the social understanding and use of language and so it is communication rather than language itself that is affected in autism.

- 3 *Thought and Behaviour*. Rigidity of thought and behaviour and impoverished imagination.

Autism is characterised by ritualistic behaviour, reliance on routines, and extreme delay or absence of ‘pretend play’. As with so much in autism it is not so much that the child with autism cannot play in this way as that such play does not develop spontaneously and, when it is taught, it remains limited to the kinds of play that have been demonstrated; there is little or no creativity. Again, the more able individual with autism may display imagination, but it is also likely to be of a limited kind and there may be difficulty then in distinguishing imagination from reality. It is as if there is no basis for distinguishing mental images from images produced from perception of the environment.

For a diagnosis of autism to be justified then all of these behaviours should be out of keeping with the child’s mental age. Most people would also want to limit the diagnosis to conditions with an onset before 30 months of age, although Lorna Wing herself feels there may be cases of late onset autism

and this should be included in a broad view of the diagnosis of autism.

This triad of impairments form the basis of the diagnostic criteria used by the World Health Organisation (ICD-10)³⁶ and the American Psychiatric Association (DSM-IV).¹

THE CAUSES OF AUTISM

There is no space here to detail the exciting research that is currently underway into the causes of autism, but it is important to discuss the level at which one might talk about causes. And it is important to be clear that because there is not one single identifiable cause, nor ever likely to be so, this does not mean that there is no actual condition with which we can deal. Autism is more than a label attached to a range of symptoms—it is a diagnosis that helps to make sense of the defining features and explain why they co-occur. In order to form a syndrome, the defining features need to be pathological, or deviant from normal development, and reflect some underlying common cause, or at least a common pathway.

Thus, at the level of biology (just as with conditions like cerebral palsy) there may be a number of different ‘causes’ that lead to this particular dysfunction in the brain. We know that genetic factors play a part but are not the complete answer. There is work showing brain chemical abnormalities that may result from an inborn failure in enzyme production. Certain illnesses in the mother may have damaged the developing foetus or there may have been anoxia or damage at birth. The point is that all these different causes may have a common effect at the psychological level—resulting in the same psychological (in the sense of the functioning of the brain) deficit that defines autism. That in turn will lead to a range of behavioural symptoms that are linked by their dependence on that damaged psychological process.

We can see how this might work if we take Uta Frith’s view of autism⁹ and examine the kinds of behaviour we would predict resulting from such a deficit in understanding meaning and developing a theory of mind.

A failure to understand how others think and feel would lead to:

- A difficulty in predicting behaviour, perhaps leading to finding people aversive.
- A lack of empathy and poor emotional expression.
- No understanding of what others can be expected to know which in turn will make language pedantic or incomprehensible.
- No idea about affecting how others think or feel, leading to no conscience, no motivation to please, no communicative intent and a lack of spontaneity in interactions.
- No sharing of attention, leading to idiosyncratic reference.

- A lack of understanding of social conventions including conversational strategies. This in turn would lead to no signalling with the eyes, poor interaction, poor turn-taking and poor topic maintenance.

These difficulties will be explored later in the book and alternative 'explanations' will be offered in some cases. What this illustrates, however, is that diagnosis at the psychological level can offer a bridge between the possible biological causes which we are beginning to unravel and the actual behaviours upon which our diagnosis must be based. Without such a diagnosis we are left with a collection of symptoms with no rational explanation and we are left floundering when it comes to thinking about how such symptoms might best be treated or even eliminated.

THE CONTINUUM OF NEED

The triad of impairments characterising autism also apply to Asperger's syndrome (or the most able individuals with autism) and to those with profound and multiple learning difficulties in addition to autism. But the manifestations of each impairment will vary according to the general level of intelligence and the existence of any additional problems. Pupils with Asperger's syndrome, for example, do not suffer additional intellectual retardation although their 'autistic' characteristics do lead to particular kinds of learning difficulties. In the social area, they may fit anywhere along the continuum of 'withdrawn' to 'active but odd', although most pupils with Asperger's syndrome will initiate and want social contact, but lack the understanding and skills to carry it through successfully. The child with profound and multiple difficulties in addition to autism is likely to be at the other end of the social continuum, withdrawn into a self-stimulatory world, and attempts by others to intrude into this world may be met by aggression. It is also possible, however, to find children with profound learning difficulties and autism who do seek out others and approach them in primitive and bizarre ways, often related to proximal sensations of smelling, stroking or biting.

In the area of language and communication skills, the most apparent difference between the group with Asperger's syndrome and others with autism is the high degree of verbal behaviour, and indeed structural language skills may be an area of strength. We have recently come across a seven-year-old boy with Asperger's syndrome who had taught himself to speak four foreign languages from tape-book packages; he was able to generalise what he had learnt (i.e. he did not just repeat verbatim the exercises in the text he had learnt) so he had clearly mastered each language and not just a series of set phrases. However, communication remained a

fundamental problem as it does for all individuals with Asperger's syndrome. This young boy, for example, would suddenly decide to switch to another language in his mainstream playground and seemed to have no awareness that others would not be able to understand him.

The child with additional profound learning difficulties, however, is likely to be mute and sign language will prove almost as difficult to acquire. What little communication there is will be of the most basic kind, usually learnt responses to meet basic needs. Often it is the teacher or the carer who is putting all the effort into the communicative exchange, just as a parent does with a young baby. The child may scream or cry in response to his or her own needs (hunger, frustration, pain) but without any realisation of the effect on others, and it is the person who responds to that scream 'as if' it meant that the child wanted something out of reach who is interpreting the scream as having communicative intent.

The rigidity of thought and behaviour is still apparent in Asperger's syndrome although it will manifest itself in more complex ways than in the pupil with autism and additional learning difficulties. Obsessional interests are more a feature of Asperger's syndrome than simple repetitive actions or stereotypes, although these too may appear at times of stress. The more profound the additional learning difficulties, the more likely are stereotyped and self-stimulatory activities to occur and this is even more so when there are also sensory disabilities.

One further difference between pupils with Asperger's syndrome and those with more classical autism lies in motor development, the pupil with Asperger's syndrome being likely to be ill co-ordinated and often having delayed motor milestones. This applies to both gross and fine motor skills and the pupil with Asperger's syndrome may be described generally as 'clumsy'. This may have implications for some teaching approaches. It also has interesting connections with dyslexic-type problems which we will discuss later.

DIAGNOSIS AND SPECIAL EDUCATIONAL NEEDS

It is currently fashionable in education to decry the value of a diagnosis and to look at the pupil's interactions with his/her environment as a way of determining special educational needs; indeed there is a tendency to leave 'within-child' factors out of the equation altogether. We would argue, however, that an understanding of the fundamental difficulties faced by a pupil at the psychological level is crucial to developing a curriculum and a teaching approach that addresses that pupil's needs. Responding at the level of behaviour only, may lead to unhelpful or even damaging misinterpretations of the pupil's behaviour and a consequent failure to identify the true educational needs.

Education is a social activity and as such it is fraught with misunderstandings for the pupil with autism, but also for the teacher of such a pupil. Unless the teacher is aware of the difficulties engendered by autism, behaviour may be misinterpreted as rude or lazy and the child either labelled as having emotional and behavioural difficulties (if there are no general learning difficulties) or said to be unmotivated with a short concentration span, or labelled hyperactive and classed as having severe learning difficulties. Thus, a declared wish not to label a child because labels are stigmatising and lead to low expectations does not result in the child being label-free and the behaviour being dealt with in a value-free way. It is part of our human condition to categorise and interpret behaviour in order to make sense of it and a policy of no diagnosis may paradoxically lead to a situation where a child has a plethora of labels, each used to 'explain' some aspect of behaviour.

PROPOSITIONS UNDERLYING OUR UNDERSTANDING OF AUTISM

In this section we set out propositions which underpin our own understanding of autism. These propositions are rooted in the theoretical understandings described in the Preface, but we have taken things further in trying to formulate a conceptual framework which will not only be explanatory of autism but will also indicate a way forward in terms of education and care. We suggest that there are two key features of autistic thinking: firstly the way in which information is coded, stored and retrieved in memory, secondly the role of emotion in those processes.

MEMORY

One of the paradoxes of individuals with autism is their good, and in some cases prodigious, rote memory ability compared to deficits in their ability to recall personal events. That is, they may be able to recall all sorts of facts about the city they live in: the dates of its history, its population, its bus routes and so on but be unable to recall their walk through the city earlier in the same day. These kinds of memory problems have generally been attributed to problems in episodic recall (the recall of events) but we suggest that the problem lies not in episodic memory as such but in the '*personal episodic*' part of autobiographical memory (the memory concerned with ourselves).

Thus, the kind of difficulty we have in mind means that the individual with autism *would* be able to recall established facts about the city (because these are part of general *semantic* memory), general semantic/categorical knowledge (about cities in general) and procedural knowledge for skills (e.g. how to get around the city on buses). There should also be little difficulty