

# **Autism and Asperger Syndrome : The State of Play**

A recent review article (Howlin 1998) provides a summary of current information concerning the nature of Autism and Asperger Syndrome, and of the various intervention strategies that have been used. Reference is made to the principles underlying those interventions that appear most effective.

These notes attempt to summarise this summary and provide an overview, albeit brief of significant issues.

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## **INTRODUCTION**

Autism is characterised by major deficits in communication and social understanding, and by ritualistic or obsessional behaviour. It is a pervasive developmental disorder that is usually apparent from early childhood.

Although there is still some debate whether high level Autism and Asperger Syndrome are qualitatively or quantitatively different, observations suggest few substantive differences either in early history or in outcome. Further, the criteria for Asperger Syndrome also highlight the obsessional and social-communication deficits. Differences may be observed in respect of the presence of adequate language development, and cognitive skills in the average range, among (many) Asperger cases.

Recent studies indicate that prevalence rates for "classic" Autism are approximately 5 per 10,000; and the rate is much higher (around 90 per 10,000) if one includes children within the wider "autistic spectrum". This latter group includes those children who show the triad of impaired social interaction, communication, and imagination, along with rigid and repetitive patterns of behaviour.

## **COURSE**

Autism has its onset in infancy or very early childhood, and concerns about the child's development are usually recorded within the first year. Such concerns relate to problems in communication, play, or social responsiveness, and to repetitive behaviour.

With time, the pattern of a child's development is influenced by the degree of cognitive impairment. While Autism may co-exist with a range of measured ability levels, the majority of autistics have some learning difficulties, and around 50% will have measured IQs of 50 or below. Among those cases with severe learning difficulties, there is unlikely to develop meaningful speech, and there will be a high probability of disturbed behaviours such as self injury. Where ability is within the average range, outcomes are more unpredictable. In many cases, there will be an improvement with age as awareness of; and adaptation to, the difficulties become greater. Within this group, some individuals will remain dependent, but others may achieve virtual independence and maintain successful employment. In other cases, problems will increase with age.

Among all autistic individuals, however, there will continue to be an impact upon their day to day lives from the communication and social disabilities.

## **MANAGEMENT**

Observations of marked improvements among some autistic children over time has led to hopes or beliefs that particular treatments can substantially affect Autism or even bring about recovery. Such treatments have included Holding, Music Therapy, Scotopic Sensitivity Training, Auditory Integration, and drug or vitamin usage. Little hard evidence or data from controlled research exist to support such beliefs.

One notes the example of "Facilitated Communication" where children are supported in their attempts to respond via various aids and where claims for marked progress and for high cognitive skill in the children were made. Controlled investigations have indicated that the responses were almost invariably under the control of the facilitator and not the child.

A variety of teaching approaches have also been linked with (claimed) major improvements ... notably the Higashi programme (Daily Life Therapy) or the Option Approach (Sonrise). Again, there is little objective evidence, and criteria for recovery may be limited in their scope. Generalisation from the treatment setting to other settings is another issue.

A much publicised current approach with very young children with Autism is the intensive behavioural intervention programme of Lovaas and his associates. Claims for the benefits of this approach must be examined in the light of procedural criticisms concerning subject selection, the precise nature of the original programme compared to that of subsequent programmes, and the definition of "normality" which largely refers to IQ scores within the average range and admission to mainstream schooling. Further, the imposition of the programme may present major practical difficulties and strains upon all concerned, given that it requires 40 hours per week of one to one intervention over two years+. Meanwhile, current observations acknowledge the value of behavioural intervention and recognise the (short term) benefits; but they are finding that, among

older subjects, there are few if any significant differences in cognitive attainments, or in measures of independence, between subjects who had received the home-based behavioural programmes in young childhood and controls who had not.

## **IMPLICATIONS FOR PARENTS**

There is no current evidence that any "cures" for Autism exist. Advisors need to tread the narrow path between appearing unduly pessimistic about treatment approaches and offering false hope, if indeed there is no universal panacea.

The role of the advisor is to obtain for the parents as much information as possible, not only about children for whom a given treatment has been claimed to be successful, but about those children for whom there has been little benefit. Suggestions that a given treatment works equally well among all cases should be afforded particular caution. Questions should focus upon which intervention appears to work best with older or with younger children, for those with and without language, and for the more or for the less cognitively able children. One should also identify what kind of assessments are completed prior to treatment and what methods (beside subjective, selective, and anecdotal reports) are used to assess outcomes; what happens to the children in the long term; what differences exist, in the longer term, between children given a particular treatment and those not so-treated; and what are the implications for cost, time, and familial pressure. Above all, families need information about local facilities, and assistance to gain early access to the provision that is most appropriate to match the given profile of strengths and weaknesses in the child.

## **UNDERSTANDING SYMPTOMS**

The kind of challenging behaviour that may be observed among children with Autism (such as aggression or self injury) may be the more understandable if one can recognise the likely impact upon a child of severe social and communication difficulties. In a world in which there is little understanding of events round them, where they cannot readily make their needs known, and where there is no internalised system for dealing with stress, the children with Autism may well react by displaying retaliatory behaviours, or a marked withdrawal and a reliance upon routine and ritual. The situation will be exacerbated if reactions to such behaviour (over) emphasise time out, or extinction, where the child may not recognise the cause-effect linkage (i.e. the behavioural approaches become part of the threat rather than part of the means of amelioration).

Therefore, interventions need to work towards compensating for the social and communication problems rather than simply working on the elimination of observed behaviours.

Before the implementation of any intervention, one needs information about the precise nature of the difficulties. Does "aggressive behaviour" result from an inability to communicate, from a lack of control over the environment, from the rewarding attention achieved, or from anxiety following an interference with routines? Might a combination of these features co-exist? Is there any impact from physical problems? For example, some stereotyped or self-injurious behaviours have been found to follow illnesses, undetected pain; and infections (and children with Autism appear unusually prone to ear infections).

Meanwhile, it is recognised that Autistic behaviour may be observed among children who show a wide range of cognitive ability. This has implications for the nature of any intervention which should not be pitched too high or too low for the child in question; and there is the suggestion that psychometric, cognitive testing does have a role to play alongside structured or unstructured observations in order to maximise the probability that particular skills or deficits will be identified.

It is also held that the "traditional" ABC approach to behavioural analysis (the examination of Antecedents, Behaviour, Consequences) may not be appropriate for children with Autism. For example, it might not be possible to determine with any certainty what are the child's perceptions of the antecedent or the consequence of a given behaviour. An observer will have no means of knowing what a given situation, or elements of it, will mean to the child.

One needs, therefore, to work towards an understanding of what a given behaviour will achieve for the child. Five main functions of the various forms of undesirable behaviour have been identified:

1. To indicate the need for help or attention
2. To escape from stressful situations
3. To obtain desired objects
4. To protest against unwanted events or activities
5. To gain stimulation.

If the purpose of the behaviour is clear, one might teach the child some alternative method to achieve the same end .... perhaps by means of teaching simple phrases, the use of symbols or pictures, or indicating choices by means of some "mechanical" aid.

However, it is noted that most of the studies of autistic behaviours have been carried out in clinical or experimental settings, and the analysis of behaviours in a more natural requires much time and care, especially if the underlying factors are complex ~ change over time or situation. Further, the kind of studies in question may well lack any controls, and are frequently single-case analyses, with the need for caution, therefore, in seeking to generalise findings from the given case to all or any others.

As an adjunct to observational methods, use can be made of questionnaires or rating scales ( such as the Motivation Assessment Scale - Durand and Crimmins 1988) which

seeks to classify behaviour under the categories of attention seeking, self stimulation, escape/avoidance, or seeking help. However, again it is necessary to accept the limitation of such scales in analysing behaviour in a natural setting, or of lining all behaviours into one of only four types.

In any event, if parents, teachers and carers can be helped to see that apparently aggressive or provocative behaviour may be linked to problems in communication, there is likely to be a positive effects upon attitudes and responses to the child.

## **AIDING COMMUNICATION**

Estimates suggest (e.g. Lord and Rutter 1994) that around half of all children with Autism fail to develop functional speech, and even among those children with adequate expressive vocabulary, there are long term and pervasive impairments in meaningful communication.

Language programmes are important in improving comprehension, intonation, and complexity of language content but it is necessary to ensure that the level of the programme is matched to the child's level of cognitive and linguistic ability and that all the people working with the child follow the same strategies to ensure consistency. Helpful published programmes, which provide the basic guidelines for language work, include the Derbyshire Language Scheme or the Social Use of Language Programme; and it is suggested that the practical value of the words taught, in enabling the child to gain access to what he needs or wants, will make extrinsic rewards unnecessary or even counter-productive.

If a child with Autism has not developed useful speech by the age of 7, it is likely that there will always be a severe impairment in all verbal communication, hence the need for some form of alternative system, such as Makaton. However, not all children will develop enhanced communication skills with these alternative systems, and there is evidence that the use of signing may also suffer from the repetitiveness or stereotyping that is observed in the speech of many children with Autism.

Pictorial systems may be most manageable linguistically and cognitively but their attraction to a child will depend upon their match to that child's particular interests or needs.

Observation has indicated that the use of alternative systems for communication does not minimise even more the probability of the development of spoken language in the child; on the contrary, competence in the use of signs or symbols may be linked with enhanced efforts to use speech in previously non-verbal children.

It should be noted that even children with no immediately observable language disabilities may still have problems with complex or subtle language, and show a

tendency to literalness. The example is given of saying to a child "Go and ask your mum if she wants a cup of tea", which would be enough for most children; but the child with Autism may require the further instruction "...and come back to tell me what she said".

It is further suggested that the TEACCH programme can be very effective in improving behaviour and learning progress by means of the very structured and visually-based sets of cues (even if a long term goal is the gradual elimination of these cues and for increased self sufficiency of the child in less structured settings).

## **ECOLALIA**

Immediate or delayed echolalia is common in children with Autism, and, while commonly perceived as inappropriate and even irritating, may actually serve to enhance communication or demonstrate a need.

For example, echolalia could indicate the child's lack of understanding of what has been said and it provides a means of consolidating the utterance and of practising new vocabulary. It might indicate increasing pressure or stress. It may be part of a system for rehearsing new or worrying situations, or for defusing anger and anxiety. Awareness of the underlying rationale, and appropriate action (such as simplifying the language used) can reduce the incidence of the stereotyped or echolalic speech.

Repetitive questioning can also be tackled by means of directing the child to lists or charts or pictures which offer the information on a permanent basis.; and a major means of minimising stress is the ensuring of consistent routines (and preparing the child well in advance about any changes that are going to occur). If it is hypothesised that repetitive speech (especially of a provocative type) is designed to attract attention, then one might try extinction (no attention) or "time out" although it is recognised that ignoring certain behaviours may be easier said than done when the setting is the supermarket or the church rather than the child's home! What does matter is that erratic or intermittent attention to an undesirable behaviour will maintain or even increase the behaviour.

As a general principle for language development, it is held that those working with the child need to monitor their own level or style of speech to ensure that instructions are simple and concise, and that slang or humour (which may introduce uncertainty in the child's mind over meaning) are avoided. One takes nothing for granted in terms of what the child understands. The example is given of asking a child "What year is your birthday?" to which one gets the answer "Every year". Appropriate language and style of questions may only be established after a period of trial and error, with the speaker working on the principle that non-response or non-compliance in the child may simply reflect a misunderstanding or misinterpreting of what has been said.

## **SOCIAL COMMUNICATION**

As a basic rule, firm and consistent guidelines are needed about what is acceptable behaviour and what is unacceptable. The point is that, if children with Autism are quite rigid in respect of behaviour patterns, it is necessary to avoid allowing undesirable behaviours to become a habit and, therefore, resistant to intervention. However, there is a danger that, with young autistic children who may be perceived as disturbed or distressed, consistent management of behaviour may be inhibited by a tendency on the part of parents or carers to give in to the demands of the children but this may only make for greater problems later.

Further, certain behaviours that are tolerable (or not seen as inappropriate) among young children will become less acceptable as the child gets older. The example is given of the young child who approaches other people and touches or kisses them, and who is not checked. That same behaviour when the child has grown into teenage may produce a very different reaction. It is necessary, therefore, to recognise the probable limitations in social understanding among children with Autism, and to introduce rules about behaviour in particular situations.

It is likely that attempts to teach skills relating to social perception, empathy, etc. will not be very successful, and the positive results that can be achieved with social skill groupwork may not readily generalise to settings outside the group. Therefore, social skill work should be practised in all the settings where the child interacts with others, in order to deliver the message about differing appropriateness of behaviours in those settings. Meanwhile, evidence exists for the effectiveness of working with non-autistic peers in order to show them how to play and communicate most effectively with a child with Autism. Simply providing peers with information about autistic characteristics can bring about greater and better interactions for the autistic child.

Further, some success can be achieved with training to overcome the effects of a deficit in Theory of Mind... i.e. to teach the child to mind-read and become more attuned to the points of view of other people. Use can be made of photographs, computer material, or "live" role play observed by the target child, in order that Theory of Mind training might be added to the educational curriculum.

## **OBSESSIONAL BEHAVIOUR**

For the child with Autism, repetitive or ritualistic behaviour can provide some protection against anxiety and a sense of control over what might otherwise seem a very unpredictable world. Therefore, attempts rapidly to restrict such behaviour may bring about even more stress and the greater entrenchment of the behaviour.

Instead, the following guidelines may be more effective:

- Establish clear rules about when, where, with whom, and for how long the behaviour is allowed.
- Ensure that change is introduced one step at a time.
- Minimise any source of stress ( such as a lack of predictable routine ).
- Avoid unreasonable demands ( such as insisting that the child takes part in certain group activities, such as games, which the child cannot understand and dislikes).
- Allow the child to avoid socially demanding situations, such as playtime.
- Help the child to cope with change, by describing well in advance what changes to routine will be happening ... i.e. ensure that changes are not unpredictable.
- Allow access to the obsessive behaviour as a reinforcer for positive and productive behaviour.

## **MEDICATION**

The use of medication might be considered if severe behavioural disturbance is noted which does not readily respond to behavioural treatment. Pharmacological treatment is already very common, with estimates suggesting that, in the USA, over 50% of children with Autism are receiving some form of drug or vitamin treatment.

However, whether medication is prescribed for specific issues or for the reduction of autistic symptoms generally, there is a lack of (long term) evaluations for the majority of the substances used, and even with those drugs that have been investigated, side effects have been observed.

As a general comment on this topic, one might quote Campbell et al (1996) who suggest that it is not appropriate to form conclusions about the effectiveness or safety of drug usage given the small sample sizes, and the lack of controls used in existing studies.

## **EDUCATIONAL PLACEMENT**

Although one must avoid over-expectations upon interventions arranged, it is recognised that early access to a very structured educational programme is an important element of successful management.

The structure in question relates to the need for appropriate environmental organisation, individual learning programmes, and the use of clear visual cues. There can be many ways of delivering an educational programme, whether wholly in a mainstream school, in a specialist school, or in a combination of settings.

The important issue is that of matching the provision to the individual needs and circumstances of the child.

It is likely to be effective to focus upon the existing skills and strengths of the child rather than to make attempts to overcome the weaknesses or deficits; and the social and emotional needs should be highlighted. Appropriate provision may be difficult to identify for the more able children since the curriculum in a specialist school may not provide the stimulation required, while the mainstream school placement may bring problems of peer (non) interaction or inconsistency of understanding/demands. The success of any placement will be facilitated if the most appropriate setting is identified early, and if all those concerned with the child (teachers, parents, carers, and other family members) work together to maximise consistency of management.

## **SUPPORTING CHILDREN WITH ASPERGER SYNDROME**

A major problem among Asperger cases (or children diagnosed as high functioning autistics) arises from the disparity between relatively good cognitive or (superficial) language usage skills and the marked difficulties in social perception and interaction, the obsessional behaviours or interests, and the weaknesses in certain linguistic skills such as comprehension of abstract or complex material.

It may be that superficial impressions lead to over-inflated expectations upon the child, and a failure to meet these expectations may be interpreted as indicating a lack of cooperation and motivation, or generally disruptive and negative behaviour. The child is the focus of intervention rather than the setting and the social circumstances.

There may be witting or unwitting pressure for such children to fit into normal settings and routines which would be thought quite unrealistic for the less able autistic children. The net effect may be to increase stress which, in turn, increases the defensive or obsessive behaviours, and social and educational progress is all the more impeded.

## **EARLY DIAGNOSIS**

A diagnosis of Autism is rare before the age of 3 years. The average age of initial diagnosis is around 5.5. For children with Asperger Syndrome, diagnosis tends to be much later, with an average of 11+. Accurate and early diagnosis can be difficult especially in the light of the overlap between children with Autism and non-autistic children who have (severe) language and learning difficulties.

The benefits of early diagnosis are associated with the establishment of a regime where simple communication systems can be taught and practised, thus to reduce the probability of disturbed and disturbing behaviours which would otherwise become the child's main means of controlling (or avoiding) events.

Further, inappropriate or challenging behaviours (which become all the more problematic as the child gets older and bigger) may be reduced by early use of behavioural strategies. A lack of such intervention may lead to behaviours becoming firmly fixed and to greater skill or determination in the autistic individual in finding opportunities for carrying out these behaviours.

The need for early intervention is all the more highlighted by the findings which indicate that ritualistic or obsessional behaviours may interfere with appropriate behaviours. Without control, these inappropriate forms of behaviour replace or inhibit other activities; and it is when the child is young and the intensity of the behaviour is less marked that parents, teachers and carers can set consistent rules and routines such that the problem behaviour does not escalate to a severe level of intensity.

The role of the professionals is to help the parents to identify potential problems and support them in responding firmly and consistently thus to minimise the impact of the problems as the child grows up.

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