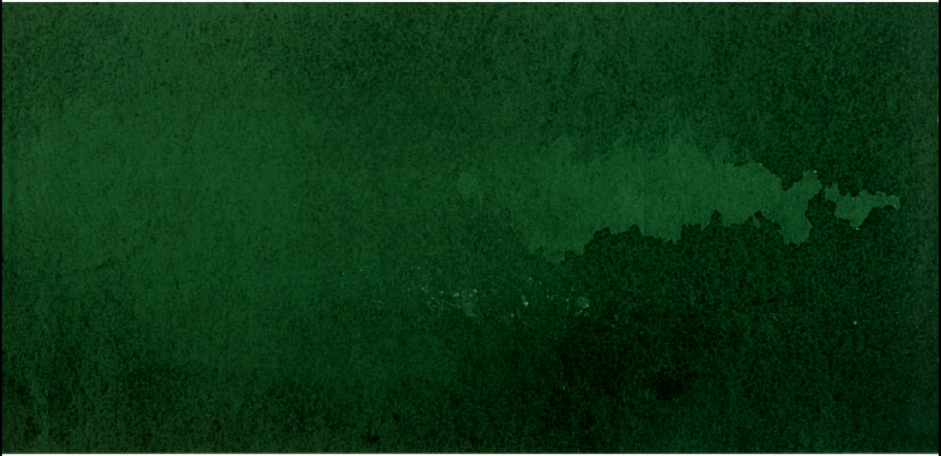
The Handbook of Autism

A Guide for Parents and Professionals

2nd Edition



Maureen Aarons and Tessa Gittens

THE HANDBOOK OF AUTISM
2nd Edition

Autism is a variable and complex developmental disorder which frequently goes unrecognised, or else is misunderstood by both parents and professionals. This new edition of *The Handbook of Autism* dispels many of the myths associated with this puzzling condition and brings up to date the relevant and practical information of the first edition.

The authors have worked with children with autism for twenty-five years and are convinced that parents have a right to know as much as possible about the condition. By clarifying the essential issues concerning the recognition of autism, their book permits parents and professionals to reach a better mutual understanding. It enables readers to understand autism in a wider perspective, both its history and current research into possible causes; it also looks at the latest thinking on diagnosis, management and education, and on medical aspects. The authors describe their developmental approach to the assessment of autism in individual children and explore areas of special difficulty, such as social understanding and communication. The case studies used to reflect the extent and variability of the condition have been updated and a revised appendix of useful addresses is included.

Essential reading for parents of autistic children, *The Handbook of Autism* will also be immensely helpful to all professionals, in training and in practice, involved in their education and welfare.

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2nd Edition

A guide for parents and professionals

Maureen Aarons and
Tessa Gittens

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CONTENTS

Authors' note vii
Foreword viii
Introduction xii

1 The variable picture of autism 1

2 The history of autism 5

3 What causes autism? 15

4 Problems of diagnosis 20

5 Understanding and assessing children with autism 29

6 Practical considerations – management and counselling 48

7 Speech and language: communication development in children with autism 63

8 Educating children with autism 76

9 Growing up – what lies beyond? 88

10 A Postscript – alternative treatments and cures for autism? 92

Appendix 1:
Case studies 100

A mother's story 124

Appendix 2:
Useful contacts and addresses 130

References and further reading 133
Index 137

AUTHOR'S NOTE

Please note that, for consistency of style, the pronoun 'he' is generally used throughout the book. The authors do not want to be considered sexist in their choice of the masculine pronoun, which was chosen because there is a marked predominance of male children with autism.

FOREWORD

Maureen Aarons and Tessa Gittens have long experience of working with children with disorders in the autistic continuum and their families. They understand the nature of autism and the distress caused to the parents by their children's developmental delays and strange behaviour. They recognise and empathise with the uncertainty and worry felt by parents before they know the reasons for their child's problems, and the shock and misery when they are told the diagnosis. They spell out clearly the long-term nature of the disabilities but they are equally clear that a great deal can be done by parents and professionals to help the children cope better with a world which they find so puzzling.

The authors give special attention to the problems of definition of autistic disorders and the need to recognise the underlying impairments in all the different ways whereby they can be manifested in overt behaviour. They also discuss the reluctance of some professional workers to use the word autism. Naming somehow gives substance and reality to previously vague fears. There is an episode in *Alice Through the Looking Glass* in which Alice enters the wood where things have no names. She meets a fawn and they walk through the wood side by side because neither knows who or what the other is. As they leave the wood, the fawn realises that it *is* a fawn and that Alice is a human being, so it darts away in alarm. When I was a child, I loved the drawing of Alice with her arm round the neck of the baby deer and felt very sad when reality spoilt the picture. As an adult and a parent, I experienced the same sad transition from ignorance to painful knowledge when our daughter's difficulties were identified and named as autism. For a time it seemed that the whole world had become grey and empty but we slowly picked up the pieces and sought for constructive ways to help our child and, in doing so, also helped ourselves.

In those days – the late 1950s – little was known about autism. In 1962 we joined with a small group of parents to become the founder members of the Society for Autistic Children, now called the National Autistic Society. We were full of determination and firmly believed that autistic children were not mentally retarded, and that their isolated, idiosyncratic abilities were the true indicators of their future potential. We did not believe the more guarded predictions of the few professionals who had had long experience in the field. We saw what some gifted teachers could achieve with some children. We did not recognise the difference between rote learning and true understanding, so we thought that appropriate education would cure all the problems and not just help to diminish them, as we know now. Because the concept of autism had been formulated only 20 years earlier, we did not know any parents of adults diagnosed as autistic who could tell us what the future might hold.

Now, as the authors describe, the situation is quite different. The National and Local Autistic Societies have many members with grown up sons and daughters. The parents of young children with autism have access to knowledge about the probable future that was denied to us founder members. It is clear that typical autism is just one sub-group in a continuum of disorders involving social and communication impairments that are lifelong in their effects, although they vary in their severity from profound to minimal and subtle but still detectable. Eventual outcome is determined more by the overall level of ability of the child than by any method of treatment. However, it is equally clear that, however severe the disabilities, a great deal can be done by parents and professional workers in collaboration to help make life more satisfying and pleasant for those affected. Furthermore, most families find that there are many compensations in the long run despite all the difficulties, not least a more realistic appreciation of what is important in life and what is trivial. Parents of all children enjoy seeing their child progress, but for parents of autistic children each small step in development brings a special pleasure.

However, as the authors warn, it takes time for the pain brought by knowledge to fade into a quiet sadness in the background and the development of an accepting but positive attitude. During this time, parents are vulnerable to all kinds of pressures, including promises of cures or, at the very least, major changes for the better, from those with a variety of different theories. For the founder members, very little was on offer; now there is a plethora of promises. There is also, of course, the desire to deny the diagnosis and to seek other explanations of the impairments of social interaction, communication and imagination with which professional workers sometimes collude. As I am a professional in the field as well as a parent, I know at first hand the emotional stress experienced by anyone who has to tell parents that their child is autistic. However many times you have had to do this, it becomes no easier. It is made even harder by the natural human tendency to blame the messenger for the message.

The vivid accounts of individual children in this book illustrate that all people with autistic disorders share the same underlying impairments, but that each child and his or her family is different. A professional worker, faced with breaking the news, must assess how much the parents know or suspect already and how much of the truth they can bear at any one time – no easy task. Diagnosis must include a detailed assessment of each child's pattern of skills and disabilities and the information explained to the parents in a way that is acceptable to them. It is absolutely necessary to be honest about the limitations of knowledge, to explain the pitfalls of diagnosis and assessment, and to allow for the possibility of a change of opinion as events unfold over the years. Ideally, there should be ample opportunity for return visits to discuss the diagnosis and its implications for the child concerned, and local support for the family should be arranged. In practice, there are constraints on the resources available. Nevertheless, I know from long experience that it is only when the truth is faced that healing of the emotional wounds can begin and constructive action planned and undertaken. Parents of older children and adults always say that, looking back, they would have wanted to be told the truth about their children as early as possible, however much this would have distressed them at the time. Of course, events always appear in a different light when viewed in retrospect.

The authors are clear-sighted, honest and positive in their approach. Their book is for parents, the great majority, who have the courage to emerge from the spurious comfort of the wood where things have no names and begin to take up the challenge. Their life will be different from how they had planned it but can be full of the satisfaction of difficulties overcome and the friendship, wherever they go in the world, of those who have lived through the same experience.

Addition to the original foreword

This most welcome second edition of the *Handbook of Autism* reflects the advances in knowledge since the first edition was written. Maureen Aarons and Tessa Gittens are closely involved in the field of autistic spectrum disorders and have followed, perceptively and critically, the changes and developments over recent years.

They emphasise particularly the importance of recognising the developmental impairments underlying autistic disorders in more able children, who have these conditions in subtle form. Despite the apparent mildness of their impairments, such children often suffer more personal distress than those who are too severely affected to be aware of their differences from their age peers. Recognising the nature of their problems can be a great relief and help for them and their parents.

The authors describe, clearly and simply, the widely varying manifestations of the autistic spectrum. As in the first edition, they give solid, practical advice on ways of helping the children. They retain their healthy, sensible scepticism about so-called therapies that promise miracles but have never been properly validated. At the same time, they understand the feelings of parents who clutch at straws in the hope of curing their children's disabilities. This book gives objective, factual information that can help parents make appropriate decisions concerning treatment and education.

It will be equally helpful for clinicians, of any of the professional disciplines, who see children with developmental delays and impairments, and who should always have in their minds, the question, 'Is this autism?'

Lorna Wing

INTRODUCTION

The first edition of *The Handbook of Autism* was written in 1992. Since that time, research has increased our understanding, not only of diagnostic issues but also of ways in which intervention can bring about changes and improvements in individual children. The concept of a spectrum of autistic disorders is now established, as is the variability of the condition. It is not simply a matter of political correctness to refer to 'children with autism', rather than 'autistic children', but a positive way of endorsing this variability.

The need for a second edition of this book became apparent as we became increasingly aware of many very able children and adults with autism, whose needs were not recognised because of their good cognitive skills and evident academic ability. We very much welcome the attention that these individuals are now beginning to receive, as so much can be done to help them and improve the quality of their lives, and those of their families.

The upsurge in numbers of children with autism which prompted us to write the first edition, has continued, if not increased. Debate about possible reasons for this increase persists. Could it be simply better recognition, or are there other possible causes? Suggestions such as environmental pollution, viruses, pre-natal scanning, immunisation, have all been considered as possible triggers for the condition. What we do know is that autism has a strong genetic component, and there are references to an 'autistic phenotype' in current research literature. Our own experience, over a period of twenty-five years, has led us to believe that while genetic factors predominate, there must be some interaction with other causes to account for the increase, which in our view cannot be accounted for simply by better diagnosis and acceptance of the wider parameters of the disorder. What was once considered to be a rare disorder now appears to be almost commonplace, and this has implications for intervention and education for this group of children. We are very aware that Health Trusts and Local Education Authorities, as well as Social Services, are all facing real problems in providing resources for both children and adults with autism, at a time when severe budget constraints are the norm.

There is a particular poignancy about the diagnosis of autism. Typically, these children look so attractive and normal that it is all too easy to ignore or dismiss the signs and symptoms and concentrate instead on the singular, often curious skills or islets of ability which the children frequently display. Our encounters with their parents had the effect of sharpening our understanding of what they were going through and our awareness of their needs. There was a remarkable consistency in the sort of questions that they asked, and the sort of information that they required as they attempted to come to terms with the complexities of the diagnosis. The realisation that the nature of their child's disability was more serious than they may have anticipated was the first reality to be faced. This dilemma was often exacerbated by the fact that professionals might have offered different explanations for the problems the child presented. Either the autism went unrecognised, and the parents were given unsubstantiated assurances that all would be well, or else they were made to feel that they had somehow mismanaged their child and were to blame for the evident problems. Misjudgement by inexperienced professionals was often compounded by the well-intentioned advice given by family friends and relatives. The most difficult situations existed when the parents themselves took opposing views.

In the last few years there has been a considerable increase in the numbers of books and articles about autism. These range from academic publications, to personal accounts written by able individuals with the disorder. There has been a positive change of direction in the way autism is presented, which is more representative of the variability of the condition. However, newspaper reports and television features still tend to promote miracle cures, which are good for media purposes but can be unsubstantiated and misleading. There are relatively few books written by those with 'hands on' experience of autism who are not researchers and who are not endorsing a particular intervention approach. While the National Autistic Society provides excellent information on a wide range of issues, we are very aware that for many parents even telephoning the society, never mind joining, implies an acceptance of the diagnosis which they are not ready to make. Parents in this situation need an honest, jargon free account of the condition so that they can decide for themselves if their child's difficulties make sense in the context of autism.

As with the original edition, the purpose of this book is to provide them, as well as other non-specialist readers, be they doctors, nursery nurses, playgroup leaders, psychologists, teachers, speech and language therapists, etc., with up-to-date information which covers such matters as diagnosis, research, management and education, as well as medical considerations in relation to autism. Whereas in the past autism was presented as a discrete condition – something enclosed in a circle with precise boundaries – it is now seen on a continuum – a line stretching from severely affected individuals to those whose difficulties are very mild and, indeed, fade into eccentric normality. For this reason, a diagnosis of autism need not inevitably imply doom and gloom. It is possible to be 'a little bit autistic', and some children make very good progress indeed. However, it must be pointed out that those who make the best progress do not have severe learning difficulties in conjunction with their autism.

Parents often feel that a diagnosis of autism has somehow been imposed on them, without regard to what this actually means. Conversely, when they suspect the presence of autism, yet fail to obtain a diagnosis, they find themselves in a state of limbo. Realistically, it is not possible for parents to get help, or even know what to ask for, if they are in a state of ignorance. They need to understand the implications involved in securing or not securing a diagnosis. We hope that this book will enable parents to clarify the issues and acquire enough knowledge to allow them to make informed choices in relation to their children's needs. This in turn should promote better understanding between them and the professionals with whom they come in contact. It is important for parents not to feel that the person offering the diagnosis is somehow 'the opposition', to be fought against and argued with. Of course we do not live in a perfect world, but there should be a feeling of partnership and shared objectives, as issues are explored and appropriate and acceptable action taken.

Most parents, when they learn that their child has autism, are anxious to help in a practical way. They abhor the feeling of helplessness when nothing seems to be happening and no specialised help and support is available. One of the aims of this book is to provide practical suggestions and advice, which we hope will go some way towards alleviating these feelings of frustration. We have included two appendices. The first consists of case histories, because we often find that parents better understand their child's difficulties if they see them mirrored in accounts of other children. The second aims to provide parents with general information and advice as well as some useful addresses. At the end of the book is a list of references and further reading.

As speech and language therapists, we are aware that it is the lack of development of language in children later diagnosed as having autism which causes most concern to parents. For this reason, we are often the first professionals to see young children with the condition. The expectation is that by some means we will provide them with meaningful language and all will be well. It is a heavy responsibility for the speech and language therapist to disappoint parents by demonstrating that their child's problems are more wide-ranging, and not confined to spoken language alone.

Our experience centres around *children* with autism. Although we include a chapter on autism in adolescents and adulthood (Chapter 9), in general their problems and needs are beyond the scope of this book.

We must not end this introduction without attempting to reach those parents who have been told that their child has autism, yet cannot accept it as an appropriate or justified diagnosis. They may feel that the very word has extreme associations and is a 'label' which can only have a negative effect on their child's future. It may be that this book has been picked up in the hope that autism can once and for all be excluded. Perhaps considerable anger is felt towards the professional who suggested the diagnosis. How was it possible to reach such a conclusion in what may have seemed such a very short time? Some parents may feel that the diagnosis was presented in the wrong way, or that, perversely, the professional's extensive knowledge of the condition predisposed their thinking. Others may feel that they inadvertently let their child down by disclosing developmental details which precipitated the diagnosis. It is not unknown for parents themselves to suggest a diagnosis of autism, yet when the professional confirms this, believing perhaps that the parents have come to terms with the notion, there may be unexpected repercussions. Confirmation of their own worst fears is the last thing they want to hear and their subsequent reactions may be no different from those of parents who are unaware of the nature of their child's difficulties.

By refusing to accept a diagnosis, parents are in danger of denying their child access to support and resources. The earlier a child's problems are recognised and identified, the sooner educational issues can be addressed. It is a fact that unless this is made explicit, support and/or funding will not be made available. The specificity of the problems inherent in autism opens doors which remain closed to those whose difficulties are described under the general heading of social and communication difficulties. These can be linked to other causes which do not have long-term implications. Parents should really do some heart searching before refusing the opportunities afforded by a diagnostic label.

1

THE VARIABLE PICTURE OF AUTISM

Until quite recently, autism, with its paradoxical signs and symptoms, was considered to be a rare condition. It had an aura of fascination – to such an extent that the majority of the population had a viewpoint about it without necessarily having had any direct experience of the condition.

Most people if asked What is autism?', are able to give an opinion covering a wide range of ideas:

> They're withdrawn . . . they can't communicate . . . they're very musical . . . they're very good at maths . . . they're brilliant at drawing . . . they're very clever . . . they're mentally handicapped.

These simplistic and disparate views reflect some of the variable aspects of the autistic spectrum which can occur in individuals. In order to illustrate this variability we shall describe three children. They are very different from each other, yet they all have autism. The common thread that links them will be explained in the following chapters.

> Lucy is an alert and very attractive nursery-age child who looks entirely normal. She is physically well co-ordinated and dances with pleasure and grace. Occasionally she will be seen to observe objects from odd angles and to lie on the floor in order to do this. Although she does not appear to seek out physical contact and cuddles, she shows no physical avoidance. Her eye contact, which was previously poor, would not now be regarded as abnormal and there is no gaze avoidance. Lucy's play seems well developed when first observed. She enjoys water and sand, spends time in the home

corner and is always busy and occupied. However, although her play appears purposeful and meaningful, it has a repetitive quality and shows no development. In addition, she does not draw other children into her activities. There is an aura of 'separateness' about her which singles her out from other children. Her attention is poor, unless it centres around her own interests. In self-care skills she is very capable and her cognitive abilities appear appropriate for her age. Evidently, Lucy has artistic abilities. Her painting is impressive, as is her modelling skill with plasticine, but both are repetitive. She shows great reluctance to extend her repertoire or to develop these skills as her capabilities suggest. Although Lucy's hearing is completely normal, she is very likely not to respond when her name is called or when she is spoken to. It is not possible to have a conversation with her and any attempts at a two-way dialogue meet with little success. However, Lucy talks a great deal, commenting on her own activities as well as making statements which, although perfectly articulated and grammatically complex, generally show little relevance to the situation. This feature is known as delayed echolalia: when phrases and sentences are repeated some time after they have been heard. Lucy did not acquire speech and language at the normal age, and for this reason was referred to speech and language therapy for assessment, where it was considered that she had an unusual disorder of language. It was not until she was over four years old that autism was diagnosed.

The second child, David, at 6 1/2 years of age, is also attractive. He is a smiling and happy child with a gaze that is often unfocused. His eye contact is fleeting, unless centred on objects that are of interest to him. These objects range from television and video screens, to insignificant details of pictures in books which he scrutinises with great pleasure. David's physical development appeared normal, although certain oddities such as tiptoe walking were observed when he was about three years old. He now appears physically immature. His habit of sucking his tongue, together with hands which are constantly writhing and flapping, presents a picture of oddity so that, in a group of normal children, he would stand out. In contrast to Lucy's indifference to physical contact, David seeks out cuddles from his mother and has to be dissuaded from touching and feeling any exposed female flesh, as well as from gazing with rapt attention at stockinged legs. Apart from the interests described, and some willingness to complete jigsaws, David willl not engage in any meaningful activities and could best be described as a 'loller', in contrast to Lucy's constant busyness. He shows no awareness of danger and, when taken to the park, is likely to 'do a runner' unless kept on a tight rein. Other inappropriate aspects of his development are a refusal to use a toilet standing up, and to eat only a very limited selection of food. When spoken to, David may or may not respond. Generally he does not use speech, although he is capable of producing words and phrases largely in response to his own needs. He is not interested in communication, but mutters and sometimes makes 'whooping' noises for no apparent reason. Occasionally short, inappropriate and meaningless phrases are uttered (for example, 'go on the District Line'), but these are rare and in no way compare with Lucy's expressive abilities. Coupled with this picture of deviant development and aberrant behaviour David's learning abilities (or cognitive skills) are very limited, and indeed do not differ from any child with severe learning difficulties.

Thomas's problems only emerged when he went to school, where difficult behaviour was ascribed to naughtiness. The situation was confused as he appeared to be an able boy with well-developed language skills. It was only after Thomas had been asked to leave two mainstream schools by the age of 6 years that a diagnosis of autism was suggested as a possible explanation for his difficulties. Once these difficulties were considered in the context of autism, many aspects of Thomas's developmental history made sense as part of an overall pattern of social impairments. Until this time, these aspects had been marginalised, possibly because he appeared to be so bright and communicative. However, with hindsight it was clear that it was not the presence or absence of particular behaviours and skills, but the *quality* of his social functioning. As a small child there was evidence of odd mannerisms, such as face and hair wiping, a range of sensory anomalies, difficulty in recognising people, poor sleeping and a liking for complicated routines. He was very physical, hugging and kissing with little discrimination. By 5 years he was bossy, demanding and argumentative, and drew no distinction between children and adults, especially those in authority, such as teachers. In their quest for a meaningful explanation for Thomas's problems, his parents had considered a range of other diagnoses and approaches. Attention deficit disorder, cranial osteopathy, sensory deficit

> disorder, family therapy, dyslexia, and migraine, among others. The diagnosis of autism enabled changes to be made in Thomas's management and schooling, which resulted in rapid and positive improvements, particularly in relation to behaviour.

Our descriptions of the distinctive characteristics of Lucy, David and Thomas illustrate the wide-ranging nature of the autistic spectrum. Although the diagnosis may explain the confusing patterns of developmental difficulties, all children with autism present in their own particular way. Indeed, they are as individual as socially normal children. Their different personalities, families, life experiences and the ways that they are managed all influence individual characteristics.

2

THE HISTORY OF AUTISM

In order to understand autism, it is necessary to look at it historically. The condition was first described by Kanner in 1943. He listed a number of features which, in theory, would identify children with this disorder. His use of the term 'autistic' caused some confusion right from the start because it had previously been used in connection with the withdrawal into fantasy seen in schizophrenia. At that time it appeared to afflict children of well-educated parents in the upper socio-economic classes, but this is now known to have reflected referral bias, rather than clinical fact.

It is worth listing these points, because they are still relevant and show the condition in its 'classic' form:

1. *An inability to develop relationships*
   This means that a child with autism will have difficulty interacting with people and is likely to show more interest in objects rather than other human beings.
2. *Delay in the acquisition of language*
   Although some children with autism do not develop meaningful speech, others do acquire language, but almost invariably it appears later than in children with normal development.
3. *Non-communicative use of spoken language after it develops*
   This describes a particular characteristic of children with autism. In spite of having adequate words at their disposal, they have difficulty in using them in meaningful communication.
4. *Delayed echolalia*
   This is the repetition of words and phrases, snatches of videos, songs or television jingles that the child has heard. This is very common in children with autism.

5. *Pronominal reversal*
   This means simply that the child substitutes 'you' for 'I'. For example: Parent: Do you want a biscuit? Child: You want a biscuit.
6. *Repetitive and stereotyped play*
   Typically, the play of children with autism is very limited. They tend to repeat the same activity and do not develop imaginative pretend play.
7. *Maintenance of sameness*
   This describes the insistence shown by many children with autism in resisting changes in their surroundings and daily lives.
8. *Good rote memory*
   Many children with autism show remarkable feats of memory and rote learning.
9. *Normal physical appearance*
   It was this last feature which encouraged Kanner to believe that children with autism invariably had normal intelligence. For many years this led both parents and professionals to have unrealistic expectations of outcome for every child with a diagnosis of autism.

Kanner later reduced these points to two essential features:

1. Maintenance of sameness in children's repetitive routines.
2. Extreme aloneness, with onset within the first two years.

This reduction caused even more confusion, as many children, while clearly showing a pattern of difficulties, did not fit these criteria which only identified cases of autism in its more classic form.

At about the same time, an Austrian psychiatrist, Hans Asperger, independently recognised a pattern of abnormal behaviour in a group of adolescents which he chose to call an 'autistic psychopathy' – that is, an abnormality of personality. As Asperger wrote in German during war years, his work, with detailed clinical descriptions, was less widely known, and not fully understood until the publication of *Autism and Asperger Syndrome,* edited by Uta Frith (1991). This includes a translation of Asperger's original paper, and clarifies at least some of the diagnostic issues. It would be reasonable to conclude that both Kanner and Asperger described aspects of the same condition. Digby Tantam, in his National Autistic Society publication, *A Mind of One's Own,* suggests that a sub-group exists of 'autistic people who are sociable, highly clumsy, verbally skilled and with highly developed special interests'. He uses the term 'Asperger Syndrome' to define individuals with this cluster of difficulties. In our experience, the label has come to be a useful shorthand for describing more able people with autism. However, debate continues about the existence of subtle distinctions between the two conditions.

Since that time, other researchers have listed their own criteria and for a number of years it was usual to diagnose autism by counting up a requisite number of points. The weakness of such a system must be obvious. A child could have eight features out of nine, and would be declared 'not autistic'. Not surprisingly this was not at all helpful for parents, who were then left in a state of limbo with little idea of what to do for the best, and the burden of making sense of a gamut of possible alternative diagnostic labels. However, in recent years, as researchers have gained a better understanding of the condition, a more common-sense approach has become established among clinicians with experience in the field of autism.

Sir Michael Rutter, Professor at the Institute of Psychiatry, has contributed considerably to the understanding of autism as well as language disability, and has led the way towards a more cohesive view of the condition. Although he too listed points, they were more broadly based. Rutter acknowledged variations in intelligence and suggested that IQ was as relevant to individuals with autism as to the rest of the population. This was important because it shifted the focus away from the assumption that children with autism were invariably of normal intelligence, which Kanner had suggested.

Dr Elizabeth Newson of Nottingham University enlarged on Rutter's criteria. Whereas he referred to 'delayed and deviant language development', she referred to 'impairment in all modes of communication', which included facial expression and gesture. Both Rutter and Newson reiterated Kanner's reference to 'the age of onset'. With better understanding of the nature of autism, this point now seems less significant. What they regarded as 'age of onset' may have been the age when the condition was finally recognised in the child.

This accumulation of knowledge about autism showed that it was not invariably a clear-cut disorder like measles which you either have or have not got, but a spectrum of difficulties with certain clusters of possible symptoms.

We feel that the descriptive definition suggested by Dr Lorna Wing, formerly of the Medical Research Council Social Psychiatry Unit, and now a psychiatric consultant for the National Autistic Society, makes best sense of this complex condition. She, together with her colleague Dr Judith Gould, carried out an epidemiological study of children resident within a particular area of London in 1979. They included in the study any child with features of autism as well as all children with moderate to severe learning disability. This study led them to suggest that the core deficit in autism is *social* in nature. This means that whereas a child with learning disability can be sociable relative to his/her mental age, a child with autism, regardless of intellectual ability will have observable social impairments. These difficulties, apparent in three different areas of functioning, were described as 'The Triad of Impairments of Social Interaction'. Subsequently, Wing underlined the view that autism is on a continuum. This means that there is no clearly defined limit to the disorder. The continuum can include all the 'odd' and atypical children who clinicians constantly come across, who do not fall strictly into the classic picture of autism as described by Kanner. Social deficits have invariably been mentioned by other researchers. Wing and Gould's work has highlighted them as being central to the disorder.

The three aspects of the Triad are:

1. An impairment of social relationships.
2. An impairment of social communication.
3. An impairment of social imagination.

We need to look at each of these areas in more detail, and for the sake of clarity we have listed below the points or levels on the continuum suggested by Wing. The lower numbers describe more severely impaired children. More able children with autism may be identified by the descriptions listed under (4) in each of the areas of the Triad. However, it should be borne in mind that the levels listed are arbitrary and that, in practice, children will be found who are functioning at any point along the way.

IMPAIRMENT OF SOCIAL RELATIONSHIPS

1. Aloofness and indifference to others.
2. Accepting of social approaches by others (passive).
3. Makes social approaches to others which are one-sided, and may be to indulge strange and unusual interests, e.g. railway time tables, vacuum

cleaners, lavatory disinfectants, airport X-ray scanners, the marks socks make on ankles, etc.

4. Makes social contact, but lacks understanding of subtle rules of social behaviour.

IMPAIRMENT OF SOCIAL COMMUNICATION

1. Absence of any desire to communicate with others.
2. Communication confined to the expression of needs only.
3. Makes factual comments, not part of a social exchange, and often irrelevant to the social context.
4. Talks a great deal, but regardless of response of listeners, and has difficulty in engaging in reciprocal conversation. (This can be very subtle indeed, especially in individuals who have had access to social skills training.)

IMPAIRMENT OF SOCIAL IMAGINATION

1. Copying and pretend play are absent.
2. May copy the actions of others, but without real understanding of their meaning and purpose (may bath doll, make pretend cups of tea for example).
3. Repetitive and stereotyped enacting of a role, but without variation or empathy, e.g. a TV character, or even an object such as an aeroplane.
4. Awareness that things go on in the minds of others, but has few strategies to discover what these may be. (Minimally affected people appear to have ability to recognise others' feelings, but this is learnt rather than empathetic.)

The behavioural abnormalities seen in children with autism are less clearly linked with these levels of social functioning. While less able children may display more extreme responses to sensory stimuli, including motor difficulties, and odd movements such as flapping, they may also display islets of ability, and even savant skills. Less severely affected children may also show sensory and motor abnormalities despite their wider range of skills. They too may demonstrate specific talents in certain areas.

The practicalities of how the Triad affects a child's development will, we hope, become clearer as we describe and discuss the assess ment of children with autism in Chapter 5. In the natural history of the disorder improvements and changes are likely to take place. For example, the unsociable child may become sociable albeit in a passive way, and the passive child may become sociable but odd. It is necessary to clarify the differences between impaired and immature social development. While children with impaired social development will display some or all of the idiosyncratic patterns described, the socially immature child will display a more normal profile which will relate to their overall developmental level, rather than their chronological age.

Wing has also contributed to the debate on the existence of Asperger Syndrome. She has described a sub-group of individuals who make naïve and inappropriate social responses, who have narrow circumscribed interests, who have long-winded repetitive speech, poor motor co-ordination and lack common sense.

It is our view that now there is a general acceptance of a spectrum of autistic disorders, with much variability, the arguments relating to possible distinctions between autism and conditions such as Asperger Syndrome are of little practical value, and may even be counter-productive. This is not to say that the identification of clusters of presenting features are not of interest for research purposes. However, sub-groups are less important when considering programmes of remediation, which should be geared to the individual's needs rather than assumptions or expectations based on diagnostic labels. We cannot emphasise enough the variability of individuals with autism.

There has been considerable argument about what underlies the varied picture that autism presents. Why does a child who has only a few of Kanner's features have autism? What has such a child in common with one more obviously and seriously impaired? Is there a common thread? What is the link?

Professor Uta Frith, of the Medical Research Council's Cognitive Development Unit, in her book *Autism: Explaining The Enigma* (1989), has made a considerable contribution to answering these questions. It is very satisfactory to be able to relate our years of clinical experience of assessing and working with countless children with autism to the theoretical model suggested by her research. Her experimental work based on Premack's Theory of Mind (this is the ability to attribute mental states with content to others – also known as 'mentalising') made sense of the apparent contradictions seen in these children.

Frith has postulated that it is the ability to mentalise that is lacking in individuals with autism. Normal children develop this ability very early in life, and even those with severe learning disability, but without the additional handicap of autism, are capable of mentalising at a level commensurate with their mental age. We will be referring again to Theory of Mind in later chapters when we look at practical aspects of assessing children with autism.

In addition, Frith describes a problem that people with autism have in processing information. She refers to this as an impairment of 'central coherence'. The final paragraph of her book sums up what parents and professionals with experience of autism will immediately recognise:

> To identify the core features we had to look below the surface of the symptoms. It was then that we could see the red thread that was running through the evidence. It is the inability to draw together information so as to derive coherent and meaningful ideas. There is a fault in the predisposition of the mind to make sense of the world. Just this particular fault in the mechanics of the mind can explain the essential features of autism. If we lose sight of this fault we lose sight of the overall pattern.

Other researchers have expanded on Frith's work on Theory of Mind, in particular, Simon Baron-Cohen and Fran Happé, who developed procedures that demonstrated the validity of Frith's ideas. Baron-Cohen (1989) described the difficulties of able children with autism, who showed that they had a theory of mind at the lowest level. When their ability to use this skill at higher levels was tested, they demonstrated severe impairments. This meant that these able children were unable to appreciate what another person might be thinking about a third person. The term 'mind blind' has been used to describe these difficulties, and many parents have found the term helpful in understanding the nature of their children's problems. Baron-Cohen *et al.* (1992) subsequently developed a remarkably simple screening schedule for detecting autism in children as young as 18 months. This is known as The CHAT (The Checklist for Autism in Toddlers). The schedule looks at five target areas: pretend play, joint attention, pointing, social interest and social play. It has been shown to be effective in identifying children who are later diagnosed with autism.

Fran Happé (1994) was also interested in able children and adults who could mentalise at a simple level. She produced a series of stories which were used experimentally with able autistic subjects. Their responses demonstrated their idiosyncratic view of events and their difficulties in attributing mental states to others. Some individuals, despite being able to interpret the stories correctly, nevertheless had difficulty in coping with the social demands of everyday life. Happé pondered on this conundrum, which we believe can be explained by the complexities of real-life situations compared with contrived experimental settings.

Having described the historical background to autism from 1943 to the present day, it is appropriate to touch upon the establishment of the National Autistic Society (NAS) in the United Kingdom. The motivation to form a Society, which was established in 1962, came originally from a group of parents of children with autism. One of its original aims was to set up schools for autistic children, who were at that time excluded from the limited facilities provided by education and health authorities for handicapped children. It was then agreed by the Society that no autistic child should be excluded from their schools. The Society schools continue to flourish. They are located in different parts of the country and, although not identical in terms of what is offered, provide a model of excellence both in educational approaches and management of associated problems. Over the years these schools have achieved much success with individual children. Their work continues unendorsed by media attention, yet establishing standards of care which are respected internationally.

As local education authorities have taken greater responsibility for the education of children with special needs, those at the upper end of the autistic spectrum are now more likely to be placed in LEA special schools and units, as well as mainstream schools with support. In addition, a range of independent special schools such as those set up by ICAN and AFASIC, have adopted a more flexible approach to their intake, and are now prepared to accommodate children with a milder degree of autism, or Asperger Syndrome. Not surprisingly, this has affected the intake of children to NAS schools, which are now more likely to be working with less able children or those who have more complex needs, such as challenging behaviour.

The lack of post-school provision for older children and young adults is a matter of concern to the Society, and steps are being taken to remedy this situation. The role of the National Autistic Society has grown over the years, but it remains a parent-oriented organisation. As a result of renewed interest in ‘alternative’ approaches to autism, the Society now accepts that it has a role to play in the evaluation of the claims made by their proponents. Their appraisals provide parents with information about any possible benefits, as well as advantages in terms of location, financial costs and possible effects on other siblings in the family. These different approaches will be described in some detail in Chapter 10.

As well as encouraging the formation of locally based support groups, the Society organises conferences, courses and study days for both parents and professionals. In addition, it publishes books, pamphlets and reports as well as a quarterly magazine *Communication*, and a newsletter. It provides an information service, and more generally, promotes better awareness and understanding of autism. It has responded to the needs of those with Asperger Syndrome, as well as their families, by developing a support network which is now incorporated into the magazine. A database of publications and research information has been established by the Society at Cambridge University, and it is now possible to access information on autism through various sites on the Internet.

A very welcome extension of the Society's services has been the establishment of a diagnostic centre in Bromley, Kent, which has provided a much needed focus for developing a standard in diagnostic expertise. Unfortunately, there is always a long waiting list, and not all Health Trusts are willing to finance referrals. For this reason, many Trusts have attempted to establish their own diagnostic teams. However, as their credibility is dependent on the degree of experience of autism among team members, which may not be very extensive, they are not necessarily able to provide parents with the specialist information they require. Parents often find that the best way to access relevant help and support is through the recommendations of other parents who are in, or have been in, a similar situation.

There have been Government-funded research projects which have investigated aspects of provision and outcome for children and young adults with autism. The first, in 1984, considered the position of able autistic people in society. A subsequent project looked at the facilities available for children and adults with autism provided by the public, private and voluntary sectors in England and Wales, and studied in detail some of the methods used to address the particular problems of autism.

With the prospect of ever-increasing movement, not only between the countries of Europe but also the rest of the world, it is likely that some parents of children with autism will settle abroad. Naturally the attitudes towards diagnosis and the provision for children with autism will vary considerably from country to country. There are two standardised classification systems for psychiatric diseases and disabilities that are used internationally. Both have sections on autistic disorders. Each is updated every few years. One is produced by the American Psychiatric Association and is called the *Diagnostic and Statistical Manual* (DSM); the latest version is the fourth edition (DSM IV). The other is produced by the World Health Organisation and is called the *International Classification of Diseases* (ICD). This covers physical as well as psychiatric disorders. The latest edition is the tenth (ICD-10).

The significant changes in the sections dealing with autistic disorders in succeeding editions of these classification systems illustrate the changes in perception of the nature of autism and the continuing debate about diagnosis. The latest editions of both recognise a range of sub-groups of autistic disorders that is wider than classic autism and which both call 'pervasive developmental disorders' (PDD). These are roughly equivalent to Wing's 'Triad of Social and Communication Impairments'. While it is of interest to researchers to investigate and carefully define sub-groups within the autistic continuum, it can lead to a proliferation of labels which is likely to confuse rather than clarify diagnosis, and may even hinder appropriate educational placement and the security of long-term support. It is important to recognise the social and communication impairments in all developmental areas and then to assess each child's own pattern of skills and deficits.

Clearly it is not feasible to write a description of the state of the art in relation to diagnosis and provision in each and every country. However, the National Autistic Society can provide a comprehensive list of autistic societies and contacts throughout most of the world.

3

WHAT CAUSES AUTISM?

We hope that the descriptions of the developments in the understanding of autism outlined in the previous chapter will enable readers to appreciate the variations and subtleties of the condition. We know that a medical model – that is, defining autism as a disease – may not be helpful. Instead, it is more appropriate to view it in terms of a socio-educational disorder. This encourages the use of the term in a contextual sense, rather than as a rigid label. In our view it would be unhelpful to abandon the use of the term altogether, as it is an appropriate framework of reference for recognising and understanding a group of children who show unusual and contradictory patterns of development.

Since Kanner's time, many theories have been suggested to account for autism and the possible causes. Initially, it was believed that the parents were at fault, particularly the mother who was held responsible for not providing sufficient warmth and affection for her child. Commonly used phrases were 'refrigerator mother' and 'cold intellectual parents'. Fortunately, such ill-considered and critical views became discredited as clinical experience and research developed, repudiating these theories. However, subsequently, there was a revival of interest in parental culpability, resulting from a theory propounded by Tinbergen and Tinbergen in 1972. They claimed that autism was caused by a breakdown in the bonding process between mother and child, and that this theory provided the basis for a cure. The idea was taken up with great enthusiasm by Dr Martha Welch, an American psychiatrist. She introduced what became known as 'holding therapy'. This was not, as we originally supposed, a warm and cosy cuddling dialogue, but a forced hold of the child by the mother, which had to be maintained, despite resistance by the child and involved much struggling, crying and shouting. The tenor of holding therapy sessions as shown on video, appeared to us to be quasi-religious, and the fervour generated caused us considerable disquiet. It was impossible to see how such 'therapy' could possibly cure (as it was claimed) a condition such as autism. The lack of evaluation and assessment by the providers of this therapy did little to substantiate their claims, which could therefore only be considered as anecdotal.

There is ample scientific data to demonstrate that in the natural history of the disorder many children with autism make good progress. This is especially evident during the middle years of childhood from about six years until adolescence, when some setbacks may arise (see Chapter 9). The features of autism may diminish and progress can occur in a number of areas in relation to social development, language and educational attainments. In the gentler and less aggressive setting of schools with expertise and understanding, children with autism will have the opportunity to develop their full potential on a realistic basis. The dramatic claims of a cure will not be made because, however much progress occurs, the underlying core deficits will remain and need to be taken into account. As we later expand on the various aspects of the autistic continuum it should become obvious why this particular and unsubstantiated remedy was ill-conceived and inappropriate. However, over the years we have met mothers who despite all evidence to the contrary insist that their child's autism was caused by them. Women with these feelings of intractable guilt are more likely to be drawn towards this theory. No amount of reasoning is likely to alter their belief, any more than a person with anorexia is able to appreciate their emaciated shape.

Holding therapy is just one of a number of so-called 'cures' for autism which emerge from time to time in the media (see Chapter 10). It is now no longer in favour, but other similarly unsubstantiated alternatives have appeared to replace it, such as facilitated communication and, latterly, auditory integration training. Some of the alternative therapies may have elements which appear plausible. However, it is unrealistic to believe that the underlying impairments can be alleviated by focusing on a particular aspect of behaviour or developmental anomoly. Another criticism is the extravagent claims that are made and that inevitably appeal to vulnerable parents who want to have their hopes raised however tenuous the evidence. They should be encouraged to maintain a sceptical attitude until evaluated data provides them with realistic expectations. All the evidence now available strongly indicates that the causes of autism are biological, and therefore it must be accepted that the rate and extent of progress is largly determined by innate factors in the child. Contrary to Kanner's original assumptions, epidemiological studies indicate that autism affects children born into all strata of society, without regard to intellectual or socio-economic factors or ethnic origins.

Whereas in the past the incidence of autism was confirmed as being 4 or 5:10,000 for classic cases, and 17:10,000 for closely related conditions requiring similar services, revised statistics (by the NAS) on the number of people in the United Kingdom estimated to have autistic spectrum disorders is now 91:10,000. These figures include individuals at the upper end of the spectrum who do not exactly fit the criteria for Asperger syndrome. The figures do not necessarily indicate an increase in the incidence of the disorder, but may reflect an increased recognition of the range of the spectrum.

Those familiar with autism will know that there are more affected boys than girls. Although the exact ratios vary, males with autism tend to outnumber females by 3 or 4:1. This prevalence of males over females, together with the known association of autism with severe learning disability, provides further evidence that the causes of the condition are not psychogenic in origin.

Research has shown that not only do relatives of people with autism stand a slightly greater than average chance of having autism, but that the families have an unusually high percentage of relatives with speech disorders, learning difficulties and other minor cognitive disabilities. There have been a number of studies of identical and non-identical twins where one or both are affected by autism. These have provided important information relating to genetic factors. Researchers have indicated that autism is highly heritable, and suggest that that there is an autism 'phenotype'. This applies to 'a range of social and cognitive abnormalities in individuals of normal intelligence, of a kind that is very similar in quality to those found in autism but very different in degree of handicap' (Bailey *et al.* 1996).

This research evidence reflects our own clinical experience that aspects of autism commonly present in siblings of more severely affected children, and in one or other of the parents, more commonly the father. Indeed, apparently sociable parents have been known to comment that they were 'like that', when they were children, and can identify very closely with their autistic offspring. When autism occurs in siblings, a diagnosis is often delayed in relation to the younger child, because he or she presents in a very different way from the older one, who is presumed to be the prototypical model for the condition.

For some time certain physical disorders have been known to be associated with autism. These include maternal rubella, infantile spasms and untreated phenylketonuria. In addition autism is also linked to genetic disorders such as tuberous sclerosis, neurofibromatosis and fragile X-syndrome, as well as Rett's syndrome. Research has also indicated that certain viruses as well as rubella may be implicated in the causation of autism. In particular, the herpes simplex virus as well as the cytomegalo virus have been mentioned in the literature. A few children known to us have apparently developed autism following chickenpox, even though the infection was not especially severe.

Candida albicans, a common yeast-like fungus causing thrush, has also been linked with autism. Interestingly, a significant number of parents have reported unexplained high temperatures or transient rashes in their autistic children. Is this perhaps evidence of yet another active virus? Recent experience leads us to believe that cases of autism are on the increase, which cannot simply be explained by increased awareness and the widening boundaries of the condition. A theory has been suggested that a virus can infect a baby in utero, but it will be only minimally damaged and appear normal at birth. Yet the virus may lie dormant in the child and be activated by the normal stresses of life such as moving house, the birth of another child, etc. This theory provides a possible explanation for the many reports by parents that their previously normal child became autistic having had these experiences. The immunisation programme (and in particular the measles component of the MMR vaccine) has been blamed by many parents for the apparent increase of autism, as well as pre-natal scanning, technological approaches to childbirth, and environmental pollutants. Many children with autism have a history of allergies of various kinds, including asthma.

It is not uncommon for children with autism to suffer from epilepsy, although sometimes its onset is delayed until adolescence. This association between the two conditions indicates the presence of overt organic brain dysfunction and again provides evidence of a biological basis for autism. In general, severely handicapped children with autism are more likely to suffer from epilepsy than those at the upper end of the continuum, but this is by no means universal.

About one-third of more severely affected children with autism tested in various studies have raised levels of blood serotonin. However, treatment with the drug fenfluramine, aimed at reducing these levels and accordingly the overt symptoms of autism, has not proved to be generally effective and remains experimental. Similarly, the use of vitamin therapy, in particular

B6, as well as other pharmacological agents such as folic acid, magnesium and zinc, have not proved to be any more successful in the long term. There is now a focus of interest in the hormones that affect early brain development, and it is to be hoped that this research may yield positive results in the future.

It seems very likely that brain damage or dysfunction is present in autism in all its manifestations. Obviously where there is severe social impairment, learning disability and physical difficulties, the extent of the damage will be considerably greater than in cases where there is social impairment but many intact areas of skill. There has been much speculation about the parts of the brain which are affected in autism, and particular areas of interest have included the right hemisphere, limbic system and cerebellum. However, as yet, no single area of the brain has been conclusively implicated which could account for the wide range of presenting features, and it seems much more likely that multiple neurological deficits exist.

Perhaps Dr Sula Wolff of Edinburgh University, writing in 1988, makes sense of all the diverse aetiological factors by suggesting that:

> For autism to develop, brain damage has to occur in the setting of a genetic predisposition . . . the causation of autism which is likely to be heterogeneous, arises when a number of quite common factors coincide.

4

PROBLEMS OF DIAGNOSIS

Considerable changes and developments have come about in recent years in our understanding of the nature of autism. We are now aware of the variability of the condition and the considerably widened diagnostic boundaries which enable us to recognise autism in its most subtle form. This means that figures that were used authoritatively in the past, quoting percentages of diagnosed cases with, for example, 'classic autism', 'autism with severe learning disability', and 'autism with higher levels of intellectual functioning', now seem unhelpful and meaningless. Another reason for questioning these figures is the fact that many individuals with very mild or atypical autism go undiagnosed, sometimes well into adolescence, if not adulthood. Ironically, it is this group who require the most support and understanding from parents, families, and teachers, as well as from peers and even employers, to enable them to make the most of their abilities in a world which may not always take kindly to their oddities and eccentricities.

When we first entered the field of autism in the early 1970s there was little appreciation of the importance of intellectual functioning in the development of children with autism. Indeed, it was believed that intensive educational intervention would 'break through the barrier of non-communication' and ultimately allow the child to develop normally. Three decades later this belief seems charmingly naïve, and reflects the dearth of knowledge and experience which existed at the time. Since then, the subject of autism has fascinated researchers and clinicians endlessly, and has provided a considerable amount of research data which is remarkably consistent. Despite this, it is perhaps understandable that many parents still cling to the simplistic beliefs that carry optimism rather than reality, and can only consider their child's development in terms of a cure, as if he/ she was suffering from a disease.

It should be obvious that children with autism accompanied by a severe degree of learning disability will present in a very different way from those who are intellectually able. In general, the most severely affected children with autism are likely to have the most severe learning disability. Those with normal intelligence are more likely to present as children with language problems, and their underlying social difficulties may be marginalised and regarded as a subsequence rather than the core disability.

In the Introduction we referred to the 'often curious skills or islets of ability' which children with autism frequently display. Although the range is circumscribed, there can be many variations. These may include abilities with jigsaws, electrical appliances, knowledge of routes, post codes, the motorway network and general feats of memory. Occasionally the skills may be quite exceptional and it is worth mentioning that the proportion of autistic individuals showing savant talents is relatively high. The talents which have been best reported (Treffert 1989) involve artistic, musical and calendrical skills (the ability to work out dates). It is truly extraordinary to encounter such abilities in people who otherwise have severe learning disability.

Problems relating to the diagnosis of autism have been apparent ever since Kanner's time. The situation remains far from satisfactory and is fraught with muddle and confusion. The point-counting approach to diagnosis referred to in Chapter 2 may well have contributed to much of this confusion. We acknowledge that the situation has progressed as researchers have largely moved away from the 'all or nothing' or 'is he or isn't he autistic?' approach. However, this has not filtered down to many professionals who, through lack of experience of the subtleties and extent of the autistic spectrum, adhere to past practice and fail to recognise the existence of autism when it does not present in its more classic form. This is surprising when as far back as 1985 Shea and Mesibov reported that 'classical cases are greatly outnumbered by cases with mixed, impure and partial characteristics'.

It is our view that a descriptive approach to diagnosis is essential. Only then will the full extent of the autistic spectrum be recognised and understood. We know that more children will be encompassed by less rigid diagnostic criteria which consider the *quality* of social functioning rather than the presence or absence of particular aspects of behaviour. A new diagnostic tool 'The Diagnostic Interview for Social and Communication Disorders' (DISCO) has been developed at the NAS Centre at Elliott House. It is due to be published in the near future.

Many professionals still tend to regard autism as a rare condition which can seriously affect their confidence in making a diagnosis. It is particularly easy to overlook autism in a one-to-one situation, as many able children with autism respond well to adult attention. Observation of children in a social setting, such as school or nursery, where their difficulties are more likely to be highlighted among socially normal peers, is always advisable.

Questioning parents about their child's development may also be misleading and result in highly skewed information. For example, to question a parent about whether their child shows joint attention is certainly relevant, but fraught with difficulties. Does the parent really understand the term, and does the professional really evaluate the answers? A child may well show joint attention when looking at his favourite dinosaur book, or pointing out items which are of special interest to him, but this is not qualitatively the same as responding actively and creatively to someone else's interests. Similarly, the question 'Can you have a conversation with your child?' can produce a range of contradictory information. People have different perceptions of what constitutes a conversation. For some, limited responses to a series of questions qualifies, as does obsessive talking about a particular topic. In other words, it is extremly easy for the professional to be misled because, although the right questions were asked, there was insufficient thoroughness in clarifying the information.

Many of the recurring diagnostic problems could be alleviated if the training of professionals included greater input on the subject of autistic spectrum disorders. It is apparent that there is a dearth in the provision of up-to-date information, not only in relation to the training of doctors but also to that of psychologists and speech and language therapists. Paradoxically, this does not appear to apply anywhere near as much to the training of teachers of children with special needs. It is an irony that they are usually excluded from the diagnostic process, yet are expected to manage and teach children with autism once they are in an educational setting. Two other groups of professionals whose diagnostic expertise is often undervalued are health visitors and nursery nurses. It is our experience that their wide knowledge of normal child development enables them to pinpoint the divergent patterns seen in young children with autism. There have been advances in some areas of the United Kingdom, however, where health visitors are at the forefront in screening young children at risk for autism using Simon Baron-Cohen's CHAT.

Research development units with specialist expertise in autism are few in number and have difficulty in coping with the referral demand. It is our view that there should be increased use of specialist schools as a resource within a geographical location, which could provide advice and information to any parents of a child with autism whether or not that child is suitable or eligible for placement in the school. Where this does happen there are many obvious benefits, not least in ongoing support and advice for parents of children undergoing statutory assessment. In addition, contacts between schools and research centres provide further opportunities to share and extend knowledge and bridge the gap between academic research and day-to-day routine experience of children with autism. It is as well to keep in mind that once autism has been diagnosed or identified, the emphasis shifts away from the clinical to an educational setting. Autism is not a disorder requiring medical treatment, unless there are accompanying problems such as epilepsy, but one requiring appropriate education and management.

In conjunction with this, links with community health and local paediatric departments could form the basis of a comprehensive team approach to diagnosis, provided that the participants are willing to spend time acquiring specialist knowledge. Although in theory multi-disciplinary assessment teams already exist in many health trusts, the reality of the situation is nowhere near as utopian as it may sound. Sometimes teams are set up as a local cost-saving alternative to the considerable expense of referrals to a specialist centre, and there is often a scarcity of experience and expertise among team members. Additionally, when teams are large it is difficult to arrive at a meaningful consensus, and subsequent reports tend to be non-committal and therefore unhelpful to parents. Sometimes it takes months for the team to write and circulate their reports, which again leaves parents in a state of unresolved anxiety. This is particularly unfortunate when a diagnosis is required in order to gain access to an appropriate educational setting and support.

In general, there are unlikely to be any formal procedures for ensuring that parents have access to a key person with expertise to advise them in what is a bewildering if not frightening situation. In addition, it is also unlikely for a diagnostic team to be in a position to provide ongoing intervention programmes. In consequence many parents report that, having got a team diagnosis, they are 'just left to get on with it'. These problems are obviously linked to the reluctance of both health and education authorities to pick up the tab and be responsible for financing a service which has long-term implications.

In spite of being critical, we have to acknowledge that there are bound to be problems in diagnosing able children with autism who are very likely to be overlooked by the usual screening procedures. They may not have a sufficient degree of disability to attract the attention of services for children with developmental delay. Instead they may be diverted to Child and Family Consultation Centres where their difficult behaviour may be seen as a consequence of parental mismanagement, with the result that family therapy and even psychotherapy are prescribed. The children's difficulties are seen as the outcome of a breakdown in family dynamics, rather than symptomatic of an underlying disorder. This misinterpretation of the causes of the child's presenting behaviour has brought considerable distress to many parents who feel that they are being blamed undeservedly for their child's problems. Yet, too often, they are not offered an alternative explanation which makes better sense. When relationship problems exist in the family of a child with a mild degree of autism, it is all too easy to jump to conclusions and be misled by what is in fact a red herring. Obviously, any child, with or without autism, will be affected by family problems, and, indeed, some of these problems may well be the result of having to cope with a difficult child.

When autism is seen primarily as a 'language disorder with social difficulties', it is likely that there will be a referral to, or re-referral back to, a speech and language therapist, with the supposition that remediation of the language problem is all that is required. This 'tidy' explanation is likely to appeal to parents, and may also be supported by speech and language therapists who fail to recognise that the social difficulties underlie the problems with language, rather than the reverse (Gagnon *et al.* 1997). It is essential to view the language deficits in the right context in order to promote realistic expectations of outcome.

Sometimes diagnostic problems arise because of the unwillingness of some local education authorities to acknowledge autism as a viable consideration. In one sense this is reasonable, since the Education Act of 1981 introduced the idea of children's individual needs rather than diagnostic labels, and autism was no longer regarded as a special education category. However, the other side of the coin is the reluctance of some LEAs to recognise the disorder because it could lead to demands for additional educational provision which they would have to finance. It is a fact that in areas where there is no provision, or willingness to finance placement in schools elsewhere, autism tends not to exist! It may be given an assortment of other labels in order to accommodate affected children in whatever special educational provision is available. Yet, in areas where there is provision, there is no difficulty in filling places. On the contrary, demand always exceeds the number of places available.

We do feel that in recent years LEAs have become more sympathetic to the needs of children with autism. This may be due to an increase in the cases of autism, parental lobbying, as well as teachers' greater awareness of the condition. Special Educational Needs Coordinators in mainstream schools have the responsibility of attending to the individual needs of this group of children and recognise that they require a great deal of specialised help and support. As a consequence they have been able to put pressure on their LEAs to increase provision and finance extra resources. Educational issues will be discussed in more detail in Chapter 8.

In the face of all the daunting obstacles the question may well be asked, why bother to diagnose at all, especially when the condition is mild, and who should actually do the diagnosing? As far as the latter issue is concerned, we have already discussed the team approach, but this is not always available and in some cases may not be helpful. We think that the professional discipline is unimportant in comparison with experience in the field of autism. The professionals most likely to be involved will include health visitors, speech and language therapists, paediatricians, psychiatrists, clinical and educational psychologists. Obviously, when there are severe disability and medical factors to consider, the diagnosis is more likely to be the responsibility of a paediatrician who may be hospital or community based. The way in which the diagnosis is presented to parents is of great importance and will be considered in Chapter 6 as part of the subject matter relating to counselling.

The justifications for providing a diagnosis are manifold; parents are entitled to know what is the matter with their own child, and more often than not want to know. Not knowing what is wrong makes them feel vulnerable and insecure, which is more upsetting than many professionals realise. It is by no means unusual for professionals to withold a diagnosis in the mistaken belief that they are protecting parents from distress. This may in fact reflect their own feelings of inadequacy in coping with the parents' response to bad news, and their own inability to offer support, for whatever reasons. It is only when their child has been appropriately diagnosed in a way that makes sense to them, that parents can begin to come to terms with the situation. It is sad to see parents continually seeking consultations, searching for answers, because no one has provided a diagnosis which directly relates to their child's range of difficulties and needs.

The provision of a diagnosis ensures that the child's often contradictory problems are not misunderstood. It is very common for the parents of undiagnosed children with autism to feel that they are responsible for their child's 'bad' behaviour. Early diagnosis relieves them of this unnecessary burden of guilt. It also relieves the child from both spoken and unspoken criticism of his behaviour, which can lead to feelings of low self-esteem and even depression. A diagnosis is also more likely to promote good management and appropriate intervention, and facilitates access to support groups, services and state allowances. With the correct diagnosis, school placement, when the time comes, is more likely to be more suitable and therefore ultimately more successful. In addition, a meaningful diagnosis enables parents to begin to make plans for the future. If parents suspect that their child has autism but have been unsuccessful in obtaining a diagnosis, we suggest that they join an appropriate support group. This will enable them to learn from the experience of other parents, and find out the best way to proceed.

As a rider to diagnostic issues, we have in mind a particular experience when we were asked to assess a young child who had been seen regularly by a multi-disciplinary team in an assessment centre attached to a children's hospital. We were warned not to distress the mother, who brought her child to the centre, by mentioning a diagnosis of autism, which we understood the team suspected and wanted us to verify. It was apparent that the child indeed had autism. During our conversation, the mother remarked, 'I have been coming here for eighteen months and no one will tell me what is the matter with my child. But I've had a letter from the Housing Department which says that my son is autistic.' This was clearly a well-intentioned endeavour by the team to obtain better housing for the family. The fact that they omitted to share their diagnostic opinions with the child's mother would seem to be a grievous omission, which led directly to her learning the diagnosis in this unsuitable way.

We are aware that there is an apparent contradiction in our discussion of diagnostic issues. On the one hand we are urging a move away from what we have described as a rigid point counting system, and an all-or-nothing approach. Yet, on the other hand, we constantly refer to 'children with autism', emphasising the import ance of a diagnosis, which in itself suggests that we are guilty of using the very same criteria ourselves! We want to emphasise that we use the term 'autism' in a *contextual* sense. It follows, therefore, that there is an expectation of a wide diversity of symptoms, features, abilities, intelligence, behaviour, etc. The common denominator will be the underlying social impairments which are on a continuum of severity.

Perhaps if, in relation to autism, the professionals talked of *recognition*, rather than diagnosis, the contradictions would be lessened and misunderstandings would diminish. At the end of the day, call it diagnosis, recognition, or whatever, the professional is confronted with the problem of conveying to the parents the nature of their child's difficulties. The terms, labels, or descriptions used will depend on the integrity, experience and common sense of the professional on whom the responsibility falls, for whatever the reason. When the term 'autism' is used, it is always necessary to provide detailed explanations of what is actually meant. The presence or absence of particular features associated with autism will then be less likely to confuse and mislead parents. We need to reiterate that diagnosis has to be a *qualitative* evaluation of the child's functioning in a variety of settings, rather than the presence or absence of particular features gathered in a clinical setting. For example many children with autism do have friends, so that it is not the absence which is necessarily relevant but the quality of the relationship. Is the term 'friend' simply applied to anyone who is familiar to the child, regardless of their age, or is the 'friend' a peer who simply interacts with him in some way?

Many parents, and even professionals, have been known to express surprise that it is possible to recognise autism with relative ease in a short period of time. It is apparent that anyone with real experience of the condition develops almost a sixth sense and somehow learns to home in on salient details, which include nuances of behaviour and movement. These minutiae combine together to provide an overall picture that indicates that autism is an appropriate diagnostic context. Those who work with children with autism on a day-to-day basis are in the fortunate position of being able to verify their initial diagnoses as the children develop and change over time. This provides them with an ever-expanding bank of information to refer to when diagnosing the condition.

It is unlikely that there will be much argument over the use of the term 'autism' when the child's difficulties are so apparent that mainstream education would be out of the question. Nevertheless, we feel that it is important not to fudge the existence of severe learning disability by focusing solely on the autism. However, the problem is considerably more complex with children who are only minimally affected with autism, and have good cognitive skills. It also has to be borne in mind that these minimal features of autism will tend to diminish during the middle years of childhood, or even fade into eccentric normality at the very top end of the continuum. This is where the professional's integrity comes in. Are the child's difficulties so mild that mention of autism would generate more problems that it would solve? Even if there is to be no mention of autism, because it would not seem helpful, it is encumbent upon the professional to clarify the nature of the child's problems so that parents are not left in any doubt of the long-term implications. This will enable them to ease the way for their child and encourage better understanding and acceptance without emphasising the child's anomalies.

It is a fact that there are children who in early childhood display overt autism, yet as they develop shed many of the behavioural characteristics of the disorder which have set them apart. Such difficulties that remain appear very subtle. This should encourage parents to understand that a diagnosis of autism is not invariably a 'no hope – doom and gloom' prospect, and that the situation is by no means as rigid and predetermined as some of the literature on autism may suggest.

5

UNDERSTANDING AND ASSESSING CHILDREN WITH AUTISM

In this chapter we are going to describe different aspects of autism in an attempt to provide a framework for looking at the whole child and evaluating his/her individual difficulties as well as skills and abilities. When this approach is used it is then possible to make sense of this perplexing condition with all its apparent contradictions.

Our publication *The Autistic Continuum* (Aarons and Gittens 1992), an assessment and intervention schedule, was designed for the use of professionals to enable them to know what to look at and how to interpret the findings in order to obtain a balanced understanding of the relative skills and deficits of children with autism. It provides a structured framework for assessment and is developmentally based. It is not necessary for parents to use the schedule itself as it is essentially a clinical tool. However, we will refer to the same key areas of the child's development which form section headings within the schedule. The areas that we look at are as follows:

1. Medical history and early development which will include relevant background information.
2. General observations of the child relating to appearance, movement, behaviour, and social development.
3. General management and problems (see Chapter 6).
4. The ability of the child to focus his/her attention, and concentrate.
5. The child's perceptual abilities, primarily in relation to vision and hearing as well as to other senses.
6. The child's ability to use objects meaningfully, and to play constructively, socially and imaginatively.
7. The child's grasp of concepts which will range from simple matching to more complex levels of understanding.

8. The child's understanding of order and sequence (both visual and auditory). The latter will include the child's interest and response to rhythm and music.
9. The child's communication development, which will be considered separately in Chapter 7.
10. The child's intellectual capability and, if old enough, his/her educational attainments, which will also be discussed as a separate issue in Chapter 8.

MEDICAL HISTORY AND EARLY DEVELOPMENT

We have already listed some of the medical conditions known to be associated with autism when considering the biological causes. In our experience it does not appear that children with autism have a more problematic birth history than the rest of the population. On the contrary, the majority of parents report that their pregnancies and labour were normal, the problems only arising in the early months or first two years of development. As well as the febrile episodes which were mentioned in Chapter 4, parents have reported food allergies and other manifestations which are now starting to be taken more seriously. At the time of writing, there is some concern about the effects of the MMR vaccine (in particular, the measles component) which has been linked to both autism and Crohn's disease. Those working in the field of autism, who have witnessed an apparent surge in cases, have pondered on possible causes, and this worrying possibility does seem credible, especially as the increase appears to have coincided with the introduction of this particular vaccination programme. However, it is beyond the scope of this book to do more than identify possible links which future research may clarify.

Nevertheless, the majority of children with autism appear to have an uncomplicated start to life and there is nothing of particular significance in records of their early development. Milestones: sitting, crawling and walking, are more often than not, within normal limits. So, in the first year there may be little evidence of general developmental delay. However, detailed questioning of parents will reveal a number of significant aspects that form a pattern of deviance which will be very familiar to the experienced clinician. Few parents have substantial knowledge of child development apart from milestones, so that the subtle aspects of their child's behaviour go unnoticed. This is especially the case in relation to social communication.

Normal infants have been observed from a very young age to engage in a synchronised dialogue with their mothers/carers. The babies' movements are timed to allow a response from her, like a two-way conversation without words. This is the basis for social development and is likely to be absent or impaired in babies who are later diagnosed as having autism.

Some parents will describe a baby who does not reach out to be picked up, yet may enjoy physical contact and being cuddled and tickled and, at a later stage, rough and tumble play. A baby described as 'very good', who will lie for hours in his or her pram, buggie or cot watching shadows, sunbeams and the movement of leaves. There may be a sustained interest in lights and reflections. Other parents will tell a different story. A baby who screamed incessantly and could not be comforted. Later, as the infant becomes more mobile, an interest in electric plugs, switches as well as appliances may develop. Although normal mobile infants may head for the television set, they are generally easily diverted, and are interested in other things. For the infant with autism, the interest may be exclusive and persistent. From an early age the child will learn to work the video, television, and hi-fi equipment, often with great facility. Later this skill is likely to extend to computers, which encourages parents to believe that their child is precocious in development. Sometimes, the infant will spend time watching the washing machine go round, and may enjoy feeling the vibrations of electrical appliances. Vacuum cleaners are often a source of great interest. Spinning the wheels of toy cars is another common preoccupation, and the young child will resort to these activities when left to his or her own devices. Conventional toys, unless they have wheels to spin, or lights to flash, may be of little interest. As the child develops, so do the patterns of deviance. Despite the normality of early milestones, an overall picture of developmental delay may emerge. Possibly the child who gazed at leaves and shadows now scrutinises objects from an odd angle while endeavouring to catch reflections or obtain some other visual stimulation. In Chapter 2 we referred to Simon Baron-Cohen's CHAT assessment for 18-month-old children, which may pinpoint the limitations in the child's social functioning, which should be considered in relation to these patterns of behaviour.

At this point we must stress that normal infants and young children may engage in many of these activities. However, they do not form an overall persistent pattern that excludes other more meaningful interests.

Many severely affected young children with autism do not show a particular preference for their parents and are undiscriminating in their responses to people. Others may display what could be described as an obsessive attachment to one or other parent. Some maintain indifference to human contact and confine their attachments to objects. If these objects are removed there may be extreme distress. This is so much at variance with children who are not socially impaired, even if they have learning disabilities. For them, people are of prime importance and interest.

It seems likely that children with autism are born with the basic knowledge that they are members of the human race either absent or impaired. It is evident that socially normal babies are predisposed to communicate from birth, and start to make sense of the world within the first few weeks of life. It must be obvious that anything that interferes with these developmental processes will have very serious, and far-reaching implications. Without the intrinsic knowledge of the importance of people, it is not surprising that children with autism commonly treat them as objects. Those who enjoy physical contact may use the loving parent rather as a ‘cuddling machine’ which they will approach to satisfy their own needs. Yet when the parent wants a cuddle, they may well struggle and move away.

Similarly, when something is wanted by the child, he or she may use an adult’s arm as a tool, or alternatively may drag the entire body towards the object of his or her desires. This contrasts with the multiplicity of ways in which socially normal children make their needs known, not least by eye contact, pointing and engaging an adult’s interest, as well as by vocalisation or, indeed, words. So many of these deviant behaviour patterns would not on their own be of particular significance. It is their coincidence and persistence which are indicative of problems in social development. We cannot emphasise enough the fact that socially normal children continually attract the attention of parents and carers for reasons other than basic needs, and actively maintain this attention by showing a desire to share interests. If a child fails to initiate this type of contact and only responds in a limited way to input by the adults, there is reason for concern.

Yet it is easy for parents to ignore or explain away many or all of the signs and symptoms that we have described. It is the child’s failure to respond to speech and to develop very little himself which causes most concern and leads them to seek professional help, usually during the child’s second year. They will often report that their child began to say a few words towards the end of the first year, which were then lost and had not formed the foundation for further development of language. Others will express concern because their children only echo or parrot words that are said to them, but again are unable to generate speech or language of their own. Some parents are not alerted until a later stage because their children may have developed a large and sometimes quite sophisticated naming vocabulary. Concern only arises when it is realised that despite the size of the vocabulary, the children are unable to communicate. However, there are children with autism who develop speech at the normal time, and whose use of language may appear precocious. It is only when other problems arise, perhaps in school, that it is realised that they are not using their language skills communicatively. We will discuss communication in more detail in Chapter 7.

While the majority of parents, for whatever reason, do not become concerned about their child's development until well into the second year, there are some who sense that something is wrong at an earlier stage. Yet, looking at their attractive, robust and mobile child the parents find difficulty in pinpointing exactly what it is that is somehow not quite right. It may be because they recognise that this child is different from an older sibling, or from other children of the same age. To take such a child to a doctor risks a rebuff and the possible label of 'fussy parent'. The course for gaining a meaningful diagnosis is strewn with problems from the outset.

GENERAL OBSERVATIONS: APPEARANCE, MOVEMENT AND BEHAVIOUR

Typically, young children with autism not only look perfectly normal, but are positively attractive in appearance. This is one of the socalled myths that seems to be commonly observed and yet defies explanation. Many of these children appear to have an almost ethereal quality, which makes the diagnosis of autism seem all the more unfair and unjust. The attractive appearance is seen in children even when there is a severe degree of learning disability. Later, however, their attractiveness tends to diminish as body language and facial expressions do not seem to reflect the everyday life experiences which are so much a part of the human condition. An 'empty' facial expression, or a far away look, as well as occasional grimacing are additional characteristics seen in many children with autism.

The avoidance of eye contact has always been associated with autism and until recently was considered to be of great diagnostic importance. This assumption is very misleading because, although many children with autism *do* avoid eye contact, just as many gaze excessively. Others not only have eye contact, but use it meaningfully, albeit at a somewhat basic level – for example, looking at an adult for reassurance or approval. It is the 'intricate dance' of interactive eye contact which socially normal people engage in that is impaired. It is not therefore the simple presence or absence of eye contact which is important, but its quality.

Many parents of children with autism will have observed their child scrutinising objects at an angle usually out of the corners of their eyes. Sometimes they will hold an object in order to reflect light, which appears to give them pleasure. Others will lie on the floor for protracted periods while for example eyeing a toy train which they repetitively push carefully in and out of a tunnel. It is not unusual to observe young children with autism walking on tiptoe. This may be accompanied by hand flapping and even movements of the fingers which may have a sinuous quality. Body twirling is an activity which may be enjoyed, possibly for the sensory stimulation it provides.

As we know, the sequence of actions which normal children use to gain the attention of others for the sharing of interests is absent or impaired. So often parents will remark, 'It's as if he's in a world of his own.' We have heard this phrase used so frequently in relation to children with autism that it could merit inclusion in diagnostic criteria! Generally, expressive body language is not much in evidence.

Although many children with autism could be described as hyperactive, just as many are 'lollers'. They will do absolutely nothing unless they are made to participate in some activity. The active children with autism may engage in repetitive but aimless activities, such as running up and down, flicking and twirling objects. More able ones may show more complex repetitive actions. They may line up objects in a set order, or adhere to certain routines, the purpose of which appears to be for maintaining sameness.

When hyperactivity and attention problems become the focus of concern to parents and professionals it is not unusual for a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) to be applied. There is a failure to recognise the behaviour problems within the wider context of autism, and social difficulties are marginalised or seen as secondary. While we fully acknowledge that ADHD does exist in children who do not have social impairments, it is encumbent on professionals to consider the presence of autism when social difficulties coexist. The needs of the two groups are very different, both in terms of management and possible medication.

Verbal children with autism may make factual comments or talk endlessly about topics which are of interest to them, yet be unable to join in reciprocal conversation satisfactorily. Less seriously affected children may show only the subtlest evidence of this characteristic. In some children the repetitive activities appear to have a degree of creativity – for example, in drawing, pattern-making or even building and model-making. However, the outcome is stereotyped, although the initial impact of the activity may create a very favourable impression. The range of particular interests and obsessions which children with autism may display is endless. We have already referred to some of them. Other topics of interest we have come across include dinosaurs, makes of cars, timetables, train numbers, maps, and even supermarket bar codes.

In order to gain a greater understanding of a child's pattern of functioning it is necessary to evaluate evidence of goal-oriented behaviour. If the child is only motivated by food, the prognosis is likely to be less favourable. It is as well to remember that the acquisition of food is a very basic instinct, and the ability of a child to open a freezer and hide away ice-cream for later consumption is not as impressive as it may appear. If, on the other hand, the child shows some resourcefulness in other areas of need and interest the outlook is more positive.

It is very usual, but by no means universal, for children with autism to show great distress when exposed to even minor changes which upset their familiar routines. Some children are so bound by their routines that family life is disrupted. They will insist on their parents and brothers and sisters performing certain rituals before they will co-operate even in such simple activities as sitting down for a meal or going shopping. Many children with autism will insist on a certain route being followed and will have a major tantrum if they are taken in a direction which deviates from the one they are familiar with. Yet, paradoxically, more radical changes and new experiences may go unnoticed and these same children will adapt to outings and holidays without any signs of disturbance.

One of the greatest difficulties, which even more able children with autism have, is the inability to generalise. Although they may know what to do and how to behave in one situation, they are unable to use that experience and adapt it when a new situation arises. There is a pervasive naïvety which sets them apart, despite adequate intellectual understanding. For example, a child may have been taught not to make personal comments about Mr Brown's bald head, but when confronted by an obese Mrs Smith will pass the time of day by drawing attention to her size. The inability to generalise extends to all areas of daily life, and the degree of difficulty may be disconcerting to the onlooker. An example of this is a boy of 12 who on a school holiday, when told to put shampoo on his hair, a task regularly carried out at home, proceeded to place the bottle on his head. It is a fact that able children with autism in mainstream schools may quickly lose any chance of making friends because of their tactless or boastful remarks which socially normal peers take exception to. All these problems can be understood in terms of impaired theory of mind and weak central coherence. The child with autism cannot put himself into another person's shoes and will have little idea of what causes upset and offence. If a child has difficulty in extracting what is meaningful and central to a situation, then he will have difficulty when a similar situation arises. Taking the shampoo scenario as an example, this particular boy could not say to himself, 'shampoo, I use it at home in the bath to wash my hair – here I am in a shower in a strange place, I have to wash my hair, I will use the shampoo as I do at home.' This may sound overly simplistic to socially normal people, but it does encapsulate daily living problems for people with autism. However, maturation together with appropriate teaching can have very positive effects on these areas of difficulty, and much progress can be made.

Awareness of danger is always a problem, because although the child with autism may be taught to avoid a particular danger in a particular situation, he or she cannot anticipate an identical hazard in an unfamiliar setting. As children with autism get older, they may learn strategies for coping with new and unusual situations, especially if they are at the upper end of the autistic continuum. Nevertheless, they will remain vulnerable as it is impossible to teach adaptive skills for all the changes and variations which are part of everyday life.

There have been many attempts to identify sub-groups within the spectrum of autistic disabilities. We have ourselves experience of a few children whose behaviour, while not homogeneous, can be depicted as bizarre in the extreme. For our own use, we have coined the term 'deviant autism', although 'Pervasive Developmental Disorder' (a wide-ranging diagnostic grouping in use primarily in the United States) would encompass such children. Typically, there is a developmental history suggesting autism, including delayed language development. Between the ages of four to five years however, language develops at a rapid rate in the more able children, and many aspects of autism appear to recede. Hopes may even be raised for an optimistic outcome as many children may make satisfactory academic progress. However, it becomes apparent that despite this, they develop a pattern of deviant behaviour. Sometimes this is manifested by especially odd and intractable preoccupations which dominate their lives.

Other variations of behaviour which encourage us to place children within this group include extreme task avoidance. Despite cajoling or even threats, such a child may spend an entire morning without achieving anything, although he is not without capability. We have encountered children who swear and use verbal abuse, and others whose physical violence resulted in exclusion from nursery school. These children appear superficially to have an awareness of what goes on in the minds of others. They are particularly adept at knowing how to disturb and annoy people around them, often causing considerable mayhem. It is our view that this behaviour seems to satisfy some perverse need in the child, and does not indicate any real awareness or concern for the needs of others. Self gratification is their maxim, and they are adept at manipulating irresolute parents. As time goes on their behaviour patterns can become habitual and present difficult management problems. Such children require considerable structure, and may respond well to behaviour modification approaches. We are by no means certain whether it is appropriate to separate diagnostically these comparatively unusual children. It may be that they could be included within Asperger Syndrome. Some behaviours seen in the ‘deviant group’ are similar to those seen in Tourette Syndrome, which has been linked to autism in the literature. Whatever they are called, and however they are grouped, these children are extremely difficult to manage both at school and in the home.

The behaviour of children whose autism conforms to the more classic picture is not necessarily dependent on the level of intellectual functioning, although the ways in which the behaviour is manifested is likely to be different. For example, lower functioning children may leap about, yelp and call repeatedly, as well as showing other behaviours which make them conspicuous in the community. More able children may giggle inappropriately, or repeatedly question and pester adults about inconsequential topics, which again marks them out in society. Whatever level of functioning, appropriate and positive behaviour management programmes can make a really impressive difference. It is a mistake to neglect behaviour problems in favour of academic goals. Academic achievement on its own will be of little practical use in adult life if serious behaviour problems which preclude social contact and damage working relationships persist.

This leads us to consider the implications of the social impairments which Lorna Wing has described and which we referred to in Chapter 2. What does this mean in practical terms? The most severely affected children not only fail to respond to language but also shun all physical contact. Attempts to touch and cuddle them are rebuffed and such children appear to be distressed by the intrusion of people. This extreme isolation is very upsetting for parents as there seems no way in which they can demonstrate affection or even offer comfort when their child is distressed. Children with autism are often described as 'withdrawn', as though they have taken a decision to remove themselves from society. This represents a misconception of the social difficulties inherent in the condition. The children have *not* withdrawn. In fact, they have not yet learnt to understand and gain pleasure from human contact. Fortunately, as they get older, the majority learn not only to accept physical contact but even to enjoy it. It may surprise people who think of autism inevitably in terms of remoteness and isolation, to learn that many children with autism not only like being cuddled, but actively seek out physical contact from which they derive great pleasure. However, as mentioned earlier, many parents, despite the fact that their child initiates such contact, have felt that it was always on the child's terms and was not truly reciprocal.

It is very usual for children with autism to enjoy rough and tumble games, such as tickling, chasing and being swung about. Many children with autism will learn to co-operate in group activities organised by adults. More able individuals will allow themselves to be used by socially normal children in their games and it is possible for them to learn how to behave appropriately in familiar situations. Indeed, at the upper end of the continuum, children with autism and adults may want desperately to participate in social activities but have little or no idea how to go about it. The social skills which normal children acquire without any teaching whatsoever, and the subtleties and nuances which we take completely for granted, are beyond people with autism, and become a source of confusion and anxiety. An approach to social skills teaching will be discussed in Chapter 7.

However great the intellectual capability, the lack of social skills is an enormous and wide-ranging handicap which affects every aspect of life. Adolescence is often a difficult time for all young people. For more able teenagers with autism, the increasing social com plexities may be something of a nightmare. They are aware that they are different, yet are unable to work out what it is they have to do to make themselves socially acceptable. For these young people a programme of social skills training will be helpful. Such intervention may avert further depletion of confidence, feelings of depression and possibly more difficult behaviour. The pervasive social naïvety inherent in autism may lead some individuals to behave with sexual impropriety. Patricia Howlin's book *Autism: Preparing for Adulthood* (1997) includes a chapter on problems with sexual relationships which should be helpful to all parents, especially those with older children.

ATTENTION CONTROL

This term describes how well a child is able to concentrate or attend. It is a fundamental necessity for all children, and there are developmental stages which range from the extreme distractability of a young baby to the sustained and integrated attention which most four- to five-year-olds demonstrate when they enter school (Cooper *et al.* 1978). In other words they are ready to learn. Typically the young child with autism is very easily distracted unless he is focusing on an activity which is of particular interest to him, or indeed meaningful. Because one of the problems inherent in autism affects central coherence (extracting what is meaningful – see Chapter 2), attention problems will invariably ensue. Those children with autism who make good progress in the acquisition of attention skills, so that they are able to respond to the interests and demands of others, are most likely to make good academic progress. We cannot stress enough how important it is to consider how well the child attends. So often there is a focus on, for example, a lack of speech, without the realisation that the child is failing to attend to what is said to him. Attention is one of the vital underpinnings on which development and learning are based.

SENSORY FUNCTION

Sensory function refers to such things as the use of vision, hearing, touch and smell. Visual perception, or the awareness and recognition of visual stimuli, is commonly an area of ability among children with autism. They often show skill in shape matching, jigsaws and formboards. Normal children's abilities in this area progress to the formation of visual concepts; that is, they develop understanding and make sense of what they see. It is always necessary to consider whether skill in the area of visual perception is age-appropriate in children with autism, or whether it is merely an area of relative ability (meaning better than other areas of development).

There is considerable evidence that children with autism learn best through the use of visual strategies. Temple Grandin, an American, animal scientist, in her book *Thinking in Pictures* (1996), explains that her thoughts are like a running video in her head, and these visual images, replacing words, provide her with meaning. This is highly relevant to the teaching of children with autism and will be discussed in Chapter 8.

Some psychometric tests place considerable emphasis on performance skills, which in essence are the abilities which we have just described. This has led some professionals to present a far more optimistic picture of a child's potential than is merited. It is as well to bear in mind that prodigious skill with shape recognition and block design does not indicate abilities which necessarily augur well for future outcome. Additionally, it is not unusual for children with autism to make use of their equally prodigious memories and provide a deceptively favourable impression of their capabilities. Other children, those with better cognitive skills, can make progress in learning visual concepts, albeit at a slower rate and often in an incomplete way.

On the auditory or hearing side, children with autism often display particular traits. It is not unusual for them to be considered deaf, because they do not alert to the human voice and seem quite impervious at times to even loud noises, and we know of one child who was given a hearing aid. Careful observation should reveal that the child hears perfectly well, if the sound is of interest to him. For example, the rustling of a sweet paper or opening of a biscuit tin or even a favourite TV jingle, will bring him running from the far end of the house. Some children with autism show extreme distress to auditory stimuli in general, while others demonstrate distress in response to certain sounds which they do not understand, such as a man coughing. They will sometimes attempt to shut out the sounds by putting their hands over their ears. They may also do this when they do not want to heed what is being said to them, or even when they want to rid themselves of an unwelcome presence.

Although some children with autism seem very fleet of foot and physically agile, especially when they are young, the majority of children with this diagnosis appear clumsy, with evident motor problems. Many seem to ignore obstructions, human or otherwise, and will walk over other people's feet seemingly unaware of what they are doing. They may also show an equal lack of awareness when a bicycle wheel goes over their own foot. In later childhood and adolescence, even the physically adept children may begin to look awkward; possibly because their lack of body language, a symptom of their underlying social impairment, limits the free expression of movement which is part of human communication. Whatever the underlying reasons, motor problems and clumsiness have long been linked to Asperger Syndrome.

Proximal senses are the senses which deal with touching, smelling and feeling. It is very usual for children with autism to sniff, lick or scratch surfaces, themselves, or even other people. These activities are generally associated with lower-functioning children. It is advisable to discourage firmly indiscriminate touching of other people, because although it may be tolerated in a young child it can become a serious problem with older children and adolescents. It is obviously easier to establish patterns of acceptable behaviour in small, physically manageable children. Another characteristic of some children with autism is a lack of awareness of pain, heat and cold. They are less likely than normal peers to be able to locate and express the source of discomfort. Generally, as they mature their body awareness improves.

In recent years, a number of very able people have written accounts of their own experiences of having autism. In terms of sensory functioning, Temple Grandin has also provided us with graphic insights into her own strengths and problems. Her ability to describe autism as a culture, and a different mode of being, enables non-autistic people to gain some understanding of another world. In childhood, exposure to bright lights and loud noises was an unbearable intrusion which as an adult she has learnt to cope with. From her descriptions it is easy to understand why so many children with autism become so difficult to manage in supermarkets or in busy, noisy and crowded places. She advises that a stimulating classroom environment, which may be ideal for non-autistic children, may be quite the reverse for those with autism.

Sensory integration therapy has been used, primarily by occupational therapists, to treat the sensory anomalies and motor problems commonly seen in children with autism. The belief is that in autism the developing brain is not able to attach meaning to sensations and organise them into percepts and finally into concepts. The treatment consists of activities involving the balance centres, skin receptors and tendon, joint and muscle receptors. Temple Grandin has consistently maintained the importance to her of applied pressure as a means of calming herslf. We will refer to sensory integration therapy again in Chapter 10.

SYMBOLIC UNDERSTANDING

This term refers to the understanding a child displays in relation to objects and their use which does not involve language. In other words, we are looking at the quality rather than the quantity of a child's play. The typical play activities, if they exist, of many young children with autism will consist of lining up cars and spinning wheels and other objects, looking or flicking through books and completing jigsaws. There is often a lot of aimless running about, and social play is confined to chasing and rough and tumble pursuits. Swinging, and even lying upside down or in odd positions, can be favoured pastimes. Parents will often report that their child's greatest enjoyment, it would seem in lieu of play, is watching videos and television. Usually there are particular favourites which will be selected time and again.

By the age of one, a normal child recognises familiar objects in his surroundings, such as his cup or bottle, brush or coat. Later, at about eighteen months, when his understanding has developed further, he will realise that small-sized objects represent the normal-sized ones which are familiar to him. At about this time, play with large dolls and toys will be in evidence and the child will begin to demonstrate simple play routines, such as feeding, washing and putting dolls and teddies to bed. From about two and a half years of age a child will begin to enjoy play with miniatures – doll's house sized people and objects. The play routines will become more complex, and imagination and creativity in the play will become more evident.

Many children are less interested in doll play, but will demonstrate creativity and imagination with constructional toys, for example, producing a wide and varied range of vehicles, buildings or roads. The normal child develops further into a social and friendly being who seeks out and enjoys the company of other children. Generally, by the age of 3 years, the child has learnt to take turns to a greater or lesser extent; and to join with his peers in group play and activities from which he derives a great deal of pleasure. The

Lowe and Costello 'Symbolic Play Test' is often used by speech and language therapists to assess a child's ability to use play materials. It consists of a number of simple play scenarios utilising miniature dolls and objects. These scenarios range from feeding, brushing a doll's hair, laying a table, to lining up and loading a tractor and trailer. However, this test has limitations since even children with autism and severe learning difficulties may get a full score, meaning that they can demonstrate appropriate use of all the miniature objects, yet in real life it is clearly obvious that they fail to play imaginatively or creatively.

The essence of developing symbolic understanding in relation to play is variety, inventiveness and imagination. These qualities highlight the characteristics of normal play, contrasted with the play often shown by even more able children with autism. The latter group may indeed play, but there will be a reiteration of certain themes particular to the child's interests. For instance, a child may repeatedly dress and undress dolls, set out meals and feed them. Some children may talk to and for their dolls, while others may produce impressive models from bricks or lego. Casual or 'once off' observation of such a child's play may result in autism being excluded as a possible diagnosis. Those with experience of the condition will, however, recognise the limitations of the play which, though more complex, is repetitive and fails to lead anywhere. Sometimes children with autism who have particular interests can to some extent manipulate and develop them and even display some apparent imagination, which again may confuse an inexperienced observer. Because there is a derived or learnt quality to such play, we would classify it as 'mitigated' rather than true creativity and imagination. In other words, it is not the presence or absence of imagination that is crucial in children with autism but its quality.

An example of well-developed, yet idiosyncratic play activity occurred in a child known to us who was obsessed with vacuum cleaners. He could not only use them, but could draw them, model them in plasticine and also pretend to plug them into imaginary electric sockets.

It is not easy to pinpoint the characteristics of true pretend play, and what distinguishes it from the play sequences that we have described. Professor John Morton of the Medical Research Council Cognitive Development Unit, in an article published in 1989, highlighted the essentials.

Not all play is pretend play. Take for example the case of a child who plays with a toy saucepan on a toy stove making the kind of movements, for example stirring and shaking, that mother makes on the real stove. This may be merely functional play, a re-enacted memory. However, if the child sniffs and says that there is bacon frying and varies the play according to the dish, then this is pretend.

Even if a child with autism is not capable of pretend play, but is able to demonstrate functional play and occupy himself pleasurably in this way, it is no mean achievement and should be developed and encouraged.

By the age of three and a half to four years, most children seek out and enjoy the company of others. Many professionals working with even the most able children with autism are astounded, when observing normal children, by the richness of their sociability and their in-built capacity to make friends. Somehow, subtle social rules are used and understood without adult intervention. Children with more specific language difficulties may also display impoverished play and sociability, but this usually reflects immaturity rather than the patterns of deviance typical of children with autism. It must be borne in mind that limited play skills alone do not indicate autism. It is the coincidence of many behavioural and cognitive aspects which makes such a diagnosis appropriate.

Yet paradoxically, as children with autism progress towards middle childhood, they may develop a real desire for friends and play opportunities. Some socially normal or younger children may be willing to involve a child with autism in their games and activities, sometimes as a 'baby' or a 'patient' when playing mothers and fathers or doctors and nurses. Chasing games allow greater scope for drawing in children with autism, although games with subtle rules will almost certainly prove to be beyond them. Board games, however, do offer scope for more able children with autism as there is a predictability about the way in which they are played, and in addition, a better than average memory may promote success. Cards, chess and draughts are likely to be favoured. Although able children with autism may refer to wanting or having friends, it is inevitable that their concept of friendship is limited; their social impairments, however mild, are an obstruction which will set them apart from the socially normal population. This is particularly poignant when children with autism express a deep-felt need for friends yet are unable to appreciate why they find it so difficult to acquire them. However, with better understanding of the nature of autism, a social skills approach through group work enables children and young people with autism to acquire some insight into the mysteries of interpersonal relationships. This approach will be explored in Chapter 7.

CONCEPT FORMATION

This term is used to describe the development of a child's understanding of the world about him. It evolves out of the perceptual processes which we described earlier. Children with autism often display skills and abilities which are either on a par or in advance of their chronological age. It is natural to assume that these skills and abilities would be accompanied by a corresponding level of understanding. Yet this is not the case. Children with autism appear to be able to learn in the absence of understanding, so that the apparent knowledge they have cannot be utilised and extended as would be expected with a normal child. Lorna Wing's comparison of this phenomenon with 'tower blocks in a desert' is a meaningful visual image. It describes well the lack of connections between what is known and explains the contradictory character of the learning of children with autism. As we have already mentioned the assumption is that these tower blocks, or 'islets of ability' as they are sometimes called, reflect the true level of the child's functioning. It would seem reasonable, therefore, to search for ways to 'unlock' or 'break through' to all other areas of development where it is assumed that latent ability lies dormant. Sadly this is not so. The remarkable thing is that very low-functioning individuals can possess skills and abilities which are not only normal but may amount to a gift. In his book *Extraordinary People*, Darold Treffert describes individuals with severe learning disability who nevertheless show amazing and seemingly inexplicable feats of apparent intellectual prowess which defy belief. The 'Savant Syndrome' which he describes is of course very rare, but awareness of this condition may enable parents of severely affected children with autism to see islets of ability in perspective.

When assessing concept development in children with autism it is useful to include, at a basic level, colour, shape and object matching. These tasks require only minimal understanding but, as they increase in complexity towards sorting and classification skills, children with autism commonly run into difficulties because of problems with central coherence. In other words, they do not know how to extract what is meaningful. Even when they have adequate intelligence, adequate language and know the facts, they may fail to 'cotton on' and see the obvious. An example of this was the inability of a group of three verbal and bright children with autism to appreciate the link between cold drinks and the use of a refrigerator. Despite the fact that they were familiar with fridges, both at home and in school, they were quite unable to respond appropriately to the question 'Where will we put these drinks to keep them nice and cold?' However, it is a comparatively easy task to teach able children these connections; what is taught they will know, but they cannot adapt their knowledge to other situations. Some children may show a remarkable degree of sophistication at times, yet remain essentially naïve and unknowing about the ways of the world.

It is also important to ascertain whether a child has developed an understanding of size – for example, big and small, long and short, fat and thin. Does the child appreciate same and different? Is he aware of quantities – for example, more or less, big, bigger, biggest? Does he understand the position of himself and objects in space – for example, in, on, under, and at a later stage, near, behind, in front of, left, right, etc.?

The sum total of the child's development of understanding the ways of the world can be coined in the current idiom 'street wise'. Children with autism do not have this capability, even when they are intellectually able. They remain naïve and unworldly, reliant on what they have been taught. This is why issues surrounding their management and education are of such importance. A focus on academic learning in the absence of social and life skills training is inappropriate for the needs of even the most academically able individuals with autism. This will be discussed in more detail in Chapter 8.

SEQUENCING AND RHYTHMIC CAPABILITIES

The ability to understand the passing of time and the sequence of events is an area of competence which has important implications. Once again, more able children with autism will be able to learn how to sequence colours or shapes in order, but may not be able to use this facility to arrange pictures to form a meaningful story, especially if the story involves the attribution of states of mind.

Sequences can range from simple 'mechanical' situations (for example, a child flying a kite which gets stuck in a tree and has to be retrieved), to far more complex scenarios which can be termed 'mentalistic'. The latter are the stories which include the attribution of states of mind which people with autism find particularly difficult. For example, a story about a boy who puts a can of coke in the fridge, then goes off to play. Dad comes in and goes to the fridge and drinks the coke. The boy returns to the fridge and finds that the can of coke has gone. To make sense of such a story sequence the child has to have an understanding of another person's perspective – in this case the boy's expectations and subsequent disappointment.

It is possible that a child with autism once shown the correct order, may learn to sequence a variety of stories both mechanical and mentalistic and even be able to accompany them with appropriate commentaries. However, it is always important to consider whether the child has really extracted meaning from the story or simply made use of good memory skills for someone else's commentary.

Eventually many children with autism learn to appreciate the passing of time. Their anxieties are reduced as they gain understanding of the world about them, and life generally becomes more predictable, and therefore less frightening. They learn to reflect on past events and look forward to the future, albeit at a simple level. Gaining this understanding can have a positive effect on management, as the child learns not to expect immediate gratification, but instead gains some pleasure from anticipation. (See Chapter 6.)

Awareness and enjoyment of rhythm and music is common among people with autism and it is not unusual for young children to show musical ability. Music therapy may have a very useful place in their education, especially with lower-functioning children where communication skills are very limited. The child is encouraged to interact through music with the therapist. It must not be assumed that music therapy will be a panacea, but it can provide not only enjoyment but the beginnings of a dialogue which may accelerate the child's rate of development.

6

PRACTICAL CONSIDERATIONS – MANAGEMENT AND COUNSELLING

Much has been written about the management of children with autism and the difficulties that parents encounter. At the outset, it is perhaps necessary to make the point that what one set of parents will regard as a major problem another set of parents will cope with and not regard as a problem at all. Indeed, some parents are so unaware that their child has problems that it is only when he goes to nursery or school that their attention is drawn to the difficulties. This is particularly the case with able verbal children whose unusual or idiosyncratic behaviour is seen simply as a manifestation of individuality if not giftedness.

However, for the majority of parents the difficulties are only too obvious. Sleeping problems are very common. Many children with autism seem to require very little sleep and parents report that nights are interrupted and the household disturbed for years on end. It is not unknown for parents to reach the end of their tether and in desperation resort to locking their child in his bedroom. Although this measure may invoke shock/horror reactions, it is entirely understandable in the context of a child wandering around the house, not only waking everyone up but possibly harming himself and not least leaving havoc in his wake. Even if the sleep problems are not as severe as this, the majority of parents do not welcome the company of their child throughout the evening and it inevitably puts a strain on family relationships if there is no time for siblings to have attention, or indeed for the parents to have time for themselves.

Because of the idiosyncratic nature of autism, other problems requiring careful management may occur. Some relate to the child's insistence on repeating particular activities such as opening and shutting doors, watching a particular video, listening to a particular CD, or persistent and meaningless questioning over and over again. One of the advantages of joining a parent support group is that problems can be aired and management techniques shared, which is sometimes a lifeline for fraught families. Many parents have shown great ingenuity in solving what appear to be very daunting problems, sometimes with the injection of humour which eases the burden.

There has been a huge increase in the number of books and articles about the management of children with autism which cover the problems commonly associated with the condition. The National Autistic Society publishes books, pamphlets and fact sheets covering a wide range of topics (see Appendix 2). The NAS also markets books on autism as they become available, which may cover personal accounts as well as more academic and factual research findings. Members of the Society, which targets both parents and professionals, have access to regular information and a quarterly journal. When children with autism have severe learning disability, parents may find some useful information from organisations such as MENCAP (see Appendix 2).

In some parts of the country, clinical psychologists are available to advise parents and offer support and management programmes. These may be especially useful for reducing behaviours which are particularly distressing and difficult to manage.

The range of management problems does appear to have a certain predictability and many of them will be similar to those encountered among children with learning disability. Sometimes progress with toilet training may be particularly slow; some children will only use a particular toilet. Others become either obsessed with, or terrified of, the flush. Soiling and the smearing of faeces are not uncommon. Dressing and self-care skills may be well within a child's capability, yet he will refuse to co-operate; hands adept for chosen activities become floppy and useless when it comes to putting on socks and doing up buttons. Parents will go on dressing an older child with autism, sometimes in desperation, in order to get him to school on time.

Eating habits and likes and dislikes are often extreme. Children may eat only a very limited range of foods or insist on eating and drinking only from certain plates and cups. Some children are resolute in their refusal to eat sensibly and consequently have a waif-like appearance while existing apparently on air. Others may be obese on a diet which consists exclusively of burgers and chips. A sustained programme of persuasion, and even coercion, to accept an increasing range of different foods has in our experience been very successful. For parents who for some time have been locked into a particular pattern of food provision, this may be impossible to carry out, and is therefore best implemented as part of a nursery/ school programme. Not only do the children then have a wider diet in school, but there is frequendy a carry over into home. With a better diet, the appearance of the children may improve quite dramatically and their behaviour becomes less 'cranky'.

Parents of socially normal children may well have encountered similar problems. However, with autistic children, their lack of amenability as well as their intractability may be of diagnostic significance when viewed in conjunction with other features of behaviour. Some parents feel that their child's anti-social table manners and unpredictable behaviour precludes the possibility of eating out as a family. Even modest excursions to the local McDonald's, let alone to grander establishments, are so fraught with potential embarrassment that they are hardly worth contemplating. One family found a solution to this problem which was both simple and effective, as well as unstressful. They decided not to inflict their son on the local community nor on people whose enjoyment of gastronomic delights would be seriously marred by his presence. They hit upon the idea of utilising the eating facilities of motorway service stations for training purposes. Their fellow diners, an anonymous population in transit, paid little heed to their son's outbursts, and while the family became acquainted with the country's motorways, the child's social eating habits improved dramatically. Later, they were generalised into other settings.

Some lower-functioning children with autism display 'pica'. This means that they will eat inedible substances, such as buttons, Blu-Tac, worms, sand, decaying leaves – in fact anything. Such children have to be watched very carefully as within a matter of a split second the child may make a grab for whatever he has a predilection for, and is well on the way to swallowing it before the adult has even realised what is happening. A variation of this is grabbing other people's food from their plates at mealtimes. All behaviour associated with pica needs an appropriate programme of behaviour modification.

We have lost count of the parents who relate horror stories about shopping expeditions and their children with autism. Many of our major supermarkets have witnessed sensational tantrums as a child with autism gives vent to his particular dislike of shopping procedures (not least the checkout queues), but it may not be as simple as this. It is very likely that some of these children are adversely affected by the lighting and the visual bombardment of displays which have the effect of over-stimulating their sensory systems. This may cause not only severe discomfort but real distress and anxiety.

Many parents have been upset by the attitude of other shoppers who, belied by the child's normal appearance, comment adversely about the lack of discipline. More resilient parents will not alter their shopping habits and will cope with trolley and child while informing their critics about the nature of autism. However, for others, for whatever reason, this is not an option.

Additionally, a child's lack of awareness of danger and tendency to run off will compound the difficulties associated with even the simplest trip outside the home. Some parents solve the problem of children refusing to have their hands held in the street by using a webbing strip with velcro fastenings which can encircle both their wrists. These simple and effective accessories can be obtained from High Street outlets such as Mothercare.

The majority of parents of children with autism are likely to alter their lives to a greater or lesser extent in order to avoid shopping expeditions and other outings too. Sadly, some parents are so stressed by the behaviour of their young or particularly difficult children outside the home that their own lives become increasingly restricted, which may have serious repercussions on partners and other children in the family. Such parents may be considerably helped by professional intervention, and should not be deterred from seeking help because of its scarcity, or from a feeling that asking for it is an admission of failure. It is a mistake to conclude that 'soldiering on' is the only option.

We have already mentioned that some children with autism are afraid of lavatories flushing. In addition some children may be fearful of a wide assortment of innocuous things which may range from the more rational, for example dogs, to the seemingly irrational, such as someone coughing. Some fears are transient, only to be replaced by new ones, while others are longer lasting. Masturbation in public is often a problem with children with autism and can cause parents a great deal of embarrassment. Sometimes common-sense strategies can prevent the most obvious excesses of the habit which may be seen particularly in lower-functioning children. For example, dressing children in trousers that are reasonably tight fitting around the waist and without elastic, with the addition of braces, can deter the child from constantly pulling down, or putting his hands down his trousers.

It is important to emphasise the fact that no two children with autism are alike. Each presents in an individual way which reflects his or her own personality, family background, experiences and, most importantly, intellectual capability. Their individuality exists in exactly the same way as in the socially normal population. We need to emphasise this, as so often professionals fail to recognise autism because the child in front of them is very different from the child with autism they saw once upon a time. This is a really important concept for both parents and professionals to assimilate, and has implications not only in relation to diagnosing autism but in relation to management and education.

Perhaps one of the most difficult situations arises when features of autism are misunderstood by well-meaning, but ill-informed, professionals who interpret the child's difficulties as symptomatic of parental mismanagement or poor parenting skills. This so often feeds on the guilt that the majority of parents appear to suffer these days in relation to hours of work, childcare arrangements, marital breakdown, and even television and video viewing. It is difficult enough to have to cope with a child with special needs, without being blamed even indirectly for causing them. Inappropriate interpretations and conclusions have the effect of delaying more constructive approaches and attitudes to the problems that the child and his family are experiencing. This may be critical if it prevents the child having access to services and resources relevant to autism. When autism is diagnosed it is essential to reassure parents that they have *not* caused the condition. This is not to say that some aspects of their management of the child could not be improved upon.

HELP AND ADVICE

Counselling is a word which has passed into common use (or even over-use) in our society and may be provided not only for survivors of disasters and the bereaved but for those with less dramatic or acute problems, such as receiving a diagnosis of autism, the effects of which may be no less devastating for some families.

There is something particularly poignant about discovering that you are the parent of a child with autism. As we have already mentioned, typically children with autism are normal and attractive looking. Developmental milestones are often within normal limits and the child may even display precocious ability in particular areas. Often, for as long as two years or more the parents will have believed that their somewhat odd or puzzling child was normal, if not bright, and at worst appeared to be delayed in acquiring language. To then learn that the child has a disability with lifelong implications is likely to come as a terrible blow. Obviously we do not want to minimise the trauma for parents learning that their newborn baby has a serious condition such as Down's Syndrome, which also has lifelong implications. However, right from the start their expectations are of necessity defined by their awareness of the condition. Conversely, parents of a child later diagnosed as having autism have expectations of normality. To then discover that the child they believed to be perfect has a condition with a name to it may be, as one parent put it, 'like being told you have cancer'.

Parents in this situation will often deny the diagnosis very vigorously, or may embark on a series of consultations with professionals of a variety of disciplines, as well as those promising 'recovery' or a cure, in attempts to prove the diagnosis wrong and to find out 'what is *really* the matter'. In fact they want to be told that their child is normal and will grow out of it (whatever *it* may be) which is perhaps understandable. Possibly this is a reason why some parents are attracted to unsubstantiated treatment programmes, such as facilitated communication, sound and light therapy, or even swimming with dolphins. They offer hope, and it must be acknowledged that there are parents who would choose to live in an unreal world where assurances of a cure are provided, despite all evidence to the contrary. This may reflect a failure on the part of professionals to provide good quality support for parents at the right time. This should follow immediately after the diagnosis. Yet the majority of parents report that they are given the label and then 'left to get on with it'. No wonder that they pursue so many false trails in their endeavours to do the best for their child. Any parent whose child receives a diagnosis of autism deserves input from a specialist in autism who is skilled at balancing realism with optimism, and who is capable of generating a positive and hopeful outlook in the parents. This should of course be done in conjunction with an early intervention programme, so that parents feel that they can play an active part in developing their child's full potential.

Yet we have been surprised by the strength of feeling in parents who assert that they would rather live with false hopes of a cure for the condition of autism than accept what we would call a realistic appraisal of the situation. We would argue that sooner or later these parents are likely to feel extremely angry and disappointed when their hopes are not fulfilled and may well blame teachers and therapists for not putting in enough effort into making their child better. We have the impression that such situations are more likely to arise where there are family problems, emotional difficulties and discord. A child with autism may be the final straw in the break-up of a relationship or else become the focus of a crusade for access to a particular remediation programme, which enables problems to be set aside at least in the short term.

We have known extreme instances where the diagnosis of autism is so abhorrent that parents will go to any lengths to avoid recognising their child's problems in this context. Threats of litigation may be directed to any professional who raises the possibility and any references to autism have to be erased from reports. Parents, if they have a mind to it, will have little difficulty in finding receptive professionals to co-operate in providing them with a more 'acceptable' diagnosis. Sadly, this may be positively harmful to the child, whose rights and needs may be subsumed while the parents mount their campaign.

Coming to terms with the diagnosis is in effect coming to terms with the loss of a child through bereavement and learning to contemplate a future for their child and themselves which is different from their earlier expectations. This process, just as with bereavement, can take some considerable time and will be as individual as the people undergoing the experience. We understand the trauma parents may feel when their child who, five minutes earlier they had regarded as normal with seemingly minor problems, is now 'autistic'. One parent vividly expressed her feelings after hearing the diagnosis: 'I looked at her and all I could feel was, you poor thing, you are an autistic child.' It was as if the child she had known was no longer there and the little girl became the personification of a label. Fortunately, in our experience, for the majority of parents, these negative feelings pass with time, and parents are then able to see that despite the autism their child is still the same. It is only their own perceptions or awareness that have altered. All children with autism have aspects of normality and these can be enjoyed. They do develop and, just as with socially normal children, they will give both pleasure and pain to their parents. Indeed, some parents come to see their child's autism as so much an integral part of his personality that they would not wish him to be different. His unusual characteristics make him the person that he is, and as such he is accepted and cherished.

We were motivated to write the first edition of this book to provide information and answers to the many questions that parents asked when their child was diagnosed. At that time, there was so little knowledge of autism among professionals that anything we could provide to prevent misinformation would be of value. Although the situation has improved – for example, in some areas early intervention projects have been established – in general the picture remains unsatisfactory. Parents are all too often still in the position of having to find things out for themselves. It is our view that the more knowledge parents have, the more they will be able to make informed decisions relating to their child's needs. Their concerns will vary, from the practicalities of daily living to decisions about education. We recognise that although many parents do require skilled counselling from professionals with experience of autism, there are too few individuals who are able to offer this help. It is often a matter of luck or chance that some parents are well supported and advised, while others flounder for years on end without receiving an appropriate diagnosis, let alone appropriate advice and support.

Rather than offer specific advice which could be misconstrued and misapplied, this chapter will focus on very general guidelines for problems relating to the management of children with autism. Once again we have to highlight the variability of the condition, and what may work for one child may not work for another. We do not wish to promote the idea in terms of success or failure. As often as not, trial and error and lateral thinking can enable parents to solve some problems as they occur. Other problems diminish with the passing of time and children may grow out of a particularly difficult phase and become easier to manage. Generally, children with autism become more amenable once past infancy. This is not to say that the troubles are over, but the most exhausting problems, relating to sleeping, eating, and temper tantrums, do tend to recede and life becomes calmer.

First of all, be consistent with your child. In other words do not keep moving the goalposts; this will cause confusion. Decide on a set of rules and try to stick to them so that the child knows where he is and what is expected of him. It is important to establish priorities. Go for the things that are essential and be prepared to waive the less important issues.

Remember that until a child can attend to a task or activity for at least a few minutes at a time, he will not be ready to benefit from attempts at teaching. It may be more helpful for parents to focus on helping their child to attend as an end in itself, rather than attempting to teach new skills. As the child's attention span increases, so will the range of relevant goals. For example, rather than trying to get a distractible child to name pictures in a book, aim to persuade him to sit down and share looking and listening activities. Try to inhibit page flipping and fixations on details, such as words or numbers on a page, which may be meaningless.

Be aware of the child's developmental level and not necessarily his chronological age, so that only developmentally appropriate skills are taught, with simple and immediate rewards for success. It may be possible to use the child's repetitive activities (such as twiddling, or watching a particular video) as a reward when he has done something that you want him to do. Physical punishment is not generally appropriate. The exception may be in an extreme or life-threatening situation such as when a child dashes into the road or climbs on to a high ledge. In such situations, any punishment must immediately follow the deed, so that an association is made, even if the danger is not understood.

It is not helpful to regard the behaviour of children with autism in terms of 'being naughty'. The concepts of naughtiness and goodness may be well beyond the child's level of understanding. Similarly, children with autism may not respond appropriately to what most people would regard as sad or worrying events. Although they may appear to understand what is happening it is very much in the here and now, and they will lack the imagination to appreciate the implications. An example of this concerned an able 11-year-old boy attending a mainstream school. His father had a heart attack on a train, which necessitated immediate hospitalisation. The only feelings about the event which the boy expressed were in relation to the loss of his Gameboy, which was left on the train.

A straightforward rule-based approach is likely to be more effective than long, involved explanations. Therefore, 'No, don't do that', is sufficient and will cause less confusion. If changes are to be made do not try to do everything at once. Deal with one issue at a time.

If your child is not yet in a nursery or playgroup, then take steps to ensure that a suitable placement is found at the earliest opportunity. It is likely that if a child is known to have special needs, priority will be given. We feel that, unless the child's difficulties are very mild indeed, parents should be open about his problems and not attempt to conceal them from the playgroup or nursery. Teachers and playgroup leaders are generally prepared to give a young child a chance and will do their best for him. However, if they feel that a child has been presented as normal when the parent is aware of social difficulties they are less likely to feel sympathetic to the situation and be able to offer appropriate support and understanding. It is simplistic for parents to believe that by setting aside a diagnosis of autism and placing their child among 'good role models' he will somehow improve spontaneously, and that the autism will vanish.

Early diagnosis of autism can be both an advantage and a disadvantage. On the positive side, it should enable parents to understand their child's needs at an early age, and take appropriate action. It should facilitate a supportive environment that encompasses not only the child's learning but also the attitudes of those with whom he has contact. In addition, it should allow them to access a range of both educational and social resources, such as Hanen, TEACCH, and the recent Early Bird NAS project. However, when these resources are unavailable, an early diagnosis runs the risk of leaving parents in a state of limbo, unsupported, and having to seek out what help they can. It is not surprising that they are often attracted to approaches that make claims for a 'cure' or 'recovery'. When eventually they are offered appropriate input, they may be unable to appreciate its value because it does not appear to be 'special' enough. It is a mistake for parents to believe that one-to-one input from an adult is the only way forward. This can be socially isolating for the child even in a nursery or playgroup. When an adult is always present as a support, socially normal children tend to interact with the adult, and not the child. Young children with autism need opportunities to mix with their peers and to learn from them in a social setting. Like their peers, they need time to mature and gain skills and social experience which will underpin their future learning. It must be emphasised, however, that while placement in a mainstream setting may be advantageous in early years, this may not be helpful or appropriate when the child reaches school age.

Children with overall developmental delay, in conjunction with autism, are more likely to be offered access to a Portage scheme, although availability as for all home-based resources is largely a matter of chance and geography. The service provides help and advice on a domiciliary basis for children, and parents are shown how to play an active part in facilitating progress in small steps towards relevant goals. Young children with autism may gain much benefit from such schemes and we would advise parents who are given the opportunity to participate, to take advantage of what is on offer.

In some areas toy libraries exist and parents may find them a useful resource. Similarly, play schemes for children with special needs may be available and are generally well organised. Again, children with autism can derive much benefit by participating. Contact addresses are listed at the back of the book (see Appendix 2).

In some families life revolves around the child with autism. Brothers and sisters are often required to put up with constant intrusions into all aspects of their lives. Sometimes they feel that they cannot entertain friends at home because of embarrassment caused by their sibling. Sometimes family outings do not happen because of problems associated with both taking and leaving the autistic child. In one family, not only had outings ceased but the parents felt such deep distress at having a child with a disability that the mother became almost reclusive in an attempt to conceal the child from public gaze. The child in question was in fact a bright little girl, a delight to look at and one who could enjoy and benefit from a wide range of social experiences.

In some families there is a tendency for the socially normal children to feel or take on more resonsibility for their autistic brother or sister than is perhaps either appropriate or necessary. This may be nurtured by the parents, who perhaps cherish the notion of family togetherness. However, when this happened in one particular family, a brother who had had to devote too much of his life to two younger brothers with autism, took himself off to the other side of the world at the earliest opportunity. We felt not a little admiration for a mother who took a very positive stance in relation to her daughter who, she vowed, would never be made to feel responsible for her very handicapped older autistic brother. However, individual families have to work out their own way of coping with sibling relationships. The National Autistic Society has always been concerned about the possible adverse effects on siblings of having a child with autism in the family. They have produced some useful books and pamphlets, and have encouraged the formation of sibling groups in different parts of the country.

It is really important for parents to remember that the needs of their socially normal children must not be neglected. However, we are very aware that it is not simply a matter of forgetting about these needs, but rather the logistics of finding time and energy to attend to them more than minimally. Even if there are no other children, the relationship between partners may be severely stressed for the same reasons. Evenings that are taken up by the demands of a difficult child do little to cement relationships. Although it may be comparatively easy to find babysitters for normal children, many parents are reluctant to impose their severely autistic child on someone outside the family, and even sometimes within it.

Respite care, for children who are especially difficult to manage, may be an option worth considering. Respite care schemes are provided by both the voluntary sector and local authorities. The schemes available may extend from babysitting services to residential placement for weekends and holiday periods, sometimes on a regular basis. Parents should contact their local social services departments for information about what is available in their own geographical area. 'Contact-a-Family' and 'MENCAP' are nationwide organisations offering help to parents. Their addresses are listed in Appendix 2. Local NAS groups may also be a source of useful information.

Sometimes, when respite care is offered to parents under stress it is rejected; however difficult the home circumstances may be, such a suggestion confirms feelings of guilt and anxiety. Although such feelings are understandable they are unproductive and unhelpful if they persist. In general, most parents come to see the advantages of time away from their child, and not only accept what is offered but take positive steps to use the time beneficially. In some circumstances where there is extreme stress, acceptance of respite care can save a family from falling apart, while the child with autism suffers no ill effects whatsoever.

Boarding schools specifically for children with autism and challenging behaviour are few in number, but other suitable alternatives may be available for placement. Sometimes families cope well until later childhood or early adolescence, when the child's behaviour, coupled with his or her ever-increasing size, may cause more serious problems. The same feelings of guilt and inadequacy may also arise when a boarding placement is offered. Yet the separation can promote an improvement in behaviour which in itself establishes a better climate within the family.

We must emphasise that there is no right or wrong way for parents and siblings to cope. Each family must work out its own salvation, hopefully with support from knowledgeable professionals with experience of autism. Although we have focused on 'worst case' scenarios in relation to practical considerations, we would be remiss not to mention the fact that many children with autism are not at all difficult to manage, and show their problems in more subtle ways. Problematic or challenging behaviour is by no means universal in children with a diagnosis of an autistic spectrum disorder.

SOME PRACTICAL SUGGESTIONS

The underlying principle in the management of children with autism, regardless of their developmental level, is the building of bridges for understanding. Bearing in mind that children with autism have difficulties in making sense of the world about them, it follows that efforts to make things meaningful to them is an essential aspect of their learning. Parents can intervene positively in a number of practical ways to enhance this learning process. To assist them, we have listed some suggestions, including those which have already been referred to in the text. For clarity these are summarised under areas of social development that relate to Wing's Triad.

Social understanding

- Give clear rules on behaviour, without long explanations, and avoid saying 'It's naughty', as young children with autism are unlikely to understand such an abstract concept.
- Discourage aggressive behaviour, even if it is unintentional, not least because of the effect it has on other children.
- Encourage sharing; other children must be allowed to have turns with toys which may be the focus of obsessive interest for the child with autism.
- Highlight the importance of set mealtimes as pleasant social occasions, with appropriate behaviour and acceptable table manners. Mealtimes also serve as markers in the routines of the day and thereby enhance the understanding of time. For these reasons, discourage 'grazing' and eating on the move. Snack times at nursery or playgroup can also provide good opportunities for learning these skills.
- If the child is in a mainstream setting, playgroup, nursery or school, a simple explanation of his difficulties will help staff to be supportive and not misunderstand behaviour which may be unusual or inappropriate.
- Try to prevent opting out of activities which are not of the child's own choosing. This may be the only way to overcome his resistance to new situations, and widen his experience.
- Reduce anxiety by building in predictability. The child needs to know what to expect in different situations, such as visits, holidays, even moving house. Pictures and photographs in sequence, showing not only these events but also daily routines, can provide a simple visual timetable to enhance understanding.

When children with autism find separation particularly difficult and distressing, it may be helpful if the adult who has to leave the child provides him with one of his or her belongings, such as a scarf or bag 'to look after'. This will help the child to understand that he has not been abandoned.

'Over-bonding' is not uncommon in school-age children with autism, who at an earlier stage were indifferent to the presence or absence of their main carer.

Social communication

- To gain a child's attention, use his name or touch.
- Talk simply to the child and do not bombard him with questions and long-winded explanations.
- Assist the child's understanding by using prompts and cues. This will include gesture, facial expression, and reminders that serve to focus attention on what is being talked about.
- Teach the child appropriate language for social occasions – for example, asking for things, seeking help, saying please and thank you.
- Give the child time to respond, to get his droughts together. Some need help to get started.
- Acknowledge the child's own communication but indicate when it is inappropriate, otherwise he will not learn what is relevant. The child may need to be told, 'No, we're not talking about that.'
- Think about what the child means, even if his words do not match. Words that are echoed may have associated meanings that are linked to particular anxieties.
- Provide the child with words to express his wishes. The term 'mapping' is sometimes used to describe this. For example, 'You want me to zip up your coat now.'
- The child may use statements rather than questions or requests. For example, 'Put it there now' meaning, 'Does it go there?', or 'Stuck' meaning, 'Will you do this up?' These provide good opportunities for 'mapping'.
- Avoid open-ended questions which the child is unlikely to understand and be able to respond to. For example, 'What did you do in school today?'
- Younger children may prove to be better 'conversation partners' than the child's own peer group. Younger siblings often stimulate the development of language and communication skills in children with autism.
- Avoid sarcasm, the child will not understand and will be confused.

- Do not tease the child. For example, 'There won't be room for you in the car, you'll have to walk home.' Be sensitive to the child's literal understanding.
- Take care not to confuse the child with well-meaning but misguided untruths. For example, a small child had been taught not to touch hot things. To dissuade her from fiddling with the video recorder, her parents told her that that it was hot. This ploy was unhelpful as it confused her understanding of what 'hot' meant. Far better to have said 'no!' consistently.

Social play

- Encourage pointing and shared-attention games with young children. This is an extension of lap play, and should be continued and developed beyond the baby stage.
- Encourage sensory activities (smelling, tasting, feeling) and the vocabulary used with them (crunchy, yucky, sweet, sour, rough, smooth, hard, soft, etc.).
- Encourage play beyond the child's own interests and routines.
- Be aware that *functional* play (see Chapter 5) is not true pretend play, though it is of great value. It is far preferable for a child to be occupied with simple play routines, even if they are learnt, rather than absorbed in aimless activity.
- Control the amount of television and video watching, especially if it is obsessive.
- When the child is mature enough to understand the distinctions, talk about what is real and what is pretend.
- Encourage simple rule-based games (for example, board games) and outside sports activities (gym clubs, Beavers, etc.).

This list is by no means comprehensive and will not necessarily apply to all young children with autism. Each and every child will have his or her own particular range of tastes and interests, as well as strengths and weaknesses.

Parents should investigate activities, clubs and playschemes that are organised in their area for children with special needs. Costs incurred may be defrayed by allowances and benefits which may possibly be available through central government, local authorities or charitable trusts.

7

SPEECH AND LANGUAGE

Communication development in children with autism

There are certain characteristics relating to speech and language development which are peculiar to children with autism. First, delay in its acquisition is especially common (and this delay has to be considered in relation to the child's overall developmental level). Delays in language acquisition may or may not indicate a fundamental language disorder. Normal children acquire language because of a strong and innate desire to communicate. It follows that if the motivation to communicate is impaired, as it is in children with autism, then this will be a contributing factor to the delay in its acquisition (Frith 1989). Indeed, this is often the reason why children later diagnosed as having autism are referred in the first place and why speech and language therapists are so often among the first professionals to become involved. Parents are likely to report that at the latter end of the first year the child began to acquire speech but then seemed to lose it. If and when speech eventually appears, there is a pattern of deviance which differs from that shown by children with more specific language difficulties.

Essentially the problems centre around the use of language. The child may acquire adequate linguistic structures to communicate and indeed may do relatively well in standardised language assessments, but fails to engage successfully in interactive communication. Many studies have been undertaken in recent years to explore the nature of these particular communication problems, and there is now a consensus of agreement, which was not always the case. Until the notion of a spectrum of autistic disorders was appreciated, able and verbal children with these communication difficulties were frequently diagnosed as having a 'semantic-pragmatic language disorder' (S-PD) and any unusual or difficult patterns of behaviour were marginalised or viewed as a consequence of the language impairment. Autism as a possible diagnosis was excluded, since the children did not conform to the classic picture of the condition. Eventually it was understood by even the most fervent advocates of S-PD that it is not possible to have this disorder of communication without an underlying social impairment. Indeed, once the ramifications of theory of mind deficits and poor central coherence were appreciated, the confusion and controversy abated considerably and S-PD is now recognised as a descriptive term for the language and communication problems seen in able and verbal children with autism. Use of the term as a diagnostic label, without reference to autism, is misleading if not dishonest. It is our view that a focus solely on language and linguistic features, without regard to the child's mode of being, is inadequate and simplistic. Knowledge of the child's developmental history and an evaluation of his interests, play, relationships, etc., are essential if the true nature of the difficulties is to be understood. In other words, the presence of autism, however mild or subtle, must be recognised. It is then that the child will make sense. The medical model notion of a disorder has generated considerable muddle among speech and language therapists and other professionals and has prevented them from appreciating the underlying aetiology which is crucial to expectations of outcome.

The following list will highlight the deviant aspects of speech and language as it develops in children with autism:

1. They do not alert appropriately and consistently to the human voice, despite normal hearing. They are more likely to respond to sounds that are of particular interest to them. These may be idiosyncratic, such as plumbing noises, particular television jingles, or may relate to food (such as a biscuit tin being opened).
2. Comprehension is poor, or even non-existent, and they show little interest in communicating, except perhaps for their own needs and particular idiosyncratic interests. Deceptively, the poor comprehension is often masked by superficially fluent expressive speech (see 11).
3. There may be little or no attempt to give messages with eyes or gesture and mime, or even to point out objects of interest, all of which demonstrate communicative intent. When evaluating this essential aspect of communication it is important to consider it in relation to a child's overall developmental level. It is then possible to assess the appropriacy of such strategies that are used. For example, a 7-year-old

may have started to point out cars; while this behaviour may indicate communicative intent, it is more appropriate for a young infant.

4. They do not engage an adult's attention to share an interest (joint attention behaviour) which is evident in socially normal children in the first year of life.
5. Many children with autism develop an impressively large naming vocabulary, which may divert both parents and professionals from appreciating that there are problems in relation to communication. The ability to name objects as an isolated skill does not indicate the development of communicative language. Indeed, the reverse may be the case.
6. Immediate echolalia is particularly common; children will repeat all or part of what is said to them. Delayed echolalia occurs when words and phrases, even tunes and TV jingles are generated at random, and without a particular trigger. They may have some sort of associated meaning for the child, and be linked to anxiety or pleasure, even when it engenders a negative reaction from adults.
7. Children with autism somehow learn phrases, sentences, even sophisticated chunks of language which they are then able to reproduce often in the appropriate context. For example, a school-age child was able to reprimand a disruptive child in the group, using verbatim his teacher's words: 'You'll have to leave the room if you can't sit still and listen.' The term 'mitigated echolalia' is sometimes used to describe this ability to manipulate learnt language.
8. Questions present particular problems. Typically, children with autism fail to acknowledge them in conversation, but may produce a reply if suitably 'cued in'. It is as if certain triggers change their meaning, for example the pronouns 'I' and 'you'.
9. There is invariably difficulty in using those parts of speech which elicit appropriate responses and associations. This also applies to the use of prepositions, 'in', 'on', 'under', 'next to', etc. These may be understood in a learnt situation, but not in a wider context.
10. There is often a delay in establishing a concept of gender, and 'he' and 'she' may be used interchangeably and without understanding.
11. Verbal children with autism appear to be able to say more than they can understand. Poor comprehension may be masked by seemingly appropriate responses. Phrases such as, 'I can't remember', may in fact mean, 'I haven't understood what you are saying'. Some children can display considerable anxiety and panic when they are spoken to in a way which does not immediately make sense to them. In other words, if what

they hear does not fit in to their repertoire of understanding they are at a loss to know what is expected of them. Hence the panic.

12. Interactive communication skills are very poor, which means that they cannot participate appropriately in conversation.
13. Turn-taking and the accompanying strategies, such as nodding and appropriate body language, are absent or impaired.
14. Although the majority of articulate children with autism do not have problems with speech production *per se*, their speech may sound rushed or ponderous, with poor rhythm and unusual pitch and intonation. As spoken language develops, children often become non-fluent and less intelligible as they grope for words, as opposed to slotting in snippets of learnt language.
15. Children with speech tend to talk *at* people, often about their particular interests, going into lengthy and boring detail, without reference to the listener. Typically, they will relate the minutiae of films, videos and computer games.
16. Understanding is literal. Children fail to pick up inferences and information which is presented indirectly. An example of this is a child who was asked by his teacher if he could find his lunch box. He looked in the appropriate place, answered ‘yes’, but made no attempt to pick it up. Another child on a school camping holiday was asked at breakfast time if he had bacon at home. He replied that he did not know as his mother might have eaten it.
17. Even bright verbal children (and adults) will have difficulty understanding metaphor, sarcasm and jokes, other than slapstick, puns and wordplay.
18. The use of language is concrete, and they show little flexibility in adjusting to changing situations and conversation partners. Teachers and adults may be spoken to as equals, and there is individuals with relatively good communication skills.
19. Eye contact during conversation is rarely maintained, even in little awareness of status.
20. Children with autism may assume that another person has knowledge about a topic when this would be quite impossible. For example, a speech and language therapist, meeting a boy for the first time, was asked if she preferred his latest haircut to the previous one.

It will be apparent from the list that what is distinctive about the language of children with autism is that it reflects the cognitive and social impairments which we described earlier. Socially normal children with a specific language disorder will certainly show difficulties with the understanding as well as the expression of language, but although probably immature, their social development is not deviant. They are likely to find alternative means of expressing themselves, and are capable of engaging in the sequence of attracting attention and sharing their *varied* interests. To clarify the differences between high level autism, with semantic-pragmatic difficulties and true language delay/disorder, we have included a chart for easy reference (see Table 7.1).

Table 7.1 Differences between High Level Autism and Language Disorder

Autism – high level (semantic-pragmatic difficulties)	Language only
1 Speech and language acquired by 5 years of age, but was delayed.	1 Language acquisition is delayed and deficits persist.
2 Language acquisition does not follow linguistic rules, but rote learned echolalic patterns.	2 Expressive difficulties exceed difficulties with comprehension.
3 Articulatory difficulties are less common.	3 More likely to show dyspraxic elements (i.e. child has articulation difficulties).
4 Echolalic patterns gradually expand (chunking) – may display skilled use of learnt language and situational speech (mitigated echolalia).	4 Echolalia if present is more likely to be simple and transient.
5 Good auditory memory likely.	5 More likely to make attempts to gain interest of others (sharing of interests not just attention seeking).
6 Expression is in advance of comprehension.	6 Behaviour generally immature, not deviant or odd.
7 Conversational impairment apparent (i.e. child is unable to maintain interactive communication).	7 More likely to show an even profile apart from language.
8 Likely to talk about own interests. Topics may be odd, range of topics limited.	8 Word finding and word order difficulties apparent – auditory memory skills are poor.
9 Talks at people rather than with people (i.e. does not appear aware of listener's state of mind).	9 Conversational difficulties due to the word finding and word order problems, not an inability to use language appropriately because of an underlying social impairment.*

Table 7.1 Continued

Autism – high level (semantic-pragmatic difficulties)	Language only
10 Often diagnosed as 'language difficulties and behaviour problems'. Child may be considered to have emotional and behavioural difficulties (EBD). Underlying social impairment* is not recognised – once it is seen, child makes better sense.	10 Social difficulties due to immaturity not underlying deviance.
11 May or may not be evidence of more overt autism in history. NB: features of autism recede as child develops.	11 Likely to show reading difficulties not hyperlexia.
12 Learns easily, but does not necessarily understand and use what is learnt.	12 Play may lack imagination and be immature.
13 An uneven profile of skills and deficits. NB: Islets of ability.	13 Milestones may be delayed – may be gross motor difficulties.
14 May be hyperlexic but there may be dyslexia linked to physical clumsiness (latter associated with Asperger Syndrome).	14 Child is able to use alternative strategies to compensate for lack of spoken language.
15 Play invariably limited, but may impress initially.	15 Child able to form real friendships.
16 Uses communication primarily for own needs, interests, etc.	
17 Physical milestones may be normal and gross motor skills may be good.	

Note: * The term 'social impairment' is used to describe the inability to understand and respond appropriately to the subtleties inherent in varying social situations. It does not necessarily mean extreme social isolation or a complete lack of sociability.

Will speech and language therapy help?

Many parents believe that if their child with autism could only be taught to speak, then all would be well. Sadly this is far from reality, and it is essential for speech and language therapists not to inadvertently encourage these expectations in their desire to help. Although we are by no means convinced that children with autism necessarily have a fundamental language impairment, there can be little doubt that their lack of motivation to communicate acts as a barrier to the acquisition of language. Therefore the delay can to some extent be remediated, in that the child can be moved along to the next developmental stage. For example, a child with a large naming vocabulary may benefit from specific help with the acquisition of verbs.

A significant number of children diagnosed with autism remain mute, and these are almost invariably lower functioning. It is generally considered that unless children with autism have acquired some useful speech by the age of five years, the prognosis is less favourable.

There is no doubt that speech and language therapists have an important role to play in the diagnosis and assessment of young children with autism, not least because they are likely to become involved at an early stage. Early recognition of the autistic nature of a young child's communication problems may be crucial in channelling the family towards appropriate agencies that are likely to offer the greatest help. Commonly, the children's learnt language and situational speech provide an exaggerated picture of their capabilities in communication. An important aspect of the role of the speech and language therapist is to put these abilities in perspective against the child's level of understanding, which may be seriously deficient. Children with relatively well-developed expressive language skills are sometimes referred to as having 'high level language disorder'. This may have the unfortunate effect of diverting attention away from underlying social impairments and the implications for communication, towards a focus on linguistic investigation.

Linguistic analysis of the utterances of a child with autism without reference to the level of comprehension seems to us to be an academic exercise which is largely irrelevant to the practical problems. The idiosyncratic nature of the children's use of language is more reliant on auditory memory than true linguistic competence. Therefore we can see little value in minutely examining the output without first considering the underlying diagnosis and assessing the level of understanding. It is apparent that 'conversations' of higher functioning children with autism may, on first hearing, appear quite impressive. However, those who know the children well will be very aware of the repetitive nature of the exchanges, which may reflect particular interests or indeed obsessions. The topics of recorded excerpts of language may be inappropriate or even bizarre. There is a non-productive quality about the discourse, despite the fact that the child seems capable of changing word order and tenses etc., and using varying and apparently meaningful intonation to produce, at least superficially, the elements of a conversation. The following dialogue illustrates this point.

Background: V, an Asian boy with autism, whose family is conscious of degrees of colour, and their own paleness of skin, is talking to C, a good looking and very black autistic boy of African origin. It is apparent that J, who is Scottish and a popular classmate, has provided the trigger for this conversation:

V:

C, whereabouts in Scotland do your cousins come from?

C:

(Who had recently returned from a holiday) Gatwick!

V:

C, are you a little bit white?

C:

(Looking carefully at the back of his very black hand) Yes, I am a little bit white, because I come from Scotland.

V:

Can you speak Scottish?

C:

Yes. Hoots!

It is our view that it is not necessary to carry out a barrage of formal assessments when the administration of two or three will provide estimations of the child's level of understanding, against which any progress can be monitored. In the first edition we referred to specific language assessments including the Derbyshire Language Scheme and the Reynell Developmental Language Scales. Since that time, a number of new assessments have been developed and it is no longer appropriate to make specific recommendations. It is up to individual speech and language therapists to select assessments which they feel are relevant for particular children.

The provision and necessity for ongoing and long-term speech and language therapy, even if it is available, is debatable. If a child's communication skills are commensurate with his overall level of functioning, then speech and language therapy is not indicated. The availability of treatment for children with autism from an under-funded and over-stretched profession is likely to vary according to geographical location, financial resources, and type of placement. The first two factors are self-explanatory. The third one refers to whether the child is being seen in a community or hospital clinic, has been placed in a playgroup/nursery, or has already entered the education system. In the setting of a clinic, the presumption must be that the child is being investigated and assessed. Any regular intervention is likely to concentrate on advice to the parents about management issues, and the encouragement of communication at the appropriate developmental stage. Programmes such as Hanen in areas where they have been introduced have become popular and are very effective. An 'early response' programme initiated immediately after diagnosis is vital for parents who are desperate for something to happen in which they feel they have a part to play. At the moment, not nearly enough is being done to address this need, yet it could be highly cost effective when set against unrealistic demands and the expense of tribunals and court cases. The appointment of 'Co-ordinators for Autistic Services', as a joint resource for health and education, would assist and guide parents in the early stages and alleviate many of the problems which arise out of a mismatch between their expectations and appropriate and reasonable provision. Early informed support might prevent parents becoming caught up with expensive treatment programmes which are not necessarily more effective than an intervention programme available locally without promotional razzmatazz.

Early placement in a nursery or playgroup setting is always to be recommended. This not only provides the child with valuable social experience and learning opportunities, but enables the child's difficulties to be clarified. The speech and language therapist's role in these circumstances may be one of liaison and regular reviews of the child's progress. If and when pre-school children demonstrate some ability and interest in communication it may be appropriate to consider whether they would benefit from participation in a small group. The aims of such a group would be to lay the foundations for the development of social skills.

The issue of finding an appropriate educational placement soon becomes paramount for the majority of parents. Ideally, this should be through a partnership between parents and professionals, including the speech and language therapist, although ultimately it is the responsibility of the LEA. If it is established that the child has special educational needs, the speech and language therapist may be required to contribute to a formal assessment of those needs, which may or may not result in the issuing of a statement. This will be discussed in more detail in Chapter 8.

At this juncture, it will be helpful to discuss the changing role of the speech and language therapist in relation to school-age children with autism, and in particular those who score well, or relatively well on standardised language assessments. When a child enters school it will soon become apparent, however, that ongoing problems in relation to communication persist, and that these problems centre around the use of language and in particular the social use of language. It is these problems which speech and language therapists can usefully address, in conjunction with teachers and classroom assistants. More often than not the most useful approach will be through activities where the emphasis is on extending the child's awareness and understanding of the world about him. Bridges need to be built to enable the child to make at least some links between things he has learnt and some strategies to enable him to deal with the demands of daily life. It is of course impossible to provide the child with all the necessary connections. Indeed, if that were the case he would not have autism! However, it must be better to have some links and strategies than none at all.

Social skills training is an area in which speech and language therapists are becoming increasingly involved. The skills should always be taught and practised in relevant and meaningful social situations that are interactive; group work is the ideal means to achieve this (Aarons and Gittens 1998). Programmes have been developed, and can be adapted to provide for the needs of different age groups or levels of ability. Right from the start the emphasis has to be on establishing attentional skills and awareness of others. Sitting without fidgeting, with appropriate eye contact, and listening to what is being said are the underpinnings of social communication.

When these foundation skills have been established, the focus moves towards the social use of language, which includes developing awareness of the needs of others, establishing good manners, and thinking about the wider world. As the children get older, social skills training within the school curriculum should link up with personal and social education, and, thereby, life skills and greater independence.

With mute, low-functioning children with autism, attempts have been made to promote communication through the use of manual signs. The most commonly used system is Makaton, which is based on British Sign Language. At one time it was naïvely believed by some that if these children were taught to sign they would be able to send out meaningful messages, bypassing their lack of speech. It is now better understood that the underpinnings of language which we have described, as well as a deske to communicate, are necessary requirements for successful signed communication, as indeed they are for spoken language. However, it is certainly worth making an effort to teach Makaton to a mute child with autism, even if the end result is only a few single signs to indicate his needs. Makaton signs may be used in conjunction with visual symbols; in general, children with autism respond well to visual strategies.

Research has indicated that children with autism do not develop language in the usual way following normal developmental patterns. They appear to acquire language through rote learnt echolalic patterns, and indeed echolalia is a characteristic element in their speech. The first speech used by the child may be meaningless echoing of words and phrases. It is necessary to ascertain the degree and complexity of the echolalia and to establish whether it has progressed from the meaningless stage to one where the stored phrases are used at all appropriately. At the former level, it is not uncommon for the echoing to take the form of hummed tunes, television jingles, or learnt phrases that either seem pleasing to the ear or appear to carry some emotional content. Even after a child has progressed beyond an echoing stage, he may revert to it in moments of stress and anxiety. In addition, the spontaneously produced speech of many of the more able children with autism seems to consist almost entirely of learnt phrases, often used appropriately but still giving the speech a mechanical quality. The dividing line between echoing and truly spontaneous speech is often very difficult to define. More able children with autism may break down the echolalia into chunks of varying sizes, and these may then be manipulated so that they result in new utterances. This has been called 'mitigated echolalia' (Roberts 1989). The children's speech is therefore derivative and the learnt chunks are associated with particular situations, contexts and interests. The child is able to slot them in when the need arises and it is evident that if an appropriate verbal trigger is applied, the correct verbal output is elicited. Before children become adept in the use of this strategy, they will give apparently inappropriate responses because they have made an incorrect choice from their lexicon of learnt language. If the child is capable of using the echolalia/learnt language appropriately, to make a simple dialogue feasible, then this development must be regarded as a communicative success in the context of autism. Indeed, the parameters of successful communication always need to be judged in relation to the child's autism, rather than the expectations of language development in a normal child.

In Chapter 2, we referred to the work of Uta Frith and her colleagues at the Medical Research Council Cognitive Development Unit. Frith has postulated that the fundamental cognitive deficit in children with autism prevents them from predicting the behaviour of other people, a requirement of social competence which, of course, includes social communication (Theory of Mind). This deficit is most clearly seen in more able children with autism with adequate intelligence and adequate understanding of language. Generally, by the age of 4 years, normal children are able to reflect on their own thoughts and are also becoming aware that other people have thoughts too. In a simple experiment which she and her colleagues developed, the hypothesis was tested with able children with autism, young normal children, and children with Down's Syndrome. The normal children had no difficulty with the test. Even 80 per cent of the Down's Syndrome children passed it. Whereas 80 per cent of the children with autism, despite having a higher mental age than the Down's group, failed the test.

For our use and interest we have adapted the basic experiment. We introduce a doll with a basket and a teddy with a box. The doll puts a sweet into her basket and then goes out for a walk. While the doll is out of the way, the teddy takes the sweet and puts it into his box. The doll is then brought back, and wants to eat her sweet. At this point the child, who has been watching all the proceedings, is asked where the doll will look for her sweet. The answer should of course be, in the basket, where the doll put it. Yet children with autism almost invariably point to where they know the sweet is; that is, in the box. When they are questioned, they have no difficulty in recalling the sequence of events, but fail to predict what the doll believes. There is evidence that autistic children may pass this test at a later age, but are still likely to fail in more complex tests of perspective taking. A range of more complex tests in the form of stories, has been developed by other researchers, including Simon Baron-Cohen (1989) and Fran Happé (1994). In her book *Autism: An Introduction to Psychological Theory*, Fran Happé explains the type of stories which are particularly difficult for children with autism to understand. These involve the process of mentalising – the ability to attribute certain thoughts, beliefs, and emotions to other people – and only make sense if other people's states of mind are appreciated. The following story requires an understanding of white lies.

> Helen waited all year for Christmas because she knew that at Christmas she could ask her parents for a rabbit. Helen wanted a rabbit more than anything in the world. At last Christmas Day arrived, and Helen ran to unwrap the big box her parents had given her. She felt sure it would contain a little rabbit in a cage. But when

> she opened it with all the family standing round, she found her present was just a boring old set of encyclopaedias which Helen did not want at all! Still, when Helen's parents asked her how she liked her present, she said, 'Its lovely, thank you. Its just what I wanted.'
>
> Is it true what Helen said?
> Why did she say that to her parents?

Even very able adults with autism are likely to find it difficult to understand such a story, and those who do will still experience problems with the complexities and nuances of social understanding in the real world. Passing a structured theory of mind task does not indicate that autism should be excluded as a diagnosis.

Difficulties with mentalising will have extreme repercussions, not only in terms of the child's understanding of events and knowledge concerning the world, but in relation to communication. The expressive language of children with autism will reflect this impairment. Simon Baron-Cohen observed that such terms as 'I don't believe you', What do you mean?', 'It's not really a . . .', 'You're just pretending', 'That's not true', 'How do you know?', were likely to be absent.

In linguistic terms these difficulties occur in the wider context of modality, which relates to possibility, necessity and obligation. Individuals with autism have problems in adapting their learnt and inflexible language to respond to subtle changes in meaning, reflected by the use of modal aspects of language. For example, in relation to auxiliary verbs, the distinctions between can, could, may, might, must, ought to, etc. will present difficulties.

There is overall, even in able people with autism, a quality of naïvety and innocence. They are the antithesis of the worldly! They do not deceive others, nor try to impress. Indeed their honesty can be counter-productive. An endearing example of this is the boy who, when asked by his teacher why he was behaving so badly, replied, 'I was doing it on purpose.'

Frith's explanation of the nature of autism makes sense of the pattern of pragmatic difficulties which are so typical of the language and communication deficits of children with autism, and indeed provides the key to understanding their conversational disabilities.

8

EDUCATING CHILDREN WITH AUTISM

The implementation of successive Education Acts, with the emphasis on providing for the individual special needs of each child, has assisted in the appropriate placement of children with autism according to their overall level and pattern of functioning, rather than focusing solely on the argument of whether or not they have a diagnosis. In other words, in the framework of educational provision, diagnostic labels are not of primary importance. However, in reality, the situation is far from perfect, with pitfalls and frustrations, which sometimes appear quite arbitrary. It is a sad fact that the ideals have somehow become subsumed by local education authorities (LEAs) with limited resources, which play down or even deny children's needs in order to save money. The other side of the equation, however, are the parents who make unrealistic demands, that develop into a crusade, so that reasoned discussion and compromise become impossible. While excessive amounts of energy, time and money are expended, the child's ongoing needs are compromised. These issues will be explored more fully later in this chapter.

We must reiterate our view that by the term 'autistic', or 'with autism', we mean a wide spectrum of disabilities and behaviour, encompassing many or few of the features commonly associated with the condition. We do not limit ourselves to so called classic cases. Therefore it does not follow that a child diagnosed as having autism will inevitably go to a school for autistic children.

In the last chapter we referred to the process of assessment and possible 'statementing' of children with special educational needs. This means that children with identifiable problems which may affect their ability to benefit from mainstream education will have their needs considered by their parents, and any professionals who may be involved. The intention is to enable parents to express their views and to have as big a say as the professionals in planning their child's educational future. Apocryphal tales are told of how in prestatementing days, children were whisked into special education without sufficient consultation with parents. It is ironic that the climate of opinion has changed to such an extent, that nowadays parents often have to fight for a place in a special school, and it is the professionals who seem intent on keeping them out!

The system of assessment provides a forum for discussion and exchange of views. Indeed, this extract from the then Department of Education and Science guidelines for parental involvement states:

> In looking at the child as a whole person, the involvement of the child's parent(s) is essential. Assessment should be seen as a partnership between parents, teachers and other professionals in a joint endeavour to discover and understand the nature of the difficulties and needs of individual children. Close relations should be established and maintained with parents and can only be helped by frankness and openness on all sides.

Following the 1996 Education Act the governing bodies of schools have an onus of responsibility to make special educational provision for their pupils with special educational needs. This responsibility extends to pupils who do not require statements, as well as to the minority with statements. This Act also obligates governing bodies to have regard to the Code of Practice when carrying out their duties towards pupils with special educational needs.

The Code of practice sets out a five-stage model of identification and assessment:

Stage 1

This involves 'taking early action to meet the child's needs within his or her normal classroom work and monitoring and reviewing his or her progress'.

Stage 2

At this stage 'the SENCO [Special Educational Needs Co-ordinator] takes the lead in co-ordinating the child's special educational provision, consulting the child's teachers, who remain responsible for working with the child in the classroom'.

The SENCO, working closely with the child's teachers, ensures that an individual education plan (IEP) is drawn up.

Stage 3

The responsibility at this stage for the child's needs is shared with an external specialist, who may offer advice, assessment or direct intervention. The external specialists may include clinical and educational psychologists, specialist teachers, speech and language therapists and psychiatrists. The provision could be a mixture of in-class support and small group teaching, or in-class support and individual teaching.

Stage 4

'The needs of the great majority of children who have special educational needs should be met effectively under the three school-based stages, without the statutory involvement of the local education authority. But in a minority of cases, perhaps two per cent of children, the LEA will need to make a statutory assessment of special educational needs. Statutory assessment is the focus of Stage 4 of the five-stage model.'

Stage 5

This final stage involves the issuing of a Statement of Special Educational Needs, which carries with it certain legal responsibilities that cover funding, resources, and an annual review of the child's progress. LEAs are obliged to complete the process of statutory assessment within a given period of time.

From a practical point of view, what are the implications of assessment and possible statementing for parents? What about young children with autism who are not yet in school? If the child is in a maintained nursery school or class, the stages described for school-age children will apply. A young child in a non-maintained setting can also be referred for statutory assessment, but the LEA will require 'clear documentation of the child's difficulties, and any action taken to deal with those difficulties'. Health Trusts have a responsibility to alert the LEA to any child of 2 years (or older) whom they feel may have special educational needs. Parental consent is always required.

While acknowledging that the figure of 2 per cent represents an approximation of the numbers of children likely to require a statement, it is reprehensible when LEAs use this figure to limit the number that they issue. Children and parents are then caught in a most unsatisfactory situation that seems arbitrary. Similarly when there is rigid adherence to a budget for special needs, children may again get trapped by an LEA's refusal to allocate resources. In such situations, parents should seek advice from a body such as the Advisory Centre For Education (ACE) (see Appendix 2).

The issue of fairness and value for money is more complicated than may appear to parents wanting the best for their children. Some authorities turn down very reasonable requests by parents, while others are obliged to spend thousands of pounds on the needs of just one child whose parents have been successful through the system of appeal. Not surprisingly, this will have a serious effect on the authority's special needs budget, depriving other no less worthy children of their share of limited resources. While in general we are in favour of parents' rights of appeal against LEAs through the system of SEN tribunals, we are concerned when large amounts of public money is spent on well-publicised but not necessarily more effective educational placements or approaches. (For example the Higashi school in Boston, USA.) There are schools in this country which achieve remarkable success, easily as impressive as those that are hyped in the media, yet their achievements are unsung. It is all too easy to assume that an expensive well-presented package with the added incentive of a promised 'cure' or 'recovery' must be superior to anything that an LEA has to offer.

A pragmatic approach to school placement is advisable and, indeed, may be absolutely essential in rural areas, where a low population does not merit a range of different educational options for children with autism. The nearest ideal placement may be at the other end of a county, which would involve two long journeys each day, or a boarding placement which might not be acceptable to parents. Therefore the only practical alternative is to consider whether a more local school would be prepared to accommodate the needs of a particular child. Parents should always be prepared to consider the schools which are available and ascertain for themselves the setting which will be most suitable for their own child.

We have already explained that children with autism do not necessarily attend schools specifically for autistic children. We know how variable children with autism may be, both in their academic capabilities as well as in their behaviour. The children who are likely to be able to cope in mainstream education will be those who are at the upper end of the continuum. Typically, they do not show behaviour abnormalities which would make them conspicuous, and their problems centre around extracting what is meaningful and organising themselves to get on with their work. They will have acquired language which they are generally able to use appropriately, and, in addition, their academic abilities will be within normal limits. Sometimes such children survive in mainstream because of the provision of a classroom support assistant who ensures that the child is enabled to function despite his problems. The assistant may ease the child's path in a number of different ways; for example, ensuring that he does what he is supposed to do, that he listens to the class teacher, understands instructions properly, and is not teased or bullied in the playground. Some children will only manage in mainstream for a period of their school lives, and much depends on the attitudes of the head teacher and staff. It must be acknowledged that as the child moves up in the school, more will be expected of him. Some children with autism manage well at infant level, but when the move is made to junior school, or from primary to secondary school, begin to flounder as there are different expectations and more demands are made of them in terms of independence and organisation, both socially and in relation to the National Curriculum. We do not believe that a child with autism should continue in mainstream at all costs. The paramount concern must surely be the child's happiness and quality of life. If, despite adequate academic capability, a child's life is dominated by stress and anxiety, then serious consideration should be given to an alternative placement. Although the academic expectations may be less, the child's overall happiness and well-being may be considerably enhanced. We believe that this is equally as important, if not more so in the long term, as the passing of public examinations.

It is not unknown for an LEA to fund an intellectually able child at a small independent mainstream school, which may provide a more structured and less confusing educational setting. It is imperative that parents do not allow a situation to develop whereby withdrawal from mainstream education is viewed as a failure by either them or their child. Children with mild autism may be very aware of success and failure and it is therefore incumbent upon the parents to explain any move in positive terms. Parents should be encouraged to consider any viable options that may be possible – for example, continued attendance at a mainstream school with regular access to a social skills group in a special school, or alternatively attending a special school with weekly integration sessions for certain areas of the curriculum in a mainstream school. These are all examples of good 'outreach' practice.

It is understandable that parents want their child to be the same as all the local children, and going to their local mainstream school is part of this scenario – it is an assumption that most people make when they become parents. Not to be able to participate in what could be described as a rite of passage is isolating and a very real loss. In addition, it is one thing for parents to accept their own child's disabilities, but quite another to accept those of other children in a special school. Parents want their child to learn from and mix with socially normal children, and it may be very painful for them to come to terms with this situation. Yet it has to be accepted that children with autism do not automatically absorb socially normal behaviour from 'good' role models; on the contrary, they may be more influenced by bad behaviour, or alternatively may be ignored or teased by their peers. It is not unknown for parents of children attending a special school to 'sabotage' the success of the placement by involving their children in their own perceptions which may be entirely unrealistic. For example, they may tell their child that he is 'too clever' for the special school. If and when that child enters a mainstream school, he is likely to be seriously undermined by the discovery that he has to struggle to keep up with his peers, both academically and socially.

When a child has learning difficulties in addition to autism it is difficult to see how a mainstream school can provide a suitable learning environment. A classroom setting, geared to the needs of the majority of children, will inevitably be over-stimulating and confusing to a child who has difficulty making sense of the world about him. Even full-time support will not necessarily help him to become an included and integrated member of the class. Indeed, the reverse may happen since it is not natural for a child to have an adult in constant attendance when he goes to school. Those professionals working in the field of autism remain highly sceptical about the wisdom of central government initiatives to promote the inclusion of *all* children with special educational needs within mainstream schools. In reality, children with autism may be put at a disadvantage, and it may do them a great disservice. It is unfortunate that special schools are so often viewed in terms of being second best – an alternative to be considered only when other options have failed – when they may provide a child with autism with a natural and very appropriate learning environment.

When children with autism have obvious behaviour problems, they are more likely to be considered as candidates for schools specific to autism. The

National Autistic Society continues to play an important role in providing a number of such schools, both day and boarding, as well as provision for adults. In general, Society schools provide placements for children with moderate or severe learning difficulties, as well as for those with challenging behaviour for whom placement in less specialised settings is unlikely to be successful.

When behaviour is less of a problem, but cognitive impairments predominate, children may be suitably placed in either schools for moderate learning difficulties (MLD) or, alternatively, for severe learning difficulties (SLD). Sometimes parents are very distressed that their child should be considered in the context of learning disability (mental handicap), especially if the child displays any islets of ability. However, it has to be acknowledged that the child's level of intellectual functioning must inevitably be regarded as the prime consideration. The presence of autism is an added dimension that complicates the picture and may lead to conflicting appraisals of the child's capabilities and potential. Parents may need to be reminded that many MLD and SLD schools have built up a considerable amount of expertise on teaching and managing children with autism, so that tried and tested approaches and programmes are the norm rather than the exception.

Some children with autism may be placed successfully in schools for language disordered children, or into local education authority language units or classes. These settings provide small group teaching and structure with the proximity of socially normal peers. Such placements may work for children who are odd, quirky, or eccentric, but who do not display overtly bizarre or difficult behaviour. They may have received a diagnosis of semantic-pragmatic disorder, and their problems will centre around their use of language, which may have been delayed, as well as their poor social skills. Although we would argue that these children do not generally have a language disorder *per se*, they certainly have communication problems. They may have acquired adequate language, but do not know how to use it. Children with these sorts of difficulties can do well if staff appreciate that although their needs differ in many ways from those of the specifically speech and language disordered group, they can be managed successfully together.

We would recommend a category of 'communication disorder/ difficulty' as an appropriate designation for schools to cater for children with speech and language problems, as well as for children with a mild degree of autism and normal or near normal cognitive skills. This would eliminate arguments about labels and would provide a background for ongoing diagnostic assessment. Firsthand experience of such a school over a number of years has provided ample evidence of the good sense of such a classification.

All statemented children are reviewed annually. This means that their progress is evaluated, and their continuing educational needs are reconsidered. It is possible that the child's needs will have changed and that different and more appropriate provision may be necessary. This review procedure has the advantage of reminding everybody concerned that even though a child has been placed in a particular educational setting, the situation may change and should not be regarded as static.

The present philosophy and methods of teaching children with autism have developed over the years and reflect better understanding of the nature of the disorder. During the 1960s and early 1970s, it was assumed that all children with autism were invariably of normal intelligence, their difficulties arising from an inability to communicate because of some sort of 'emotional block'. Many schools were established in the belief that intensive educational intervention would 'break through the barrier' of non-communication and allow these children to develop normally. It became apparent that these optimistic expectations were ill-founded and nowadays a more realistic attitude prevails. Autism can certainly coexist with high intelligence, and those with ability, while showing the triad of social impairments, will have substantially different needs from those with accompanying cognitive deficits. In other words, education for children with autism must always be tailored to individual needs and not to the diagnostic label.

Lower-functioning children with autism commonly show pseudoacademic skills such as mechanical reading or calculation abilities. It was natural for professionals in education to assume that these abilities represented the child's true potential. We now know that remarkable though these skills may be, the child remains seriously handicapped and is not able to utilise them in the normal way.

The pursuit of academic goals is no longer seen as the only priority, and the development of social and life skills has assumed more importance in the curriculum. Indeed, it has become very apparent that academic achievements are not an end in themselves. In order to use them successfully in terms of employment and career purposes, they must be underpinned by ability to interact socially. This is as important in the workplace as it is in any social situation. It is a cruel fact that high academic qualifications alone do not ensure a happy and successful life.

Social skills training will include learning to attend to others, to take turns, to give and share information, and generally to acquire strategies for understanding not only other people but also the ways of the world. Life skills will include independence training and self-care, shopping and cooking simple meals, as well as other everyday activities which the normal population take so much for granted. It is all too easy to put these areas of learning to one side and assume that individuals with autism will pick them up as they go along. This is simply not the case, and time spent from an early age on these aspects of learning will be invaluable.

The introduction of the National Curriculum has challenged the teachers of children with autism to provide as wide an educational experience as possible, while acknowledging the particular difficulties of the children they are teaching. Since the first edition of this book, an increasing number of publications have been produced on all aspects of education for children with autism. Rather than make specific recommendations, we would advise anyone involved or interested in education to obtain information about recent publications from the National Autistic Society, and to visit one of the annual special needs exhibitions, which display newly published and current materials and books.

Although a description of the TEACCH programme (Treatment and Education of Autistic and related Communication handicapped Children) could be included in the list of alternative treatments for autism in Chapter 10, we refer to it now because it has been evaluated and used with great success over many years and in many different settings. The programme which provides services for children and adults was developed by Erich Schopler and Gary Mesibov in North Carolina. It has evolved over twenty years and covers most aspects of family services connected with autism. There are both language- and behaviour-focused programmes, which are drawn up on an individual basis for use in schools and places of work.

TEACCH manages the individual's environment through structured teaching and an emphasis on task completion. It aims to adapt the learning environment to the needs of the person with autism and not the reverse. TEACCH works with people from all parts of the autistic spectrum and offers continuing support with the aim of enabling them to live as members of the community. Many of the ideas have been incorporated into schools in the United Kingdom and regular training courses are held. The approach is endorsed by the National Autistic Society, and makes very good sense to most professionals with experience in the field of autistic disorders. TEACCH has been evaluated in the United States and has been shown to have important benefits.

Sometimes children with autism make good academic progress and a structured and formal learning situation is much to their liking. Many have little difficulty with the mechanics of reading and may score extremely well on word recognition tests above their chronological age and well in excess of their other abilities. Yet when it comes to understanding what they have so ably read they display severe deficits. This is particularly evident when meaning is embedded in the text and information is implied rather than explicit. The term ‘hyperlexia’ has been used to describe this prodigious ability. An example of this phenomenon was a little boy of 6 years who received a party invitation which he read perfectly, yet had no idea what it was or what it meant. Parents are sometimes perturbed because a teacher appears to be holding back their child’s reading. However, unless the written material is meaningful to the child, the reading of it will become one more skill that will have no real value. Therefore, the child’s comprehension should always be matched to his mechanical reading ability.

Depending on their level of functioning, children with autism may have no difficulty with the mechanics of writing. Although more able children can be taught to produce properly constructed sentences, or narrative, they will be unable to use the skill with true creative ability. However, at the upper end of the autistic continuum there are children who appear to demonstrate aspects of creativity in their writing, but the topics remain eccentric, bizarre or repetitive. Others surprisingly seem to have a particular facility with words, and can manipulate language in an impressive way. Nevertheless their output has a derived quality, and they may be adept at reproducing ‘storyteller expressions’ with meticulous attention to punctuation. Again, depending on their intellectual ability, many children with autism will develop number concepts and be able to calculate with varying degrees of skill. Numeracy skills may also be an isolated talent and exist as an islet of ability, sometimes in conjunction with calendar skills. The ability of some individuals with autism to almost instantaneously work out dates is truly baffling.

In the 1980s, Dr Lorna Selfe made a study of art and autism and observed that there were a small number of children who displayed an amazing ability with line drawing, and whose development of drawing skills was ‘totally anomalous'. She concluded that what the children might be doing was 'translating visual experience into drawing, untrammelled by normal conceptual analysis and reorganisation'. It was as if the child recorded as a camera. Stephen Wiltshire's books of remarkable pen drawings, with minute attention to detail, bear this out.

Unfortunately, it is by no means unknown for parents of children who do not progress well to blame their child's teacher. Although parental disappointment is very understandable, it has to be accepted that those children with autism who make most progress do so largely by virtue of inherent developmental factors rather than any special teaching or treatment methods. Sometimes, parents have been misled by well-meaning professionals whose comments can give rise to unrealistic expectations. The words, 'access to the National Curriculum', for example, in relation to a child with severe learning disability may encourage parents to assume that their child will move through the key stages, simply at a slower rate than his peers. The fact that he cannot achieve even Key Stage 1 comes as a grievous disappointment.

Despite this somewhat gloomy comment, we have witnessed great progress in individual children and can applaud the persistence and innovation which many teachers demonstrate in their daily contact with autistic children.

Activities outside school

Activities outside school and home are a normal part of the majority of children's lives, and there is no reason why children with autism should not participate in them as well. Because the condition is so variable, it is not possible to be specific about activities which will be successful for all children on the autistic continuum. Apart from individual likes and dislikes, the degree of learning disability as well as possible behaviour difficulties must be taken into account when choices are made. However, most certainly, something will be available if parents are prepared to search about in their own locality. The societies set up for children with disabilities (such as MENCAP), may have much to offer which will be appropriate for children and young people with autism. Other facilities may be provided by associations for more specific impairments such as AFASIC.

Many higher-functioning children with autism, although unable to benefit from mainstream education, will enjoy opportunities to mix with their socially normal peers. Out of school activities will help them develop an awareness of the larger world outside. Organisations such as Beavers, Cubs, Brownies and Woodcraft Folk are usually willing to include a child with autism, and are very responsive to the special needs of individual children. It is important for parents to be open and honest and prepared to take group leaders into their confidence in order to maximise the chances of success both for their child and for the group itself.

Other activities which in our experience have been successful for particular children are trampolining, gymnastics, swimming and dancing, as well as horse riding. Drama and art classes may also be suitable for some children. Parents need to be very flexible in finding the activity which is right for their child. For example, a child who loved to dance, failed as a ballet dancer because she was unable to count steps. In the informality of disco-dancing, however, she blossomed!

Older children who show a liking for social contact may enjoy attending youth clubs, both for able young people and those with special needs, providing that they are well run and adequately supervised. In addition, many of the parent support organisations provide facilities which may be tapped. Activity holidays for older children with disabilities are available and are worth investigating. There is no reason why children with autism should not enjoy the achievements of abseiling, as well as canoeing, camping, climbing and other outdoor pursuits.

9

GROWING UP – WHAT LIES BEYOND?

Almost as soon as parents learn that their child may have autism their thoughts inevitably turn to the future – what will the outcome be? Because of the 'loss' of the normal child, there is a need to reconstruct a future which takes account of the changed circumstances, and this is very understandable. Parents will couch their enquiries with phrases such as 'I know it's asking too much, but what will happen when he/she is grown up?' or 'Will he get better/worse?', 'Will he be able to get a job and be independent?', 'Will he get married and have children?' and 'Are we always going to have to look after him?'

While autism in adolescents and adults is beyond our brief, we feel that we cannot ignore what is clearly a fundamental issue arising out of the diagnosis. However, we can only provide an overview of some possible options, and would suggest that those who require more specific information should refer to appropriate literature, such as Patricia Howlin's book, *Autism: Preparing for Adulthood* (1997). Awareness of the needs of adults with autism is increasing, as are the facilities for meeting these needs, and many initiatives have been instigated by parents and support groups.

At the outset, it is perhaps worth pointing out that looking into the future of normal children is also fraught with imponderables, as many parents know. The bright articulate 5-year-old who subsequently does brilliantly in school, in adolescence may become wayward and rebellious and the academic future with high expectations dissipates. The potential brain surgeon becomes a lorry driver, while the slow starter emerges as a skilled entrepreneur. Concern about drugs, sexual promiscuity and orientation, AIDS, smoking, dropping-out, etc. are additional anxieties which parents of socially normal teenage children have to contend with. Although the time of growing up is worrying for all parents, for those with children with special needs the concerns are greatly increased; additionally there is an extra dimension of concern, which is 'What will happen when we are gone, or too old to look after him?' The normal expectation for parents is that their children will grow up and leave home sooner or later, allowing parents some time in middle age to enjoy the freedom and opportunities which life has to offer. For the parents of handicapped children, this scenario is at odds with the likely prolongation of the parental caring role into their child's adulthood. It is for this reason that we recommend that parents be in touch with organisations which can offer help and advice, while addressing these issues.

The National Autistic Society publishes a list of establishments specifically for adolescents and adults with autism. Some are run by The National Society, and some by local autistic societies. In addition, the NAS provides a comprehensive list of organisations which run centres for people with learning difficulties which also accept residents with autism. Many of these are registered charities.

Local authority funding may be obtained for placements in communities run by voluntary organisations or independent companies. However, the NAS does not monitor these establishments and therefore cannot recommend any particular organisations to families.

The decisions parents make about the future for their older children will reflect their own personal circumstances and philosophy, as well as availability of facilities and resources. What is right or acceptable for some parents may be quite unacceptable and totally at odds with the views and feelings of others. Compromise may be possible for some but not for others. Some parents feel very strongly that they want to keep their child at home with them for as long as possible. Others welcome the chance for their child to leave home and lead a separate life as soon as the opportunity arises. There is no right or wrong about this, nor should there be any feelings of guilt or failure if parents do decide not to keep their grown-up child at home. We recommend that parents keep an open mind and start to consider the options earlier rather than later. Often there are waiting lists, and putting the child's name forward may increase his chances of being considered for placement when the time comes. We feel that it is not too early to start thinking ahead constructively when the child is about 13–14 years of age. Visits to different establishments, when there is no pressure to make decisions, are often the best way to evaluate the kind of setting where an individual young person is likely to be happy and enjoy a lifestyle which parents feel is appropriate for his needs. This is particularly so in relation to young people going to live in a community.

We must remind readers that children with autism are very variable and therefore the outcome will also be variable. At the lower end of the autistic continuum, which will include individuals who not only have autism but also severe learning disability, the picture will be much the same as for those with severe learning disability who do not have autism. Such people are likely to require care and support throughout their lives. This may be in a variety of settings, either day or residential. Some of these may be specifically for individuals with autism and are geared towards coping with the behaviour problems associated with autism in low-functioning individuals. Those young people who can cope may find places in local authority residential homes, where they function as a group with supervision and support. This means that they can live apart from their families, enjoy social activities and have a purposeful routine of daily attendance at a training centre or sheltered workshop.

More able young people with autism may well be able to attend post-16 courses at tertiary or further education colleges. These courses are specially aimed at young people with special needs and there will be an emphasis on the teaching of life skills. The curriculum may include solo shopping expeditions, cooking simple meals, coping with transport, gaining work experience and learning to manage finances at a basic level. There are also residential courses where the content is much the same as we have described. The aim is the promotion of independence as well as the enhancement of social development and experience. Sadly, despite the excellence of these courses, the student at the end of his time may find himself in limbo. Unless further plans have been made he may find himself back at home with his family and with the prospects of employment virtually non-existent.

The more we learn about people with autism, the more we have become aware that within the so-called 'normal' population there are individuals with social difficulties of an autistic nature – the autism 'phenotype' (Bailey *et al.* 1996). These may be serious enough for the individual himself to feel that he has problems, not only in regard to his social life but also in relation to the workplace. It is likely that others will regard such people as being particularly gauche, odd, eccentric and somehow difficult to get on with. If this is the situation for people who are within the normal population, it is hardly surprising that those with a diagnosis of autism will inevitably have more testing problems to contend with. However sympathetic supervisors and fellow workers may be, the most able of the autistic population, despite adequate intelligence and the acquisition of many useful skills, may fail to survive in the world of employment.

Why is it that despite so much costly input and despite the acquisition of so many skills, the young adult with autism more often than not fails to adapt or cope in the real world? It has to be recognised that the special area of difficulty in autism – the social impairment – is an incapacity which is fundamentally detrimental to securing and holding down a job. For example, preoccupation with routines may make it difficult to work alongside other people. The lack of ability to adapt to changes – to hurry, to complete a task, to see things from another's point of view – although seemingly trivial factors, can combine with others to form real obstacles to success. Unfortunately, there is a dearth of suitable placements for young people with autism which will harness their skills while coping with and managing their difficulties. One of the many strengths of the TEACCH programme in North Carolina is its focus on preparation for work. However, because of the links with service industries in the United States, it is not easy to transfer its ethos to the United Kingdom. Nevertheless, we hope that the increased provision of social skills training programmes for children with autism may provide them with skills and strategies to enable them to function more successfully as adults (Aarons and Gittens 1998).

Sometimes the best possible placements are in community settings. These may be village communities in a rural location, but may also be in residential urban areas where accommodation and support is provided in a house adapted for this purpose. Within such communities the individual with autism may flourish, and parents can feel that as the young person establishes a home there the burden of responsibility lightens.

Although we have focused on some of the negative aspects of growing up with autism, there are many success stories concerning individuals who have done well, and are able to lead happy successful lives. Inevitably they will tend to be those with good intellectual functioning, but personality factors as well as supportive families and schools will all play a part.

10

A POSTSCRIPT – ALTERNATIVE TREATMENTS AND CURES FOR AUTISM?

At the outset, we have to express extreme scepticism about the effectiveness of any of the alternative treatments/therapies/cures that we have come upon. We cannot see that there can be a panacea for such a variable condition as autism, which has so many different possible causes. It is, of course, reasonable to suppose that certain approaches may benefit particular children. However, to expect that such a complex and multifaceted condition can be cured by a single method or drug really makes little sense.

Parents of newly diagnosed children with autism are in a very vulnerable position. It is a fact that very few indeed are offered specialised support, and the usual scenario is for them to get a diagnosis (if they are lucky) and then be 'left to get on with it' as parents so often report. Little wonder that they are prey to any promise of alleviation or cure, especially when reported in the media. Something is needed to fill the vacuum, give them a sense of purpose and allow them to have hope. By and large those who promote an alternative approach are well meaning, but typically are characterised by their fervour in promoting their message and encouraging parents to mount a crusade on their child's behalf. Sometimes, the child's needs seem to be subsumed by the crusade which can take over and become the dominant feature in the life of the family. We do deplore those who take advantage of parents in a state of distress by promoting their views with immoderate zeal. To promote a cure, usually for a considerable fee, without back-up of objective facts and figures (rather than anecdotes) is not good enough. Neither is their insistence that the 'autistic establishment' is biased against them an appropriate response to criticism. The National Autistic Society is very much involved in evaluating research and developments in the field, and those that have proved to be of value are incorporated into teaching and therapy. (For example, the TEACCH approach – see Chapter 8.) Unless claims for successful treatment can be supported by objective evidence, parents and professionals should continue to remain sceptical and wary. It is often reported that the introduction of a new regime, be it school, drug or diet, has brought about significant improvements. However, although such spurts are not uncommon they are not necessarily sustained in the long term. There is current interest in the use of the hormone secretin as a possible cure for autism. We will learn some time in the future whether this is yet another false hope, or a real breakthrough for at least some children with the condition.

There will always be a small percentage of parents who cannot be helped by conventional methods and who feel compelled to try approaches which are outside what they regard as the autistic establishment. Often it is this 'establishment' which has made the diagnosis of autism. Understandably, these parents' feelings of upset and anger are then directed towards this body. It is as if the messenger bearing the bad news is to be blamed, and therefore any help that is offered is not acceptable. Within the alternative approaches there may be elements which are perfectly sensible and reasonable and indeed may provide some amelioration of some of the facets of autism. Different parents have different needs in the type and amount of support they may require. If they feel happy and comfortable with a certain approach, then it will be of benefit to them, even if it is not of great benefit to the child. Over the years we have heard about some quite extraordinary claims, the most extreme gleaned from the Internet by a parent and apparently taken seriously, involved the child living in a horse-manure-rich environment in Arizona! Swimming with dolphins and pet therapy have also been promoted.

Facilitated communication

We would include facilitated communication in the same grouping, in that extravagant claims were made which simply did not make sense in the context of autism and required a large dose of gullibility. This strategy involved a facilitator with a communication aid supporting the arm or finger of an individual with severe communication problems, thereby enabling him or her to use the aid more effectively. This often resulted in the production of highly sophisticated comments, expressions and requests which were believed to be evidence of the individual's true ability. In some extreme cases accusations of physical and sexual abuse were made against carers and families, with disastrous results. Facilitated communication has been very thoroughly researched, and it has been shown to be invalid. The output proved to be the expression of the facilitator, albeit at an unconscious level, and not that of the individual with autism. The process could perhaps be likened to a ouija board. Facilitated communication first came to our notice in the mid-1970s and was resurrected a decade or so later. At the height of its popularity, professionals who expressed doubts were subjected to much disparagement by its proponents.

Drugs and vitamins

We have already referred to the administration of certain vitamins and drugs in Chapter 3, in which we discussed the causes of autism. None of these medication programmes have proved to be successful, despite some early optimism. Additionally, allergies to certain foods have provided another possible explanation for the presence of autism. Avoidance of particular foods such as chocolate, fizzy drinks, milk and milk products, as well as such additives as tartrazine, has brought about an improvement in the behaviour of some children, but not cured the condition. Tartrazine has been linked to hyperactivity in children, and so it would seem wise for parents to eliminate this substance from their children's diet. The subject of additives and allergies is quite rightly an area for concern to the population in general and is likely to continue to be so. Parents of children with autism would be well advised to eliminate additives where possible, and to note whether episodes of particular behaviour can be linked to certain foods as well as to possible environmental factors.

Holding therapy

In the same chapter we also mentioned holding therapy, which some years ago received much publicity in the media. What possibly lay behind the claims for improvement in some children was the fact that during holding therapy there was considerable physical activity while the child struggled and raged. This coincided with observations that after vigorous physical exercise, children with autism tended to have periods of calmer behaviour. It was possible therefore that Bernard Rimland's suggestion that 'holding therapy does not restore maternal/infant bonds, but rather stimulates the brain's production of endorphins' was a reasonable explanation. Endorphins are naturally occurring substances which are produced by the brain and have the effect of controlling anxiety. Having observed video footage of holding therapy, it would not be difficult to construe the process as a form of abuse.

Higashi

Another approach with emphasis on vigorous exercise, as an integral part of a school curriculum, is used at the late Dr Kiyo Kitahara's Higashi School in Boston, USA. The original Higashi school was established in Tokyo in 1954. In 'daily life therapy' as practised at the Higashi School, group activities are emphasised, and with the guidance of trained teachers, children with autism are put through intensive physical activities under a highly regimented schedule without letting the child lapse into his or her autistic patterns of behaviour. Although the method is generally approved of in terms of the structured programme, which may have a very positive effect on behaviour, it does not address the social and communication impairments which are intrinsic to the condition. Higashi has attracted a lot of media attention, with the result that some parents feel compelled to get their children to the school in Boston while remaining dismissive of equally effective but unsung approaches in specialist schools in the UK. (It may be of interest to some parents to learn that a Higashi school is shortly to be opened in the United Kingdom.)

Option method

The option method is a US-based approach which has also received media attention, and been shown in a very positive light. Parents and children spend two weeks at the centre in Massachusetts, receiving intensive therapy/philosophy from a trained mentor with the aim of enabling the parents to accept and enjoy their child for what he is. The idea is that they will make a 24-hour commitment to their child when they return home. This involves a team of volunteers and a specially adapted room. When the option method was first promoted some years ago, parents were encouraged to take their child's lead and allow him to initiate activities – in other words, to empower him. This did not seem to make much sense because so much of the activity was inappropriate. However, it now seems that some changes have been made, and parents are now given some helpful guidance about how to develop play with their child. The proponents of this approach, however, also make extravagant claims which can mislead parents – especially those who deny the seriousness or extent of their child's difficulties. A child known to us with severe learning disability was taken to the centre but has not progressed. Yet his parents remain convinced that the promise of normal functioning in four years, when he will 'choose not to be autistic', will be realised. This appears to be in direct conflict with the alleged philosophy – to accept and enjoy the child for what he is. As a result of the parents' refusal to look beyond this promise, their child's well-being is being seriously compromised as they cling to a fantasy which has little to do with the welfare of their son.

Auditory integration therapy

Many exaggerated claims have been made for this treatment, and the advocates are ambiguous in denying that they are promoting it as a cure, yet claiming an '80% success rate'. It originated in France and involves the use of a machine known as a 'kinetron'. The training lasts for two weeks and consists of two half-hour listening sessions twice a day. The aim is to re-train hearing through the use of processed music. There is no research to support the theory behind this approach, and there is no evidence that all children with autism have auditory integration problems. There is no contact between the providers of the training and professionals working with the children on a day-to-day basis. We have known a few children who have undergone this training, and no changes whatsoever have been observed. We are open-minded enough to consider that it is possible that individuals with extreme auditory sensitivity could be helped with this method. However, this would in no way constitute a cure for their autism.

Sensory integration therapy

This is an approach used primarily by occupational therapists and developed in the United States by Dr Jean Ayres. Although the neurology cited to support this type of intervention is questionable, if not dubious, the belief is that in autism the developing brain is not able to attach meaning to sensations and organise them into percepts and finally into concepts. Sensory stimulation is seen as playing an essential role in neural development. The treatment consists of activities involving the balance centres, skin receptors and tendon, joint and muscle receptors.

Many children with autism display motor problems; indeed, they are among the most commonly associated difficulties. These problems are frequently referred to in terms of 'motor planning' – which affects organisational skills. Whereas we see these difficulties as an aspect of impaired central coherence and executive function, proponents of sensory integration therapy see the accompanying social impairments as secondary, and call the condition 'dyspraxia'. We do not dispute the existence of dyspraxia as a disorder that may benefit from sensory integration therapy. Indeed, it is possible that in some individuals, dyspraxia can coexist with autism, but it is essential not to confuse the two conditions. It is not surprising, therefore, that although we know many children with autism who have received this therapy, we have not seen evidence of its relevance to the social impairments which are the core disabilities within the condition.

Lovaas (behaviour modification)

Behaviour modification methods were first used by Lovaas in the United States in the 1960s. At that time, quite extreme methods of punishment were used to reduce inappropriate or self-injurious behaviour. It then went out of fashion.

Behaviour modification re-emerged and has become extremely popular as an intervention for young pre-school children with autism, because it delivers a package of care (at considerable cost) with a promise of 'recovery', at a time when very little else is likely to be on offer. From the parents' point of view it has a lot more going for it than a collection of advice sheets and a promise of a review.

A reward system has replaced the ethos of punishment. There is little doubt that these methods can be effective in focusing a child's attention and bringing about improvements in behaviour. However, transferring these skills to other settings may be a real problem. Another problem can emerge when parents become so absorbed in the method and the intensive one-to-one programme that they fail to appreciate when their child is ready for wider and less structured social activities.

Some LEAs have been persuaded to fund individual children's Lovaas programmes, because they have been led to believe that the intervention will enable a child to progress into mainstream education after two years' treatment and then make no further demands on special needs resources. This is both unrealistic and simplistic. The ethos of the Lovaas programme does not sit easily with current research findings about the nature of autism, and largely marginalises the cognitive nature of the condition.

In the context of behavioural approaches, aversion therapy should be mentioned with regard to children displaying very severe behaviour problems such as self-injury and serious aggression. It has been more commonly practised in the United States rather than the United Kingdom. It involves the use of an unpleasant stimulus to reduce undesirable behaviour. The application of such methods would be abhorrent to most people, and their use could be deemed unethical. In addition, there is little evidence of improvement over the long term if the therapy is suspended.

Psychotherapy/family therapy

It is not uncommon for the difficulties of higher-functioning children with autism to go unrecognised and instead be seen in terms of emotional disturbance and/or poor parental management. For this reason, some of these children and their families are referred for family therapy, or else the child is seen by a psychotherapist and treatment may be prescribed. Sometimes the treatment programmes are offered because the autism is not recognised. But in some cases psychotherapy is offered on the basis that autism has an underlying emotional cause. As far as family therapy is concerned it seems to us that failure to recognise the true nature of the child's difficulties does little to inspire confidence in this approach amongst those with experience of the condition. Nor do we think it is helpful to give parents the idea that their child's problems are caused by their mismanagement, rather than a biological condition. It must be said though, that when the condition is appropriately diagnosed the entire family can benefit from discussion about how best to manage the individual with autism, and this approach may then be very helpful and constructive.

Over the years we have come across a small number of children with autism receiving psychotherapy. In some of these cases autism was not diagnosed, while in others it was acknowledged yet thought by the therapist to be treatable by this approach. One could argue endlessly and inconclusively about whether a child's educational and management programme in school had brought about improvement, or whether the claims of the psychotherapist had any substance. We can only make comments based on our own experience of individual cases. These suggest that psychotherapy is not an appropriate treatment for autism, and the claims made for its efficacy reflect optimism in the mind of the therapist, rather than actual evidence in the child. It is all too easy to project thoughts and feelings onto a child with seriously limited communication, and to make interpretations of anomalous behaviour based on analytical theory. Intelligent, verbal adults with autism have expressed strong feelings of disapproval about the relevance of psychotherapy to their condition and inherent problems.

It is most regrettable that a considerable number of professionals involved with young children still do not recognise autism, or only recognise it in its most classic form. Parents are then put in the position of having to find answers for themselves as well as ways and means to help their child. Even where good diagnostic services exist, there may well be an absence of provision from both health and education resources, and therefore, it is inevitable that alternative approaches will fill this gap. Many parents, even in an area of relatively good awareness and provision, have said, 'Okay, we know our 2-year-old has autism, but what now?' In some areas of the United Kingdom, 'immediate response' initiatives have been set up to support parents from the moment they are given the diagnosis. In other areas excellent 'outreach teams' with specialists in autism provide a similar service. Unfortunately these pockets of excellence are far outnumbered by areas where parents are given nothing at all, or are referred to non-specialist services which are already overstretched with long waiting lists. LEAs are becoming increasingly aware of the need to provide specialist provision if only to stem the succession of often unrealistic demands made by some parents through tribunals and the courts.

Nevertheless, until consistent and appropriate provision is more widely available, we do urge parents to adopt a questioning stance before embarking on any so-called cure or treatment which is not based on a realistic assessment of the child's overall functioning. The National Autistic Society publishes a regularly updated and comprehensive guide to some of the many diverse approaches that are employed or associated with the education and care of children and adults with autism (see References and further reading at end of volume).

APPENDIX 1

CASE STUDIES

The following case histories, although based on real children, have been altered in certain ways to protect identity and ensure anonymity. The cases described reflect the wide range of presentation within the autistic continuum.

Since the original publication, contact has been maintained with many of the children, so that where possible we have been able to update the studies, albeit briefly, and report on their progress.

Tanya: now aged 13+ years

Referral

Tanya's initial referral was to the community speech and language therapist for non-development of language. Autistic features were noted and there was a subsequent referral to the specialist speech and language therapist within the district, who wrote the following report when Tanya was aged 4 years.

Background information

Tanya is the fourth child of parents from Eastern Europe. The older children have no problems and attend mainstream schools. A mixture of English and German is spoken in the home.

Early development and medical history

Tanya was a very difficult baby and it was only later, with hindsight, that it was apparent that subtle developmental abnormalities were present, but remained unrecognised. Tanya's physical development and milestones were normal, in spite of which her mother sensed that all was not well and that somehow Tanya was different.

As she had three other children, Tanya's undiscriminating friendliness to strangers was ascribed to a personality difference, rather than a symptom of abnormal social development.

From an early age, Tanya showed an interest in electrical appliances. In the past she has used an adult's arm as a tool, but this is no longer apparent.

It was reported that Tanya displayed certain skills which she then lost – such as counting objects, etc.

Tanya will occupy herself for long periods and is able to engage in symbolic play (feeding, washing dolls, etc.) but cannot develop it creatively. There is no history of any serious medical conditions. At one stage, there was a query about Tanya's hearing ability, due to her failure to alert consistently. It has been observed that Tanya will put her hands over her ears on hearing loud or unusual noises. She enjoys listening to music.

Appearance

Tanya is a very attractive and dainty little girl with an alert and enquiring expression. She has good eye contact and superficially appears normal. However, careful observation reveals a number of small behavioural abnormalities which include odd hand postures and some body twirling.

Behaviour

Generally Tanya's behaviour could be described as immature. Until very recently she had an obsessive interest in a particular video which she would insist on watching continually. She has also shown a sustained interest in particular books, which she would look at *ad nauseam.* Recently, Tanya has become aware of shadows and at the moment this is a focus of interest for her. It has been observed that Tanya will come up close to people and stare at them. She habitually carries round a baby bottle for drinking and for apparent comfort.

Sociability

Generally, Tanya does not like being touched. At nursery, she will play alongside other children but not with them. Her earlier lack of discrimination towards people has been replaced by clinging to her mother and objecting to being left, although this reaction is now diminishing.

General management and problems

As mentioned earlier, Tanya is a difficult child to manage. She does not go to bed until 10.00 or 11.00 p.m., yet it is very difficult to rouse her in the mornings. For this reason, she attends the nursery in the afternoons. Tanya is toilet trained, and will take down her own knickers if encouraged. She is exceedingly fussy about food and mealtimes are particularly difficult. Her difficult behaviour and parental feelings of guilt, if not shame, about her handicap have led to the family isolating themselves from contact with friends and neighbours.

Attention control

Tanya is able to concentrate on tasks which interest her for a considerable period of time.

Cognitive development

No formal assessments have been carried out. On visual perceptual tasks, Tanya shows capability. She holds a pencil very well and can colour in. She can name colours and will sometimes use them as labels for objects.

Speech and language

No formal language assessments have been carried out. Generally, Tanya is spoken to in English at home to avoid confusion. It is likely that Tanya's language comprehension skills are limited. She is able to label objects and apply some learnt and situational phrases to obtain her needs. Some echolalia is evident.

Conclusion

The profile of Tanya's developmental abnormalities and social and communication impairments is consistent with a diagnosis of autism.

Update (1991) Age 6+ years

Tanya's parents were understandably upset by the diagnosis of autism, and this was complicated by the fact that a parallel referral to a Child Development Centre resulted in a different diagnosis of 'severe communication problem'. Speech and language therapy was prescribed and the idea was promoted that this would solve Tanya's problems. This confused the parents and did not provide a satisfactory explanation for Tanya's diverse difficulties. Meanwhile, referral had been made to an appropriate school for higher-functioning autistic children, which was able to offer much support and guidance before Tanya's admission there. A subsequent meeting between the professional agencies involved with the family resulted in agreement and better understanding about the true nature of Tanya's difficulties. A unified approach was agreed upon, which has proved to be both acceptable and productive.

The family was encouraged to participate in social activities once again, which was important for the other children whose needs were being ignored while the focus of attention was on Tanya. Tanya herself was in need of more social contact to widen her experience, and this has been of great benefit to her as well.

Once Tanya was admitted to the school some four months later, more formal assessments were undertaken. At the age of 4 years 4 months, her understanding of language scored at 2 years 2 months, and her expressive language scored at 2 years 1 month. Six months later her comprehension had not improved, but some progress had been made with expression and there was an increase in the use of situational speech. It was very difficult to get her to attend to tasks which were not of her choice. Great progress was made at this time with Tanya's eating habits, using a structured programme which was also carried out at home. Subsequently, her physical appearance became more robust. Her behaviour improved and her temper tantrums decreased. Further language assessment at the age of 5 years 9 months resulted in a comprehension score of 3 years 9 months and an expressive score of 3 years 1 month. The most recent assessment at age 6 years 4 months shows a slight acceleration of progress, with scores for both comprehension and expression of 4 years 7 months. Tanya's attention is now entirely satisfactory and she is making good progress with reading and number skills. She now plays *with* other children in her class group, and has started attending integration sessions in a mainstream school, which have so far been successful.

Tanya now presents as a somewhat 'quaint' child. On first encounter she may seem socially normal. She gives information, asks questions, and the idiosyncrasies in her behaviour have diminished. However, it does become apparent that there is a repetitive quality about her activities and communication so that, although great progress has been made, it would be unrealistic to presume that Tanya will ever cease to show features of autism.

We have no reason to doubt that she will continue to make good progress, and it is felt that increasing contact with socially normal children will provide her with good models on which to pattern her own behaviour.

Update (1998) Age 13+ years

The integration sessions led to Tanya's full-time integration into a mainstream primary school. This particular school provided a very nurturing environment, and Tanya was befriended by a particularly supportive peer group. Her progress was such that the LEA made efforts to withdraw her statement of special educational needs. Fortunately this was resisted by her parents, as her transfer to a mainstream high school precipitated the re-emergence of her social difficulties. By a happy chance, links between Tanya's high school and the special school she had formerly attended were well established. She was able to participate in a joint ongoing social skills group which she continues to benefit from. Tanya is an attractive teenager with an awareness of current teenage interests. Nevertheless, her social naïvety leads her to make inappropriate social approaches, and these are the issues which the group will attend to.

Hannah: then aged 5 years 9 months

Referral

Hannah was referred to the community speech and language therapist for delayed language development. Autistic features were observed, and

Hannah was consequently referred to a specialist speech and language therapist. This report was written when Hannah was 2 years of age.

Background information

Hannah is the daughter of an English mother and a Turkish father. Her older brother had a congenital abnormality, affecting his digestive system, but was otherwise normal. Hannah's birth history and early development are reported to have been entirely uneventful and her developmental milestones were normal. However, careful questioning of Hannah's mother revealed that, in retrospect, some subtle indications of abnormal social development were evident from an early age. She is reported to have been a very 'good' baby who did not appear to initiate social interaction nor show reciprocity. There was an early interest in television and video knobs, yet Hannah's attention could not be gained when picture books were introduced. Hannah's responses were different from those of her elder brother, but at this stage they were explained away by the belief that she simply had a different personality. The parents were not seriously concerned about her development until Hannah was around 18 months old, when her lack of alerting behaviour to speech prompted investigations for the possibility of a hearing loss. It was obvious though that Hannah had no difficulty in responding to sounds that were of interest to her. For example, the television being turned on when she was in another room. Subsequent investigations revealed that her hearing was normal.

It is reported by her mother that Hannah has never established a good sleeping pattern. Recently this has deteriorated and is now the main management problem and is causing concern. Hannah is not yet toilet trained and shows no signs of awareness. More significantly perhaps, her mother has observed that Hannah does not seem able to anticipate the outcome of daily routines; for example, that putting on her coat is a preliminary to going on an outing – an activity which she particularly enjoys.

In response to further questions, some hand flapping was reported, as well as tiptoe walking, and very poor eye contact. Hannah dislikes any intrusion into her own activities, but will indicate to her mother an occasional desire for cuddles. This extends to enjoyment of rough and tumble play. Generally, however, she could be described as aloof and self-contained.

General observations

Hannah is a most attractive little girl of normal appearance, who is physically well developed and seems rather older than her chronological age of barely 2 years. During an observation session, when no formal assessment was attempted, Hannah occupied herself with the toys that were available. However, her play consisted of handling and moving items around, rather than any meaningful activity. It is reported that she enjoys using bricks and can construct, showing considerable dexterity. Her 'play' was accompanied by constant vocalising, which included intonation patterns and babble, but there was no recognisable speech and language. Hannah is indifferent to all attempts at social interaction. No bizarre behaviour has been observed.

Conclusions and indications

Hannah's pattern of developmental abnormality, encompassing social impairment and language delay, suggests autism is an appropriate term to describe her spectrum of difficulties. Although Hannah was seen on a number of occasions at a major teaching hospital, no diagnosis was offered and both parents were anxious to know what was the matter with Hannah. It seemed appropriate, therefore, when Hannah's mother requested a diagnosis, having expressed exasperation with the hospital, to suggest autism. Some information was provided about the nature of the condition, and the parents seemed relieved that at last there was an explanation for their puzzling daughter.

Update (1991) Age 5 years 9 months

Despite initial euphoria at having a diagnosis, when the parents found out more about the condition they became angry and depressed. They found fault with the way the diagnosis had been given, even though they themselves had requested it. The community speech and language therapist, who saw Hannah regularly, was able to offer some ongoing support while arrangements were made for Hannah to see the community paediatrician and educational psychologist for assessment. At this time it was assumed that Hannah's developmental progress was not seriously delayed, and indeed, when she was seen again by the specialist speech and language therapist five months later, some progress had been made. Body twirling, however, was much in evidence, but Hannah was beginning to imitate some situational words such as 'bye-bye' and 'again'. Generally, management had become less of a problem and Hannah was beginning to anticipate routine events, such as getting ready for playgroup. Her mother appeared to have come to terms with the diagnosis, but expressed extreme sadness, and it was felt that she would be very vulnerable to unwise counsel and promises of a cure for autism. Although the parents wished to make their home in Turkey, lack of provision of special education there made them decide to stay in the UK for the time being.

In the meantime, the parents attended a support group at the school which, it was presumed, would later provide for Hannah's educational needs. Hannah was reviewed again at the age of 4 years when it was very obvious that, regardless of the autistic features, Hannah had severe learning difficulties. This was yet another blow for the parents, who now had to come to terms with the fact that Hannah was not only autistic but also severely mentally handicapped. This blow revived all their former anger, especially when an alternative educational placement was deemed more suitable for Hannah's needs. The school suggested was for children with severe learning difficulties, a fact which the parents took some time to come to terms with. However, as the school was particularly well run and well equipped, the place was accepted and Hannah has settled well and made progress. She continued to develop some language, although only for her own needs.

When Hannah was 6 years old, the family finally decided to leave the UK and went to settle in Turkey.

There has been no further contact with Hannah and her family.

Jason: now aged 13 years

Referral

Jason was referred for speech and language therapy by his mother at the age of 3 years 8 months, when she became aware that his language was not developing normally. This report was written two months later.

Background information

Although there was nothing untoward in Jason's developmental history, he appears small for his age and generally functions as a child younger than his chronological age. Both fine and gross motor control are immature, although he shows good capability in self-help skills. Jason has attended a nursery school since before his third birthday.

Attention control

This is very satisfactory indeed, when Jason is provided with tasks which interest him and are within his capability. When tasks are beyond him, he opts out and refuses to co-operate.

Symbolic understanding

Jason has no difficulty in this area and was able to score fully in the Lowe and Costello Symbolic Play Test, although it must be pointed out that the ceiling score is at a 3-year level. However, Jason appears unable to develop play imaginatively, and when observed merely repeated a single play 'routine' and displayed no interest in utilising the play materials he was given.

Social development

Jason enjoys the company of other children and responds to them but is not able to initiate or play imaginatively with them. He has been described as 'solitary' and will spend time looking at books rather than involving himself with his peers. There is no doubt that he enjoys nothing better than sitting down with an adult and being directed to perform the sort of tasks in which he shows capability. However, in school, when left to his own devices, he does not seek out constructive means of occupying himself and will sit and look about until an adult intervenes.

Speech and language

It was reported that when Jason started at the nursery his comprehension of language was very limited indeed and his utterances consisted of single words.

Assessment

Reynell Developmental Language Scales

Chronological age:	3 years 7 months.
Comprehension:	2-year level.
Expression:	2 years 2 months.

Derbyshire Language Scheme

Chronological age:	3 years 7 months.
Comprehension:	2 information carrying words.
Chronological age:	3 years 10 months.
Comprehension:	3 information carrying words.

These scores indicate that Jason's language development, encompassing both comprehension and expression, is delayed. His speech is generally easy to understand.

There is evidence of echolalia, and the higher Reynell score for expression reflects the learnt language and situational speech which is typical of Jason's output. However, more importantly, Jason's communication skills are limited and he does not seem able to initiate social communication or devise other means of communication to compensate for deficiencies in his spoken language (i.e. gesture or mime, etc.).

Verbal concepts when taught tend to be context-bound and Jason's ability to generalise is restricted. He appears to have difficulty extracting implications from situations unless they are of a concrete nature or familiar to him. Jason is reported to be good at doing jigsaws. In school, he can sound words out and match them to objects. He can name colours successfully and is capable of 1:1 correspondence (beginning to understand the nature of number). Nevertheless in tasks involving classification skills (i.e. sorting) he requires 'cueing in' to enable him to understand the essence of the task.

Progress

Jason has made progress with his listening skills. His comprehension of language has improved, as well as his ability and willingness to communicate. Progress has also been made with verbal concepts. Two months ago Jason was completely unable to draw and held his pen with an immature grasp which is now less in evidence. He responded to verbal directions (i.e. 'Draw a head', 'Where do the eyes go?', etc.) and, having 'learnt' to draw a man, persisted in a very stereotyped way and refused to try and draw anything else. After a fortnight's holiday, he had forgotten much of the routine and the man he now persistently draws is minus many of the attributes which he had presumably previously memorised.

Conclusions

It is apparent that Jason's difficulties do not relate simply to delayed language development, but are of a more complex nature relating to social development. These difficulties encompass relationships, communication and understanding and imagination. This suggests a very mild form of autism.

Update (1991) Age 6 years

Jason continued to make good progress. His entry into mainstream school was deferred for a few months, during which time he received speech and language therapy. It was apparent that his cognitive development was satisfactory and it was for this reason that the school was not advised of the precise nature of his difficulties. It was felt that a diagnostic label would in no way ease Jason's path, since there was a very good chance that he would succeed in mainstream education without any special provision. Jason settled into his primary school quite happily. He has made good academic progress and has become particularly skilled at reading, though it is evident that he does not understand when the meaning is embedded or implied. However, his social difficulties are of some concern to the school. It is evident that he does not always understand what is expected of him, and in the playground he is usually on the periphery of games and activities and is 'used' by older children as a patient/ baby, etc. When the others lose interest, he is unable to initiate a new activity for himself, but is prepared to join in rough and tumble games.

It is hoped that Jason will continue in mainstream education. His intellectual capabilities enable him to learn at least some of the subtle rules of social functioning, though life may not always be very easy for him.

Update (1998) Age 13 years

There has been little contact with the family since they moved to another part of the country. Jason obtained a place at a very academic independent school where he is doing really well in all subjects. However, he remains socially rather isolated.

Sean: now aged 11 years 2 months

This report was written when Sean was 2 years 2 months.

Referral and background information

Sean is Jason's younger brother. He was referred for speech and language therapy by his mother when he was under 2 years, as language was not developing. Ironically he had been seen well before his second birthday, during the time that Jason was receiving speech and language therapy. With hindsight, it was unfortunate that more attention was not focused on Sean's early development in the light of what later became so apparent. What can be recalled is the fact that Sean appeared to be very robust compared with his brother. When given free rein, Sean crawled and later walked off in a seemingly purposeful manner, but did not in fact engage in any meaningful activity. He appeared unconcerned about leaving his mother and showed no interactive communication.

At 1 year 10 months, autistic features were observed by the speech and language therapist who carried out a developmental assessment. It was evident that Sean was delayed in all areas and particularly in relation to communication.

Early developmental history

It was reported that the pregnancy and birth were normal and that there were no feeding difficulties. Developmental milestones appear to have been within normal limits. There were indications that all was not well, in that Sean attended more to lights and things that glittered, rather than to people. Sean does not alert to speech, even to his name being called, but a hearing loss has been excluded.

Appearance and behaviour

Superficially, Scan presents as a normal child. However, closer observation reveals not only general immaturity but aspects of deviant development. His looking behaviour is fleeting and eye contact occurs only if his interest is engaged. When left to his own devices, Sean wanders about aimlessly, often holding a car in his hand. He has an interest in cars and will run them up and down and spin the wheels. Hand flapping is in evidence and there is a lack of body language. He often uses peripheral vision, eyeing mainly lights; rapid head shaking, combined with an oblique upward gaze, has also been observed and he appears to be doing this for reasons of self-stimulation rather than negative expression. Unless controlled, Sean will run off, showing no awareness; he does not appear to mind being left and will go to strangers. Generally his behaviour could be described as passive and much of the activity he engages in is purposeless and repetitive (e.g. opening and closing doors). He very much enjoys physical movement, such as swings and slides, as well as general rough and tumble play. He will, however, sit down and watch children's programmes on television.

Sociability

Sean makes his needs known by pulling at an adult. According to his mother he likes being with other children but has very little social understanding indeed. He will seek out physical contact and enjoys being cuddled. His mother remarked, 'He is in his own little world.'

General management and problems

Little progress has been made with toilet training. Sean sleeps very well and has recently started to feed himself. He does not present any management problems and his mother describes him as 'very good'. However, his failure to advance and show motivation causes parental concern and his mother observed that considerable input is required to get any response from him.

Attention control

This is generally fleeting and highly distractible. He shows rigid attention when playing with cars which, as already mentioned, are of considerable interest to him.

Assessment of sensory function

Visual

It was not possible to persuade Sean to co-operate in assessment. He will, however, place one beaker on top of another when his mother facilitates the activity.

Auditory

Sean enjoys toys which play tunes, despite the fact that he does not alert to the human voice.

Proximal senses

Sean still mouths objects.

Communication

Eye contact often occurs but it is fleeting – he will look at an adult for a response if he is disobeying. Generally Sean will not attend to the speech of others, unless the context is clear and of interest to him. On the expressive side, Sean will shake his head for refusal. There is some intonated babble, but generally he is fairly silent, though he has at times echoed single words.

Conclusions

The pattern of development described in this report indicates not only developmental delay but suggests in addition an autistic impairment.

Update (1991) Age 4 years 2 months

Since this report was written, Sean made slow but steady progress, although he became less easy to manage. He developed food fads and temper tantrums. He was subsequently referred to a consultant paediatrician who could find no evidence of neurological signs nor any syndrome, although it was not possible to carry out any metabolic investigations.

At the age of 3 years 8 months he entered an autistic unit attached to a school for children with severe learning difficulties, where he continues to make progress. A recent developmental assessment has indicated that his self-care skills are within normal limits. Locomotor, manipulative and visual skills are still somewhat delayed. Social development and communication skills remain severely impaired. On assessment, Sean functions at approximately a two and a half year level, but an increase in his use of learnt phrases enables him to function more successfully in everyday situations than formal assessment results suggest. Sean no longer presents in the same robust way and is now a somewhat oddly proportioned little boy.

Update (1998) Age 11 years 2 months

After the family moved, Sean attended a language unit where he made good progress. He then moved to a prep school until the age of 11, but continued to have problems with written language in particular. On the advice of a private psychologist he recently transferred to a school for children with dyslexia. His social behaviour is still a matter of concern, especially when he becomes angry and gets involved in fights.

Freddie: then aged 4 years 6 months

Referral

Freddie was referred to a clinical psychologist by his nursery, with the agreement of his parents, when his behaviour, which was aggressive and destructive, did not show any improvement. He was subsequently referred to an autistic unit for initial assessment. This report was written when Freddie was 4 years 3 months.

Background information

Both parents are high school teachers and Freddie has an older brother in mainstream education who is reported to have had some early difficulties in relation to social development. No details are available. At the age of 2 years 6 months Freddie began attending a nursery. After a few months it was apparent that he would not settle and he was difficult to contain. A place was found for him at another nursery, where the staff have had some experience of children with special needs. The nursery is able to contain him, albeit on Freddie's own terms, so that other children are not too disturbed by his behaviour.

Developmental history

The pregnancy was normal and, despite some distress during labour, Freddie's early months were uneventful and no developmental abnormalities were observed. Apart from the fact that Freddie walked at 10 months, neither parent was able to recall any details of his early development and had particular difficulty with questions relating to his early sociability. He was, however, described as a good baby. At the age of 2 years, however, Freddie became very active indeed. He would run around in circles and was destructive and aggressive. The range and scope of this behaviour extended sufficiently to make family life very difficult. However, Freddie's parents attributed all the mayhem to the notion that it was normal for a boy, and the behaviour was seen in terms of being naughty and seeking attention.

General observations

Freddie's appearance is normal and attractive. He has a somewhat intense gaze, as though he is trying to ascertain the effects of his behaviour. He is able to use language to communicate his needs and interests, but it is not possible to engage him in interactive conversation.

When observed in the nursery, he moved about the room being a tractor, and making engine noises; this activity was sustained for much of the morning. Freddie appeared uninterested in other children and made no attempt to join in their activities. Indeed, his disregard was so great that he was seen to walk over their legs and feet as he wandered about muttering to himself. He did not engage in any purposeful activity and attempts to persuade him to join a group were met with an aggressive outburst, which resulted in him lying on the floor and pulling a picture off the wall and tearing it up. When approached during this activity, Freddie's response was 'Are you going to start the engine?' At home, however, Freddie occupies himself mainly out of sight, but he will play, albeit in a limited way, with such things as a road lay-out.

Assessment

On the second occasion that Freddie was seen, he co-operated very well in the activities that were presented. He was able to match shapes and do simple jigsaws, but used only trial and error tactics. He sniffed many of the pieces before using them. Although Freddie could match colours using like objects, he had difficulty when the objects were different – likewise with shape. He could match objects to pictures, but not pictures to objects, despite a demonstration. A later attempt to continue the assessment resulted in a demonstration of wild behaviour, when Freddie pinched the clinician, pulled hair, tore up papers, threw objects out of the window and even bit her.

Discussion

Freddie's range of developmental problems suggest that autism is a relevant context in which to consider his management and educational needs. It is not helpful to regard his behaviour as simply naughty and attention seeking. This diverts attention from his underlying difficulties, and disregards the many indications that the problems are more wide-ranging and complex.

Although Freddie shows some social awareness, he does not show social understanding and appears uninterested and unconcerned about the needs of others, unless they coincide with his own. His interests are circumscribed and he does not show appropriate imagination and creativity. It is felt that he is not well managed at home, but it would be simplistic to attribute such serious behavioural problems to bad management alone.

Update (1991) Age 4 years 6 months

The very experienced clinical psychologist involved with this little boy considered that a diagnosis of deviant autism would account for his problems and extreme behaviour. These certainly encompass the essential areas of Lorna Wing's triad. Yet the parents were angry and outraged at the diagnosis and refused to accept her views. Although they do now acknowledge that Freddie has special needs, a suitable educational placement is likely to be hard to find because of the severity of his behaviour difficulties. The situation remains unresolved.

The family moved away and there was no further contact.

Fiona: then aged 8 years

Referral

Fiona was referred to a specialist speech and language therapist from the community as a deviant pattern of language delay was recognised. This report was written when Fiona was 6 years of age, a year after the initial referral.

Background information

Fiona is the younger of two children. Her sister is normal and attends a mainstream school.

Developmental history

Fiona was a full-term baby and was born after a long labour. From birth she screamed a great deal, slept very little and was not a good feeder. Weight gain was slow and she had constant diarrhoea. Both parents felt that something was wrong, especially as it was almost impossible to comfort her. Numerous medical consultations proved ineffective in providing any relief until her mother, through a support group for parents of hyperactive children, was put in touch with a practitioner with an interest in dietary/metabolic causes of behavioural difficulties. His investigations revealed that Fiona was severely deficient in zinc.

At about the same time, it was observed that Fiona was suffering from spasmodic episodes, mainly at night, when her body was seen to shake and her eyes deviate. Epilin was prescribed for what was considered to be an epileptic condition. The parents were reluctant to give Fiona this drug as she was about to commence treatment with zinc. Following the administration of zinc, there was an immediate and dramatic change in Fiona's sleeping pattern and a subsequent improvement in her behaviour. As well as the zinc treatment, dairy products and artificial additives were excluded from her diet; she was also given vitamin supplements. No further episodes were reported and, according to her mother, recent neurological examination has not revealed any abnormalities (see *Update 1991*).

Recently, however, Fiona's behaviour at home has reverted. She sleeps very little at night, but this appears not to have any deleterious effect on her energy output during the day. She is a very difficult child to manage at home and causes considerable disruption to other members of the family.

General observations

Fiona is small for her age. She has good eye contact and an alert, enquiring facial expression which, together with a remarkable lexicon of social chat, gives an impression of greater ability than is subsequendy revealed by close examination. Fiona's present appearance and happy demeanour do not compare with the way she presented less than a year ago, when her waif-like figure and anxious facial expression were not enhanced by a 'tonsure' on the crown of her head where she had pulled out her hair. Apart from a tendency to lick her chin excessively, causing almost constant soreness, her appearance is essentially normal.

In school, Fiona is easy to manage, which is in contrast to the management problems she presents at home. Her repertoire of behavioural characteristics are, at the present time, perseverative, rather than bizarre. However, it is worth mentioning that the range of abnormalities was greater when Fiona was younger, which is of diagnostic significance. These included body spinning, hair pulling, resistance to change, unreasonable fears, distress caused by certain sounds, temper tantrums and an insistence on undressing herself, a skill which she was able to execute with remarkable speed. Most of these behaviours have disappeared or diminished considerably.

When left to her own devices, Fiona's general activity could be described as aimless. She has a particular interest in clothes and shoes and shows a remarkable ability to remember the appearance of cars belonging to people known to her.

Within the context of her difficulties, Fiona gets pleasure from being with people. She is very adept at knowing how to annoy others and uses this ability with considerable effect at home.

Within the classroom group she will join in with the games of other, socially normal children, but is unable to initiate meaningful play herself. Her own play is symbolic, but she cannot develop her play imaginatively and creatively.

Although Fiona's self-care skills are age-appropriate, she still wets at night and has to wear a nappy.

Attention control

This is at a single channel level, which indicates that Fiona can attend to an adult's choice of activity but her attention is difficult to control.

Sensory function

Visual perception

This is not an area of relative ability, and her skills are not age appropriate.

Auditory perception

This area of functioning is undoubtedly an 'islet of ability'. In all aspects of auditory skills, Fiona exhibits a level of capability in excess of her general level of development.

Body awareness

Fiona functions well in this sphere and shows good co-ordination.

Proximal senses

Fiona likes to smell people and food; she shows a normal awareness of heat, cold, pain, etc.

Non-verbal symbolic function

As mentioned earlier, Fiona plays symbolically and can be drawn into the games of other children. She is also able to role play in a limited imitative way, according to her mother who has described Fiona's actions with a toy microphone.

In all her play activities, however, Fiona is unable to develop beyond a certain level.

Concept formation

Although Fiona can match objects according to different criteria, her classification skills are limited to colour. Her verbal concepts are limited and are not age-appropriate.

Sequencing and rhythmic abilities

Visual

This is not an area of special competence.

Auditory

Fiona is good at dancing, which is an activity she enjoys. She is able to recognise complex rhythm sequences in music and clap them with accuracy.

Speech and language

Comprehension

In this area Fiona has considerable difficulty, which becomes very apparent on assessment.

In day-to-day situations, provided that the language and context which act as a ‘trigger’ are familiar, Fiona is able to respond deceptively well. However, when the wrong triggers are provided, comprehension breaks down and it is not possible to pursue a conversation with her; she is unable to utilise semantic information. In a limited way, Fiona demonstrates a sense of humour.

Expression

Fiona has a remarkable ability to recall and imitate the speech of others. She constantly talks and mutters to herself and it is possible to pick out the ‘ownership’ of her utterances. Provided the appropriate triggers are delivered by the listener, Fiona is able to use her echolalia to communicate, and this ability elevates her social functioning considerably, giving, as mentioned earlier, a false impression of her capabilities. When conversation is attempted beyond the confines of her interests or immediate experience, she will quickly resort to stereotyped repetitions and it becomes obvious that she is unable to communicate normally. Generally, Fiona will readily respond verbally but the content of her utterances, though linguistically intact, is more often than not irrelevant to the situation. Remarkably, Fiona can manipulate language grammatically, whether or not meaning is attached to what she is saying. Fiona’s articulation and vocal delivery sound very mature; this also enhances expectations of her abilities and provides a very misleading impression.

Educational attainments

Although Fiona attempts to ‘write’ there is little progress in the acquisition of literacy and numeracy skills.

Results of Assessments

Reynell Developmental Language Scale – 26.11.87
Chronological age: 5 years 6 months.
Comprehension: 2 years 9 months.
Expression: 2 years 7/8 months.

Derbyshire Language Scheme – 24.9.87
Chronological age: 5 years 4 months.
Comprehension: 2/3 information carrying words.

Schedule of Handicaps Behaviour and Skills (Wing MRC) – July 1987
Chronological age: 5 years 2 months.

A developmental profile shows clearly that Fiona's level of functioning in areas other than self-care and gross motor skills are well below her chronological age.

Sheridan – November 1987
Chronological age: 5 years 6 months.
Posture and large movements: 4 years 6 months.
Fine motor: 3 years.
Hearing and speech: 2 years 9 months.
Social behaviour and play: 2 years 9 months.

Overall, Fiona presents as a 2 years 6 months to 3-year-old, apart from gross motor.

Diagnosis

The spectrum of behavioural and learning difficulties which Fiona presents indicates that autism is an appropriate context in which to consider them – indeed the conflicting pattern of her developmental profile and history is very common in autistic children. Although by no means a classic 'Kanner type', Fiona's autistic features, together with possible metabolic factors, demonstrate a familiar pattern within the autistic continuum. It is worth noting that Fiona's initial dramatic response to the administration of zinc mirrors similar dramatic improvements in other children treated with a range of drugs, including fenfluramine, vitamin B6, as well as mega-vitamin therapy.

Over the years, Fiona's parents have seen a number of doctors in a quest for an answer, if not a cure, for Fiona's difficulties. This has not happened and, most surprisingly, when a diagnosis of autism was made by Dr X in 1986, the parents were not told. Ultimately it was the school which informed the parents that Fiona's difficulties were of an autistic nature and the autistic continuum was discussed,

Although the parents were most upset and at the time confused by the diagnosis, believing that Fiona simply had a language disorder, they have since become reconciled and have a better understanding of the implications of Fiona's deficits and difficulties.

Update (1991) Age 8 years

Since this report was written, Fiona's behaviour has had its ups and downs, and she has continued to be a difficult child to manage at home. However, overall there has been steady improvement. Shortly after the report was written, when Fiona was over 6 years of age, a paediatric department of another teaching hospital finally diagnosed a genetic condition which is frequently linked to autism as well as mental handicap. This was present from birth, but went unrecognised. Because of the presence of a known condition, the effectiveness or otherwise of the zinc supplements cannot be evaluated.

Fiona's physical condition improved dramatically once a sensible eating programme had been introduced at school. Her appearance changed dramatically. The Dickensian waif was replaced by a robust child, who could best be described by the epithet 'bright eyed and bushy tailed'. One year later, Fiona's comprehension of language had improved more than could be accounted for by maturation. Although on formal assessment her score for expressive language was not much in excess of her level of understanding, the language which she generated herself on topics which interested her was considerably better. Her capability with spoken language is in fact quite remarkable and may be regarded as an islet of ability. However, Fiona's skill in using language for interactive communication, when she has not chosen the topic, remains extremely limited.

Now, at the age of 8 years, Fiona has made satisfactory progress in educational terms, given that she has marked learning difficulties, particularly in areas of development which relate to the acquisition of number concepts. She has been able to make a start in the core areas of the

National Curriculum. Fiona's play with other children is participatory and, within the limits of her social skills, gains maximum benefit from contact with other children, although in a wider mainstream setting she is not yet able to cope satisfactorily. Fiona's communication skills are entirely equivocal. On the one hand, she is an excellent communicator, her body language is normal and she gets great pleasure and enjoyment from group language sessions – both from listening and communicating herself. Yet her ability to use language creatively remains limited. She has a good vocabulary and it is certainly true that at times she can say absolutely the right thing, often with appropriate humour. However, her underlying difficulties emerge, despite her lively personality, her zest and interest in the world about her.

It is apparent from these observations that Fiona's autism has receded, which is not to say that her difficulties are over, but it does indicate how well autistic children can progress and what enjoyment and pleasure they can provide.

Update (1998) Age 15 years

Fiona continues to attend a special school for able children with autism (which she entered at the age of 4 years). Her academic progress has not been spectacular, but is commensurate with her cognitive skills. Socially, Fiona has made considerable progress. She has a lively personality and contributes a great deal to the discussions that take place in her weekly social skills group. She is interested in teenage culture – clothes and make-up, TV soaps and is an excellent disco dancer with a natural sense of rhythm. Outside school she enjoys attending a drama group for young people with special needs. Fiona's facility with language continues to impress, and she can use words and expressions that are both apposite and sophisticated. However, because her ability with words has a learnt quality, incongruities inevitably occur.

Fiona attends a weekly session for young people with special needs at a local college, where the focus is on developing life skills. She does not enjoy this and becomes very upset by the behaviour of others attending the course.

At home, Fiona is still difficult, and now adolescent moodiness has been added to her spectrum of behaviour problems. Generally, in school she is not difficult to manage and will respond to reason and encouragement.

A MOTHER'S STORY

This poignant account written by the mother of a young autistic child vividly describes her experiences as she struggled to find out what was the matter, and how to help her son. Although we have minimally edited the narrative, changed names and disguised locations, the text is essentially as it was written. We are grateful to this parent for allowing us to present her story.

'You have asked for a profile to the best of my knowledge on Scott's five years which he will be on 10th April 1990. I will do this profile with all honesty and to the nearest and most accurate as I can. I will start from 0–6 months, then 6–12 months and 12–24 months, etc.

'Starting with 0-6 months. Scott was born on 10th April 1985. From the time I was expecting to when he was born I felt really well and his birth was normal, drug-free except for gas and air. When he was born, he was 7 lb 6 oz and healthy. I was also fine. He was a really good baby. You would call him an angel because he was such a quiet baby. He would sleep, feed, then sleep and feed. This went on until he was 6 months, when he did not need so much sleep. Around 6-7 months, he would just sit in his baby bouncer for hours, not really looking at anything or taking much interest in anyone. When Scott got to about 11-12 months, all he used to do was cry a lot. He still did not take much notice of anything and as a mother I really thought he did not like me much. He was very spiteful and distant, and what I noticed the most at this time was an incredible anxiety with his personality. It was terrible. He showed this with anybody and everything, especially with me, maybe because I was with him all day and I was his lifeline. If he got frustrated, he would take it out on me.

'Around 12-24 months. He started walking at 17 months, but did not venture much as another baby would when starting to walk. Scott would walk around in a kind of routine. What I mean is, he would walk from the front room into one bedroom, out again to the other bedroom, then into the bathroom, then the toilet and then the kitchen. He would do this for hours, just walking in and out of the rooms. His behaviour if you tried to distract him would be crazy. He would scream and cry so bad it was like you were trying to kill him. I would try and play with him with toys, books, etc. but he would not do anything with me. He would throw cars, toys, bottles.

Anything he could get his hands on would be aimed at me. He would not look at me or anyone else. He would not make any eye contact.

'Age 24 months–3 years. Scott was I would say at his worst. I could not take him out anywhere. I became like a prisoner in my own home. It was at this stage, when he was so bad, I must admit I thought he was a little crazy and I knew he was not getting any better, and he didn't have any speech. A lot of outsiders were more worried about his speech, and thought if his speech was better so would his behaviour be better. But I knew as a mother and living with Scott twenty-four hours a day, that there was more to it than speech and behaviour problems.

'So I heard about autism. I read a lot of books and had seen a few programmes on telly but what I had read and seen, and the people I had seen and read about were so severe, I thought Scott can't be autistic because he was not as bad as that. But always in my heart, I still thought well maybe just slightly autistic. Anyway, people said, No way. So I pushed it to the back of my mind and coped the best I could. Scott at this stage just destroyed everything he got his hands on. He would not listen to anything or anyone. He could also sit for hours, looking at the carpet, but was not looking at it. He seemed to go into a trance, and if you would try and distract him from his trance, he would hit, bite, scream, throw objects, go crazy. You would really have to let Scott have his own way and let him do his own thing to a certain extent. This way, I could get more peace, to go on with life. He was just like a loner, in his own world, and who didn't want to be distracted.

'At 3 years 6 months, when he started nursery it was terrible. The teachers had a terrible time. They did not know where to begin. He would not do anything he was told. They asked on a few occasions about did he hear properly. He would not mix with his peers, or could not! Nobody could understand what he was saying, because he sounded dumb and could not speak anyway. I could understand Scott more, because I was with him all day and got to know his language. I could also feel his emotions – sounds crazy, but I could feel his needs mentally and understand to a great length what he wanted or did not. At nursery, his behaviour remained the same, destructive, throwing tantrums, screaming, crying. He would not listen to any story. He would do what he wanted to do and at any time he wanted to do it. The teachers did their best, but were also tried and tested with Scott and were at a loss because they did not know how to treat him. So they did their best to stop him harming himself and others, and trying their best to get him to join in. They have been brilliant and done very well with him.

'Three to 4 years 6 months. Scott was still bad at 3 years 6 months, but was now able to sit and do more. For instance, he would watch videos for about two hours, but you were not allowed to sit with him, touch him, kiss or cuddle him. He hated any physical emotion. But towards being 4 years 6 months, he was improving greatly. I would make him sit, kiss, love, touch, cry, smell, and feel, until he would respond. This was a great help, but at first he was so bad, he would go crazy, really, really bad. It hurt me to see Scott suffering, but I had no choice. What else could I do? I had a son who needed help and I was the only one who would or could help him.

'Also at home, he would only need about 6 hours sleep. He always went to bed at 8 o'clock in the evening, then awake around 2–3 o'clock in the morning and just destroy everything. He would rip wallpaper, pull everything out of kitchen cupboards, pour milk all over the floor, flood the bathroom. One day he found paint, poured it all over the hall carpet, and all over the walls in the bathroom. My opinion was, still autistic and also speech frustrations very bad, and anxiety as well.

'I hope by now you have got a general picture of Scott's behaviour and speech. So I will continue with my worry about education. I am really worried about Scott's understanding. He cannot understand anything he has not already learned. For example, if you say to Scott, "How old are you? Where do you live?", he cannot answer, because he does not understand. He has no concept of numbers. Well, he has no concept of anything really. I have drummed into Scott everything I can and his improvement in the last eight months is remarkable. Eight months ago he could do nothing. He could not speak. He had totally no understanding at all. So I thought to myself, well, if I don't help, nobody will. So I bought books, and toys, and sat down with Scott and worked very hard to make him listen, play and read to him, talk with him. What I did was not to give in to him any more. I gave nothing to Scott's demands. I let him scream, cry, throw tantrums, hit out at me. It took months before any progress was seen. But Scott saw that I was not going to give in, so after having a very hard battle of wills, I was finally winning, and Scott finally started to stop crying and screaming, and slowly listened to me. And then, because he was so behind, it also took a lot of patience to teach Scott.

'I started with words like cat, dog, etc. and a b c d e, etc. And then talked to him, like saying, "Look at the water coming out of the tap", and then saying, "The reason why we wash is to get clean, because dirty looks silly." I tried to explain reasons why about everything, so he started to get more involved. For instance, if a cat was meowing, I would say to Scott without him even being interested, "Scott, listen to that cat, he is crying because he wants some dinner." I would say this about twelve times, before he could take it in, or even be interested. I would never ever stop talking or singing and acting as he would like me to. I was always trying to be funny, and he would love me being funny. If he showed interest in anything, I would always let him look, listen and join in, with him acting as he would.

'By now, Scott became very close to me. A miracle was, he showed me love, kissed and always cuddled me. I was so happy. He also now wanted to kiss everybody and has a great love for other children. His teachers at school, who he has now known for nearly two years, he loves, and his brothers. He has two brothers. Steve, he loves very much. Steve is 11 in September, and has always treated Scott normally and protected him. But Steve gets very frustrated at times with Scott, because how do you explain to an 11-year-old, about Scott's mentality? He sees Scott as normal, which is good. Scott also has a baby brother called Paul, who he adores, but does not like the baby to touch him, and kiss and cuddle him.

'Scott has a cousin called Marie. He hated her at first until he reached about 3 years old. Now he will play with Marie more than his brothers or children at school. He will share most things with her, but there are times when he still won't talk or play or kiss with anyone. Unless Scott wants to, the only one he will love and protect, at all times is myself, his mother.

'Scott, as he is today. Scott is so different these days you would think he was a new boy from a year ago. He can now talk in little sentences to me. He can make eye contact. He can show anger, fear, love, kindness as well. He can show almost every emotion as a normal child. But my biggest worry is his understanding. He can only understand what I have taught him. His mind is just like a video recorder, only remembering the input which he has learned, and beyond this, he does not know or understand. He does not know why we eat, drink, laugh, and sleep. He has no concept for money. He does not know why we have to pay for everything in shops, why his brothers have different ages, or why his baby brother cannot speak yet and why his baby brother does not understand him when Scott talks to him or wants him to do something. Scott still gets very aggressive and has tantrums still. He will not listen or try to learn songs and stories, unless it's what he wants, and then it all depends on what mood he is in.

'Scott is now very loving, but I have noticed over the last couple of weeks, Scott is only very loving and kind to the people who spoil or give in to him. I find this quite upsetting, because people who don't let him have his way, he will say to me, or the person concerned, "Scott is not your friend." He is quite aggressive towards them. I am the only person who is very strict and firm with Scott and he still loves me very much, although he gets very hurt, and sometimes if I have been very firm, this shatters Scott's emotions so much he gets very depressed. Scott's personality is so very hard to cope with. He wants attention from me all the time, and always has got to be the centre of everything. At the moment he is more demanding which may be because my baby son Paul is taking up a lot of my time now he is getting older. It is hard to judge.

'Since I started writing this, Scott's speech and understanding has greatly improved and I am quite surprised.

'The main worry is I do not think he is ready for mainstream school. He cannot understand well enough to go to mainstream, or speak well enough. He cannot dress himself well enough. He cannot feed himself (or maybe he is just lazy!). I feed him at home, because he will not eat unless I feed him, and then it's a battle, because Scott has a terrible appetite. He hardly eats anything. He cannot or won't wash himself. I still wash him. I mainly do everything for Scott, so I am worried about when he goes to school. He will not be able to sit in a classroom full of children, because he will not understand hardly anything which is being said. He understands a lot better, but with great difficulty. For instance, when I am washing him in the morning, and I pull the plug out, he will say, "Mum, where is the water going?" I say, "Down the pipes, because it's dirty water." He will say, "Why is it dirty?" I will say, "Because your hands and face were dirty, we wash them with the water, so now it's dirty water." Why is it dirty water? etc, etc. This can go on and on for about ten to fifteen minutes, until he gets fed up. But he still doesn't really understand why. He just gets fed up and goes off.

'But to finish off, Scott is very clever and even crafty, and knows a lot more than he lets on. I do not know why this is so, maybe it's his personality. He pretends or hides his true ability to a certain extent, but my last word is, he is not clever enough for mainstream schooling. All I know is, there is something wrong in most areas which needs special attention.'

Scott's mother unfortunately received shamefully little help and support during his pre-school years. It was not until Scott was over five years of age that he was correctly diagnosed, and appropriate educational placement offered.

Scott now attends a special unit for children with autism. He is very happy and is making good progress.

Update (1998) Age 13 years

Scott continues to attend the same special school, with integration sessions into a local mainstream high school. Things have not been easy for the family. The birth of another baby, a boy, who subsequently was found not only to have autism but also severe learning difficulties, had a profound effect on Scott, who deeply resented having to share his mother's attention. Scott remains very attached to his mother. In addition, two close family members died, and the upset caused was reflected in a period of very difficult behaviour in school. Nevertheless, Scott has made outstanding progress. In his weekly social skills group he contributes to discussion, expresses his feelings and opinions, and talks appropriately about current events and his own experiences. He loves football, which he plays in school, and is friendly and sociable with his peer group. Scott remains extremely sensitive, but can now reflect on his feelings – for example, why he resents his youngest brother. He does not enjoy the integration sessions as he finds the larger school environment both confusing and worrying.

APPENDIX 2

USEFUL CONTACTS AND ADDRESSES

This appendix is addressed to parents of young children who are beginning to think that their child is not developing normally and have an inkling that he or she could have autism. Perhaps they have already consulted their family doctor and been encouraged to stop worrying, and yet doubts remain. They feel embarrassed about making a return visit with their healthy and attractive child, and hate the idea of being labelled as a fussy parent. What, in these circumstances, is the best thing to do? We would suggest that first of all they contact their Health Visitor. It is apparent that many families lose touch with their Health Visitor after their child's very early infancy, especially when all seems satisfactory and the mother is coping well. When features of autism emerge, often as late as the child's third year, there is no immediate professional to turn to and it is difficult for parents to know what to do, let alone how to evaluate their child's difficulties.

Another course of action is to make direct contact with the local Community Speech and Language Therapy Service. It is not necessary to have a doctor's referral, simply contact the manager of the service and ask for a consultation. Although there is a national shortage of speech and language therapists, sooner or later an appointment will be made available. Speech and language therapists, even if they have little, if any, experience of the condition of autism, are trained to assess a child's overall communication skills in relation to development. As a professional group, they are the most likely to offer support. In recent years they have started to play an increasingly important role in the recognition and assessment of autism in young children.

Although the speech and language therapist may be the most useful professional contact for parents in this situation, they should not necessarily assume that a course of treatment will be offered. What is most likely is that their child will be assessed, possibly over a number of weeks. It will be this assessment which will hopefully enable parents to begin to understand their puzzling child and additionally provide indicators for future management and appropriate onward referral. This is most likely to be to a child development centre.

Advisory Centre for
Education (ACE) Ltd
1b Aberdeen Studios
22 Highbury Grove
London N5 2DQ
Tel: 0171-354 8318
Fax: 0171-354 9069

AFASIC
347 Central Markets
London EC1A 9NH
Tel: 0171-236 3632
Fax: 0171-236 8115

Autism Research Review International
Institute for Child Behavior Research
Director: Bernard Rimland
4182 Adams Avenue
San Diego, California 92116
USA
Web: www.autism.com/ceri

Autism Research Unit
The School of Health Sciences
University of Sunderland
Sunderland SR2 7EE
Tel: 0191-510 8922
Fax: 0191-567 0420

Contact-a-Family
170 Tottenham Court Road
London W1P 0HA
Tel: 0171-383 3555
Fax: 0171-608 3254

Hanen UK
8 Campion Close
Eccleshall
Staffordshire ST21 6SR
Tel/Fax: 01785 851 771
(Hanen materials are published by Winslow Press)

Makaton Vocabulary
The Makaton Vocabulary
Development Project
31 Firwood Drive
Camberley
Surrey GU15 3QD
Tel: 01276 61390

MENCAP
MENCAP National Centre
123 Golden Lane
London EC1Y 0RT
Tel: 0171-454 0454
Fax: 0171-608 3254

TEACCH (contact in UK)
Mr K. Lovett
Society for the Autistically
Handicapped (SFTAH)
199/201 Blandford Avenue
Kettering
Northants NN16 9AT
Tel/Fax: 01536–523 274

The Centre for Social and
Communication Disorders (NAS)
Elliot House
113 Masons Hill
Bromley
Kent BR2 0HT
Tel: 0181–466 0098
Fax: 0181–466 0118

The National Autistic Society (NAS)
393 City Road
London EC1V 1NE
Tel: 0171–833 2299
Fax: 0171–833 9666
email: nas@clusl.ulcc.ac.uk.
website: http://www.oneworld.org/
autism uk/

Autism Research Centre (NAS)
University of Cambridge
Douglas House
18b Trumpington Road
Cambridge CB2 2AH
Tel: 01223 336098
Fax: 01223 322661

The National Portage Association
127 Monk Dale
Yeovil
Somerset BA21 3JE
Tel/Fax: 01935 471641

The Paget–Gorman Society
2 Dowlands Bungalows
Dowlands Lane
Smallfield
Surrey RH6 9SD
Tel: 0134–284 2308
email: Prup@compuserve.com
website: http:/ /www.pgss.org/

The Royal College of Speech and
Language Therapists
7 Bath Place
Rivington Street
London EC2A 3DR
Tel: 0171–613 3855
Fax: 0171–613 3854

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INDEX

abilities 21, 45, 85–6
  academic 37–8, 83–4
able children xii, 8, 11, 48
  and concept formation 46
  diagnosing 20, 24, 43
  and friends 36, 44
  and language 73, 74–5, 85
  see also intellectual functioning
academic achievements 37–8, 83–4
ACE (Advisory Centre For Education) 79, 131
activities and interests 8, 31
  outside school 62, 86–7
  in play 42–3
  repetitive and aimless 34, 35
ADHD (Attention Deficit Hyperactivity Disorder) 34–5
adolescence 38–9, 59, 88–9
  see also older children
adults xii, 7, 74–5, 88–91
  writings of 40, 41, 42
adult's arm as a tool 32
advice, help and 52–9
Advisory Centre For Education (ACE) 79, 131
AFASIC 12, 131
age 6, 7
  improvements with 16, 27–8, 44, 47, 55
  see also adolescence; older children
allergies 18, 20, 94
aloneness 6
aloofness 8
alternative treatments 16, 53, 92–9
  auditory integration therapy 96
  drugs and vitamins 18, 19, 93, 94
  facilitated communication 93–4
  Higashi School 95
  holding therapy 15–16, 94–5
  Lovaas 97–8
  option method 95–6
  sensory integration therapy 41–2, 96–7
  TEACCH 57, 84–5, 91
American Psychiatric Association 14
appearance 6, 33
art and drawing skills 85–6
Asperger, Hans 6
Asperger Syndrome 6–7, 10, 13
  and deviant autism 37
  and motor problems 41
assessment 29–47
  of language 69–70
  see also statementing; tests
attention control 34–5, 39, 55–6
Attention Deficit Hyperactivity Disorder (ADHD) 34–5
auditory function *see* hearing
auditory integration therapy 96
autism

  assessment 29–47, 69–70
    see also statementing
  causes of xii, 15–19
  classical 5–6, 20, 21
  deviant 36–7
  diagnosis *see* diagnosis
  and gender 17
  history of 5–14
  incidence of xii–xiii, 17, 30
  management of 48–62
  spectrum of xii, xiv, 8, 10
  variability in 1–4, 10, 51–2
aversion therapy 98

Bailey, A. 17, 90
Baron-Cohen, Simon 11, 22, 31, 74, 75
behaviour 30–9
  and family therapy 24
  and Higashi School 95
  problems with 24, 26, 37
    and autistic schools 81–2
behaviour modification 37, 97–8
boarding schools 59, 82
body language, lack of 34, 41, 66
bonding 15, 94
books xiii–xiv, 49, 84, 89, 99
brain damage or dysfunction 18, 19

Candida albicans 18
case studies 1–4, 100–29
causes of autism xii, 15–19
CHAT (Checklist for Autism in Toddlers) 11, 23, 31
chickenpox 18
class, social 5, 17
classical autism 5–6, 20, 21
classroom support 80, 81
clumsiness 41
cognitive deficit 73–5
  see also coherence
coherence 11, 36, 45
  and attention 39
  and language 64
  tests for 73–5
communication 63–75
  social 9, 30–1, 61–2
  specific problems 64–6
  see also speech and language
concept formation 45–6
Contact-a-Family 59, 131
conversation 9, 22, 66, 67, 69–70
Costello, A. 42–3
counselling 52–9
Crohn's disease 30
cures xiii, 16, 79
  see also alternative treatments; therapy
cytomegalo virus 18

danger, awareness of 36, 51
deafness 40
  see also hearing
delayed echolalia 5, 65
Derbyshire Language Scheme 70
descriptive approach 7, 21
development
  communication 63–75
  early 30–3
  and expectations 55–6
  and improvements 16, 27–8, 44, 47, 55
  pervasive developmental disorders 14, 36
deviant autism 36–7
diagnosis vii–x, xiii–xvi, 20–8
  and alternative treatments 53, 92–3
  and referrals 13, 23, 130
diet, eating habits and 49–50, 60
Down's Syndrome 74
drugs 18, 93, 94
DSM (*Diagnostic and Statistical Manual*) 14
dyslexia 68
dyspraxia 67, 97

early development 30–3
eating habits and diet 49–50, 60
eccentricity xiv, 20, 28

echolalia 5, 65, 67, 73
education 76–87
  early expectations of ix
  LEAs 24–5, 76, 78–9
  placements *see* educational placements
  post-16 courses 90
Education Acts 24, 76
educational placements 71, 76–82
  pre-school 56–7, 60, 71, 78
  schools *see* schools
  see also education
empathy, lack of 9
employment, success in 83, 90–1
endorphins 94–5
epilepsy 18
eye contact 33–4, 64, 66

facilitated communication 93–4
families 24, 54, 58–9
  autism in 17
  see also parents
family therapy 24, 98–9
fears, irrational 51
finance 24–5, 70, 76, 78–9
  and referrals 13, 23
fragile X-syndrome 18
friends 27, 36, 44–5
Frith, Uta 6, 10–11, 63, 73–4, 75
functional play 43–4, 62

games 44, 62
  see also play
gender
  delayed concept of 65
  and incidence of autism 17
generalise, inability to 35–6
genetic factors xii, 17, 19
goal-oriented behaviour 35
Gould, Dr Judith 7–10
Grandin, Temple 40, 41, 42
growing up 88–91
guilt, parents' 16, 26, 52

hand flapping 34
Hanen 57, 71, 131
Happé, Fran 11–12, 74–5
health trusts 13, 23, 34
hearing 40, 41, 64, 96
help and advice 52–9
herpes simplex 18
Higashi School 95
high level language disorder 69
history of autism 5–14
holding therapy 15–16, 94–5
hormones, therapy with 19, 93
Howlin, Patricia 39, 88
hyperactivity 34–5, 94
hyperlexia 68, 85

ICD-10 14
idiosyncrasy 48
illnesses 17–18
imagination 9, 43
immediate echolalia 65
immunisation 18, 30
improvements with age 16, 27–8, 44, 47, 55
incidence of autism xii-xiii, 17, 30
independent schools 12, 80
indifference 8
infantile spasms 18
infections 18
intellectual functioning 20–1, 83
  and behaviour 37, 41
  and skills 21, 45, 85–6
  see also able children; learning disabilities
intelligence 6, 7, 83
  see also intellectual functioning
interests *see* activities
International Classification of Diseases (ICD) 14
Internet 13, 93
intervention programmes 53, 55, 71, 99
  see also TEACCH
islets of ability 21, 45, 85

jigsaws 40

joint attention 22, 65

Kanner, L. 5–6, 7
Kitahara, Dr Kiyo 95

labels, diagnostic xv, 14, 76
language *see* speech and language
language disorders 44, 66–8, 82
  see also speech and language
learning disabilities
  compared to autism 8, 74
  coupled with autism 21, 49, 81, 82
    and adult provision 90
  and the National Curriculum 86
  see also intellectual functioning
LEAs (local education authorities) 24–5, 76, 78–9
leaving home 89–91
local education authorities (LEAs) 24–5, 76, 78–9
  see also education
lollers 34
Lovaas behaviour modification 97–8
Lowe, M. 42–3

mainstream schools 12, 60, 79–81
  for early years 57
  Special Educational Needs Co-ordinators 25, 77–8
  see also nurseries
Makaton 72–3, 131
management 48–62
  practical suggestions for 59–62
masturbation, public 51
media attention xiii, 95
medical history 17–18, 30
memory 6, 40
Mencap 49, 59, 86, 131
mental handicap *see* learning disabilities
mentalising 10–12, 74, 75
Mesibov, Gary 21, 84
milestones 30, 52, 68
mind, theory of 10–11, 74
mitigated echolalia 65, 67, 73
MMR vaccine 18, 30
mothers 15–16, 94
  case history 124–9
  see also parents
movement 33–9, 40–1, 96–7
music 47
mute children 69, 72–3

National Autistic Society (NAS) ix, xii, 132
  books from 13, 49, 84, 89, 99
  evaluating claims 12–13, 92–3, 131
  history of 12–13
  local groups 59
  schools 81–2
National Curriculum 84, 86
naughtiness 56, 60
neurofibromatosis 18
Newson, Dr Elizabeth 7
numeracy skills 85
nurseries 56, 57, 60, 71
statementing in 78

objects, interest in 5, 32
odd children 8, 10
older children 80
  improvements in 16, 27–8, 44, 47, 55
  see also adolescence
option method 95–6
outreach 80–1, 99

Paget-Gorman Society, The 132
parents
  attachment to 31–2, 60–1
  autism in 17
  blaming 15–16, 24, 52, 98
  and diagnosis viii–x, xiv–xvi, 52–4, 92–3
  fussy parent label 33, 130
  mothers 15–16, 94, 124–9
  need for information xiv, 54–5

- in statementing 76–8
passivity 8, 10
PDD (pervasive developmental disorders) 14, 36
perception 39–42
pervasive developmental disorders (PDD) 14, 36
phenylketonuria 18
physical contact 31, 32, 38
  - and alternative treatments 94–5
physical disorders 17–18
pica 50
placements, adult 88–91
  - *see also* educational placements
play 6, 9, 42–4
  - and language disorder 68
  - social 62
play schemes for special needs 57
playgroups 56, 57, 60, 71
point-counting approach 7, 21
pointing 62, 64
Portage scheme 57
post-school provision 12, 90
pre-natal scanning 18
pre-school children 30–3
  - and behaviour modification 97
  - diagnosis with CHAT 11, 23, 31
  - placements for 56–7, 60, 71, 78
predictability, building in 60
pregnancy 18, 30
pretend play 9, 43–4, 62
professionals
  - and diagnosis x, 24, 25
    - failures in xiii, 21, 98–9
  - first approaches to x, 63, 69, 130–1
  - knowledge of 22, 54–5
  - and psychometric tests 40
  - *see also* diagnosis; psychologists; speech and language therapists
pronouns, difficulty with 5–6, 65
proximal senses 41, 62
psychologists 22, 49
  - *see also* professionals
psychometric tests 40
psychotherapy 98–9
punishment 56, 97

questions 61, 65

reading 68, 85
recognition of autism 27
referrals 13, 23, 130
refrigerator mother 15
relationships 5, 8–9
repetition 6, 9, 34, 35, 43, 48
  - in language 5, 65, 67, 69, 73
research on autism 7–8, 13, 17, 85–6, 131
  - and alternative treatments 92–3, 94
resources xiii, 57
  - and LEAs 24–5, 76, 78–9
  - and speech and language therapy 70–1
respite care 58–9
Rett's syndrome 18
Reynell Developmental Language Scales 70
rhythmic capabilities 46–7
rituals 35
rough and tumble games 31, 38, 42
  - *see also* physical contact
routines 35, 91
rubella 18
rule-based approach 56, 60
running off 51
Rutter, Professor Sir Michael 7

S-PD (semantic-pragmatic language disorder) 63–4, 82
sameness, maintenance of 6, 34
savant talents 21, 45
scepticism of alternative treatments 16, 92–3
schools 76–82
  - boarding 59, 82
  - mainstream *see* mainstream schools

  special 12, 23, 81–2
  and statementing 76–8, 83
  see also education
secretin 93
self-care 49
Selfe, Dr Lorna 85
semantic-pragmatic language disorder (S-PD) 63–4, 67–8, 82
sensory function 39–42, 62
sensory integration therapy 41–2, 96–7
separation difficulties 60–1
sequencing capabilities 46–7
serotonin 18
sexual activities 39, 51
shape matching 39, 40
shared-attention games 62
sharing, encouraging 60
shopping 41, 50–1
siblings 17, 58
sign language 72–3, 131
skills 21, 45, 85–6
sleeping problems 48
smelling 41
sociability 44
  see also social impairments
social class 5, 17
social impairments 38–9
  and communication 9, 30–1, 61–2
  and employment difficulties 91
  and imagination 9, 43
  interaction with peers 57
  and language disorders 67–8
  and play 62
  and relationships 5, 8–9
  and social skills 9, 38–9, 44–5, 71, 72, 83–4
  and social understanding 60–1
  Wing's Triad of 8–10, 14, 44
special educational needs 25, 76–8
special schools 12, 23, 81–2
spectrum of autistic disorders xii, xiv, 7, 8, 10
  see also variability in autism
speech and language 5, 63–75
  conversation 9, 22, 66, 67, 69–70
  development of 32–3
  and deviant autism 36–7
  echolalia 5, 65, 67, 73
  schools for 82
  verbal children 35, 63–4, 65, 66
  see also speech and language therapists
speech and language therapists 22, 24, 130, 132
  first approached xv, 63, 69, 130–1
  and school-age children 71–2
  see also professionals
speech and language therapy 68–75
statementing 71, 76–8, 83
  see also assessment
sub-groups ix, 6, 10, 14, 36–7
supermarkets 41, 50–1
support groups 48–9, 88
Symbolic Play Test 42–3
symbolic understanding 42–5
synchronised dialogue 31

Tantam, Digby 6–7
task avoidance 37
TEACCH 57, 84–5, 91, 132
teachers 22
  see also professionals
team diagnosis 23
teenagers *see* adolescence
television and videos 31, 42, 62
tests
  of cognitive deficit 73–5
  of language 69–70
  psychometric tests 40
  Symbolic Play Test 42–3
  see also assessment
Theory of Mind 10–11, 74
therapy
  auditory integration 96
  aversion 98
  family 24, 98–9
  music 47

  psychotherapy 98–9
  sensory integration 41–2, 96–7
  speech and language *see* speech and language therapy
  see also alternative treatments; cures
time, understanding of 47
Tinbergen, E. 15
Tinbergen, N. 15
tiptoe walking 34
toilet training 49
touching 41, 62
Tourette Syndrome 37
treatments *see* alternative treatments
Treffert, Darold 21, 45
Triad of Impairments of Social Interaction 8–10, 14
tuberous sclerosis 18
turn-taking 42, 66
twin studies 17

USA
  TEACCH programme in 84, 85, 91
  therapies in 95, 96-7, 98

variability in autism xii, 1–4, 10, 51–2, 90
  see also spectrum of autistic disorders
verbal children 35, 63–4, 65, 66
videos, television and 31, 42, 62
viruses 18
visual perception 39–40, 41, 50–1, 86
vitamins 19, 94
vocabulary 65

Welch, Dr Martha 15
Wiltshire, Stephen 86
Wing, Dr Lorna 7–10, 14, 45
Wolff, Dr Sula 19
World Health Organization 14
writing skills 85