

# **Guides for Special Education No. 10 Education of Children and Young People with Autism**

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## **PREFACE**

This guide is the tenth in a series on “Guides for Special Education ” published by UNESCO.

The guides which are intended for teachers, parents, professional groups and community workers, aim at stimulating discussions on basic knowledge, approaches and methods relevant to the education of children and young people with special educational needs.

The first eight chapters of the guide provide information of direct relevance to parents and practitioners working directly with children with autism, the detailed table of contents points out to the different issues covered. The guide is rich with concrete advice on way of responding to the wide range of needs and challenges which educators have to address in their work. Chapter nine, however; deals with organisational aspects, providing some insight into the development of educational services for children with autism based on examples from four countries - France, Hungary, Spain and South Africa. The views expressed in this guide are those of the authors and do not necessarily reflect those of UNESCO.

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## Chapter 1

### UNDERSTANDING AUTISM

#### Explaining autism

The term 'autism' is used in this book to mean 'autistic spectrum disorders' as a whole. It covers a number of different diagnostic categories in medical terms (such as Asperger's syndrome, Kanner's autism, 'atypical autism'), and describes what is considered to be common to all of those diagnoses. The aim is to arrive at an educational definition of autism from which, in part, a child's special educational needs may be derived. Autism is defined and diagnosed medically from its characteristic pattern of behaviours, yet there are no behaviours that of themselves will unequivocally indicate autism. Concentration on the behaviour alone will often lead to misleading interpretations and thus to inappropriate treatment. Behaviour is essential in our recognition of autism but, by itself, it does not help us understand the condition or decide how to approach it.

#### Autism and Asperger's syndrome

Autism was first described by Kanner in 1943. He originally believed that all children with autism had normal levels of intellectual functioning but this has been shown to be incorrect. There is a substantial group of children with autism who have additional general learning difficulties. Autism also commonly co-occurs with a language disorder, and may co-occur with a motor or sensory impairment. At almost the same time, Asperger was also identifying a group of children as having autism (Asperger, 1944, translated Frith, 1991).

Kanner's work became well known and had great influence throughout the world, but it is only comparatively recently that Asperger's work has been taken up internationally. Diagnostic systems now use Asperger's syndrome to refer to people with autism who have normal levels of general intellectual functioning and good structural language skills. It is not clear whether this is separate from Kanner's autism or whether it represents autism without additional language or intellectual impairment. However, for the purposes of education, the same understandings and teaching approaches will benefit all children with autistic spectrum disorders of whatever kind.

Wing (1988) has identified a triad of impairments which now underpin all diagnostic criteria for autistic spectrum disorders. It is this triad that expresses what is common to the disorders within the spectrum. The triad expresses difficulties in three areas of development as indicative of autism and no one area can be taken on its own to be 'autistic'. It is the triad in full that indicates that the child may be following a different developmental path, and, if there is only one area of impairment, then that may arise from an entirely different cause.

## A definition for practice

When we are considering the special educational needs of individuals, we need to consider all those who will have specific needs arising from their autistic spectrum disorder, in relation to the curriculum offered, the teaching approach and the environment. Within this group there will be those who have additional profound and multiple learning difficulties through to those within the normal range of intelligence. The range of difficulties in the triad of impairments are:

**-Social impairment:** There are difficulties in interacting with both adults and peers. This will include the classically 'aloof' child, but will also include those who respond to social interaction, although they may be unable to initiate it, through to the 'active but odd' child who seeks social interaction but is socially naive and cannot quite 'get it right'

**- Communication impairment:** There are difficulties in all aspects of communication. The autistic problem concerns communication rather than language per se. One child may have good grammar and articulation and may speak fluently, but his or her speech may have odd intonation, may show echolalia (repeating) and 'reversal' of pronouns (at least when young) and understanding of speech may be literal. There will be difficulties in holding conversations, with the child with autism talking 'at' rather than 'to' or 'with' people. There will also be difficulties in understanding and using facial expressions, body postures and communicative gestures. Another child may have the same difficulties in understanding all forms of communication, but will have no speech and will not easily compensate with sign or communicative gesture. Communication, at all levels of ability, is directed at getting needs met, rather than sharing information or interests.

**- Flexibility impairment:** There are difficulties in flexible thinking and behaviour. This is shown in repetitive stereotyped behaviour and, in some individuals, an extreme reaction to change in expected situations or routines. Play tends not to be creative or truly symbolic (although symbolic play acts may be copied) and is often isolated. It may involve spinning objects or a fascination with light or angles. The more able show similar difficulties, but in a more intellectually demanding way, in their development of obsessive interests or 'hobbies', that are pursued at the expense of everything else. Understanding of fiction is minimal, or related to stock characters (often associated with a favourite video). Learning is easiest by rote and is difficult to generalise.

## Individual differences

Of course, the same fundamental disability will have different effects in different individuals and even in the same individual over time. So, while some individuals with autism avoid social contact, like Kanner's cases, others are merely passive, or even actively seek social contact but are unable to understand it fully or get it right in practice. The special needs of any individual will, of course, not be determined solely by developmental difficulties but will be the result of interactions between abilities and disabilities and the learning environment. As the child grows to adulthood, the effect of education and the kind of experiences the person has had will have an increasing role in determining current behaviour and ways of thinking.

## **What is autism?**

Can you have autistic features or tendencies?

As indicated above, there is no one behaviour that is 'autistic' and it is the total pattern of behaviour, plus the reasons that underlie it, that indicates autism. That is one of the reasons why professionals cannot just operate at this behavioural level. Thus, a congenitally blind child may share some of the characteristics seen in autism, without necessarily having autism, and a child who has been severely traumatised (following a war situation or after abuse) may also appear to show the same 'features'. The behaviours produced (avoiding people, social anxiety, inappropriate social behaviour such as avoiding eye contact) may be very similar, but they have a different cause and, therefore, a different prognosis. The blind child will learn other ways of knowing the world and (unless he or she has autism in addition) the 'autistic' behaviour will lessen over time. Similarly, the traumatised or abused child, once placed in a secure caring environment, will learn to trust again and the 'autistic' behaviour will go.

Children with autism will also improve, given the right treatment, but they follow a different developmental path, due to differences at the biological level, and so the treatment and education they need will also be different. It should also be remembered that many apparently 'autistic' behaviours can be seen in anyone under a sufficient degree of stress and this suggests that what may appear as an 'autistic feature' (even in those with autism) may in fact be a secondary effect of stress.

## **Can autism be cured?**

None of the claims for a complete 'cure' or recovery from autism have been completely validated by independent researchers. There are also anecdotal reports of young infants who appear at eighteen months or so to have the symptoms of autism, but then to 'grow out of it'; this is particularly likely where the child has been premature or suffers from a sensory loss. All we can say for certain is that autism is a life-long condition but that there may, of course, be considerable improvement over time, especially with appropriate education. It is also true that some more able individuals do learn to function in ways that may be indistinguishable from the norm. It is a moot point whether they can then be said to be 'cured' of their autism. In my experience there is little point in labelling them at this stage, but we should recognise that they may still need to work much harder than others to maintain this 'normal' existence. It is also the case, that the more adapted the environment to meet the needs of a particular individual, the less 'autistic' they may appear. Thus, as people get older they may be placed in specially adapted environments, or they may lead restricted lives so that they are not under the continual stress of new demands or different social situations. All this needs to be considered when judging the effectiveness of a treatment programme.

## **Do parents cause autism?**

There is a genetic base to autism but it is not caused by anything the parents have done (or have not done). Parents of children with autism have been shown to be just as caring and loving as other parents and they often have other children who do not have autism. The myth of 'refrigerator parents' (especially mothers) has been shown to have no basis in fact. Sometimes parents may seem to be acting oddly with their child with autism (especially by the time they reach school age, and when there has been little support for the family) but this is likely to be the effect of having a non-responsive child, rather than the cause of it. Nor is there any evidence that grossly abused and neglected children go on to develop autism, although they may have other emotional and behavioural difficulties. The growing evidence of a genetic factor in autism, however, means a proportion of parents may share some of the difficulties experienced by their children, albeit in a milder form.

## **Do people with autism also have general learning difficulties?**

If we exclude those with Asperger's syndrome, then around three quarters of those with autism will have additional learning difficulties, but autism can co-exist with very high levels of intelligence, at least of a particular kind (such as that associated with mathematical or engineering ability). There can also be different degrees of severity of the autism itself but, in the early years at least, there is no one-to-one correlation between severity of autism and level of intelligence. As individuals with autism grow into adulthood, however, the more able generally do learn ways of overcoming or adjusting to their difficulties and so more intellectually able adolescents and adults with autism do appear to be less 'autistic' than those with additional general learning difficulties.

## **Should we use a label?**

An able young man with autism (Exley, personal communication) was discussing the value of the diagnosis of autism in relation to his own unhappy school experience, where he had not received a diagnosis until well into his teens. He acknowledged the difficulties that can come from labelling but argued that autism was not so much a label as a sign-post. This is a good way of thinking about it. It is not that knowing a child has autism will tell you exactly what you should or should not do with that child on a day to day basis, for each child is an individual whose needs will vary. Rather, it is a way of understanding how a child is behaving and how he or she might be helped to learn through an understanding of the autism which would not be 'hit upon' simply as a result of good practice or one's common understanding based on professional and personal experience.

## **Summary**

The autistic spectrum comprises developmental disorders with a biological base that lead to a different and characteristic pattern of perceiving, thinking and learning. Appropriate teaching approaches and educational environments enable the child with autism to develop and learn and many make significant progress. There is no single approach, since there is great individual variation in learning needs. We can, however, make judgments about the kinds of approaches that will be useful and the following chapters will include an exploration of the range of needs and effective approaches for

meeting them.

## **Chapter 2**

### **IDENTIFYING SPECIAL NEEDS IN AUTISM**

#### **The role of diagnosis in education and care**

An understanding of the fundamental difficulties faced by a child is crucial to developing a curriculum and a teaching approach that addresses that child's needs. Responding at the level of behaviour only, may lead to unhelpful or even damaging misinterpretations of the child's behaviour and a consequent failure to identify the true educational needs. Each child will still be an individual and will need careful observation to determine his/her level of understanding and capacity, but that observation needs to be informed by the knowledge of what particular difficulties the child is facing in making sense of the world.

An example of this in practice is the case of a young girl with autism who came to a specialist school at the age of seven years. She had good structural language skills and could speak in sentences. She also had reasonably well-developed self-help skills, having been toilet trained from the age of two years. However, once she started school, a problem had emerged with respect to her toileting. Whenever she knew where the toilet was she took herself there, without difficulty, but, if she did not know where the toilet was, she wet and soiled herself.

This was a puzzle to her teachers because she appeared to have all the prerequisite skills to ask to go to the toilet (she had good language skills and she could identify when she needed to go to the toilet) and yet the problem persisted. By the time she entered the specialist setting she had undergone a series of different interventions aimed at resolving this 'problem' but all to no avail. Her mother, in desperate frustration, had punished her for soiling by hitting her with a hair-brush; the home where she went for respite care had given her cold showers for the same reason; family therapy sessions had focused on resolving supposed tensions at home and had discussed marital problems with the parents and interpreted her behaviour as a symbolic 'giving' of herself in terms of her faeces to test their love for her; a visiting clinical psychologist had put her on a behavioural programme whereby she could earn 'points' for being clean and dry and she could save these for horse-riding sessions, which she loved.

None of these 'interventions' had any effect. They failed because they were related to different interpretations of her behaviour and how it could be controlled but none of them took account of her autism. What was needed was the understanding that, although she appeared to have all the skills to express her needs she lacked one vital element: she did not understand about the need to communicate. Once this was recognised, a solution could be worked on. Her teachers blocked her taking herself to the toilet, in situations where she knew where it was, and prompted her to ask for the toilet. Once this had been done consistently for a few days, she changed from taking herself to the toilet to asking for it. In new situations, her new habit of asking meant the problem was solved. Once she reached her teens another problem arose in that asking just anyone would not be appropriate and might put her at risk of abuse. She was then trained to recognise that she did not know where the toilet was and to develop a range of strategies to find out. Thus, it is important to take account of the diagnosis when interpreting the behaviour of

the child and when working out teaching approaches. Education remains the one treatment approach with the best 'track record' for dealing with the difficulties associated with autism. It is not just a matter of 'access' to education as a statutory right for children with autism, but about how education can have a central role in 'remediating' the effects of autism (not 'curing' it) and improving the quality of life for individuals with autism throughout their life span.

### **Primary and secondary difficulties**

The problem with any developmental disorder like autism is that an initial difficulty can lead to restrictions in the child's learning opportunities which then go on to cause further secondary difficulties. One of the key roles of education is to identify key developmental areas that have been missed or distorted and to build up strategies and experiences to compensate for the lost opportunities. Where possible, education may even get in early enough to prevent the secondary difficulties from occurring at all.

Yet it must be remembered that autism is a biological difficulty, so it is of little use merely to put the child through the stages of early development again; if he or she were capable of learning from that experience they would have done so in the first place. What education must seek to do is to find ways of achieving the same ends through routes to which the child with autism has access.

Such routes involve a slowing down of interaction to give more opportunities for the child to process the information presented and to formulate a response. They involve using short sentences or phrases (or even single words) with greater pauses between them, for the same reason, and making everything as explicit as possible. This does not mean that everything has to be explained in words, but actions may need to be exaggerated to get the child's attention, games may need to be played alongside rather than facing the child (more likely to be tolerated in that position as well) and facing a mirror so both their own and the other's face can be seen at the same time, and the tuning of the interaction may need to be emphasised through music or singing.

But the most important aspect of working effectively with children with autism is understanding them. As indicated in the first chapter, it will not be enough just to respond to behaviours, but rather to have some understanding of the more fundamental underlying difficulties that offer a rationale for those behaviours.

### **'Theory of mind'**

One fundamental difficulty, identified in autism (Frith, 1989), lies in understanding about mental states such as thinking and feeling. This can be seen to lead to a number of developmental consequences in learning and behaviour. In the first instance it helps to explain why children with autism may be fearful of others or may strike out at people who try to interact with them. We make predictions about other people's behaviour based on our understanding (or assumption) of what they are thinking, feeling and intending. A lack of knowledge of such mental states, therefore, will lead to difficulty in predicting behaviour and this in turn will mean that people become unpredictable and therefore frightening and even aversive.

If there is no understanding of thoughts and knowledge, then there will be no

understanding of what others can be expected to know. Effective communication involves building on common understanding. If you tell someone something they already know then your language becomes pedantic and boring. Equally, if you do not establish any common understanding (e.g. "he did it", without establishing who 'he' is or what 'it' is), then your language becomes incomprehensible or ambiguous. The language of individuals with autism falls into both of those categories.

Without this understanding of mental states, there can be no idea that it is possible to affect how others think or feel. This means that the child with autism will have no conscience, no motivation to please, and no communicative intent. This means that the teacher cannot use a personal relationship with the child to foster learning and moral behaviour. In autism, the normal process may need to be reversed; rather than waiting for a relationship to develop before starting to work with a child, the teacher may have to work with the child consistently on a joint project in order to establish that relationship.

Even then, the teacher will not be able to appeal to a sense of empathy ("Think how you would feel if someone did that to you") to control behaviour, nor a sense of shame or embarrassment ("What would your mother say if she could see you now?"). The best one can often do is to provide rules for conduct, but this also has its drawbacks.

Another result of a failure to understand about mental states and to engage in activities such as pretending is that the child with autism is often shut off from the forms of play and social exchanges through which cultural meanings are established. This lack of understanding of social conventions includes conversational strategies and will lead to no signalling with eyes, poor interaction, poor turn-taking, and poor topic maintenance in conversations. Such strategies for joining groups will need to be taught directly, as will the meaning of cultural events such as parties (that they are supposed to be 'fun' even though they rep- resent terror - of balloons, of crowds, noise, unpredictable non routine activities- to the child with autism), presents, religious ceremonies and so on.

### **Effects on learning and teaching**

In educational terms, thinking of the behaviour in autism as reflecting a problem in understanding mental states offers a way of accounting for it that most teachers would not come up with spontaneously (however 'good they are) and which will allow them to adopt strategies that can help at both the compensatory and the remedial level. Thus, lack of eye contact might be seen in a strictly behavioural way as needing a teaching programme to prompt the pupil to make eye contact (perhaps by head turning, at first) and to reward him or her for doing so. The results of such training on individuals with autism are often meaningless 'staring' which is neither socially appropriate nor helpful to the individual in making further progress in understanding the world or how to react to it. It is also likely to be misinterpreted as a sexual advance or as aggression, both of which interpretations will make the child vulnerable to attack from others.

However, an understanding that lack of eye contact does not relate to some motivational or performance difficulty but to a fundamental problem in understanding what eye contact is for (and therefore an inability to profit from it) would redirect the teacher to a programme that would help make one purpose of eye contact as explicit as possible.

Most sensibly this would start with what the pupil is most likely to understand most readily - the making of requests. The child can then be taught to move from non-communicative grabbing to a situation where eye- contact allied to pointing achieves the same end and thus has a meaning. It is not a very full meaning of the communicative use of eye pointing, but it is a start.

Development of Request Function:

Temper tantrum -->

Grabbing hand -->

Whole hand touching -->

Touch and check -->

Pointing (and checking) -->

Request sign/word plus point -->

Request sign/word plus sign/word label -->

Full grammatical sentences/ signed phrases -->

Pragmatic variation in request form according to context.

### **Failure in 'inter-relatedness'**

If there is a fundamental difficulty in recognising and responding to emotional and social cues (Hobson, 1993), the individual with autism will have particular difficulty with those that do not result in clearly differentiated facial expressions. They may learn to identify 'happy' with a smiling face, for example, but then will never understand what a 'brave smile' is; they may learn to label a sad face as such but still have no idea of the underlying emotion and so are still capable at laughing when they see (to them) the funny expression of sadness on their mother's face and water coming from their mother's eyes. This lack of empathy can be hurtful and can lead to others judging them as cruel or cold. They are also likely to show poor emotional expression themselves.

Yet there is no evidence that people with autism experience emotions any less than others. In fact, their behaviour suggests that their feelings are often very strong and that they often have great difficulty in controlling them. The problem lies in not being aware of their emotions at an explicit level, which also makes it more difficult for them to exert control. It may also mean that their expression of emotions may be primitive and in the form of emotional outbursts.

### **Effects on teaching**

The teacher who understands these difficulties may still need to develop short-term strategies for overcoming reluctance to sit with others and to get the pupil to a situation where s/he is able to learn in a group, but s/he will also be working on long-term approaches to build up understanding of emotions. This may be by making them explicit, by teaching about the perceptual indicators of emotion and how these vary together to express emotion - facial expression, voice quality, body posture, actions etc. so that people are no longer so unpredictable and frightening.

Awareness of emotions will also have greater benefits in learning on a more general plane and making that learning more flexible since this is one of the key roles that emotions play in cognition. Such understandings of autism also indicate the value of approaches that foster emotional sharing through the use of music to accompany social actions or through joining the children in their own area of intense interest.

### **Failure to establish an 'experiencing self'**

Thinking and learning in autism may be very different from the norm (Jordan and Powell, 1995; Powell and Jordan, 1997). Individuals with autism may have difficulty in establishing a sense of themselves at an experiential level and this lack of an experiencing self would have a number of direct consequences on development and behaviour.

There will be problems in developing a sense of agency. This will lead in turn to difficulties in using the first person pronoun 'I', in an inability to be aware of intentions and therefore to plan actions, in a lack of goal-directedness in actions, and thus in difficulty with spontaneous or creative behaviour.

If one does not have an experiencing self then there is no sense of events happening to oneself; rather, they just happen. The individual may have a concept of him/herself but it is limited to autobiographical knowledge, knowing oneself from the 'outside' as it were. An experiencing self is also important in memory processing and so a failure to develop this will lead to poor personal episodic (event) memory. This will mean that all episodic memories have to be cued in some way i.e. there will be no way of searching the memory. It also means that self expression will be limited to what others have 'fed in'.

### **Effects on Teaching**

Without a sense of oneself in one's dealings with the world, there will be a failure to adopt an 'attitudinal stance'. This will lead to difficulties in 'foregrounding' relevant information (because what is relevant is determined by one's intentions and attitudes to what is being perceived), and difficulties in categorisation (because these are based initially in development on the child's attitudes to objects i.e. the potential that objects have in relation to the actions of the child - things that can be rolled, things that will taste nice etc.). This may in extreme cases lead to failures to discriminate e.g. PICA (where the child will eat all manner of non-edible objects), or to failures in attributing meaning or seeing overall coherence.

Without an understanding of these kinds of difficulties a teacher is at a loss in attempting to improve thinking and learning and has to resort to teaching that builds on habits that are cued in an increasing range of situations, in the hope of producing generalisable learning. Understanding the source of the difficulty may mean that these compensatory strategies are used for much of the time but it also enables the teacher to focus attention on more effective strategies at the cognitive level.

For example, at a purely behavioural level it seems either incomprehensible, or a matter of motivation, that the child may appear to have such an excellent memory in some contexts and not in others. Knowing that the child may not be experiencing things in the

same way (i.e. as happening to him/herself, rather than just happening) helps the teacher realise that memories will need to be cued and s/he can then teach the child to pay attention to certain cues and how to use those to trigger the memory when necessary (the basis of all memory-improving techniques). Children with autism may also find it easier to say what happened to a classmate on a trip than to tell what they have experienced themselves. The teacher can also decide to devote some time to the 'remedial' task of helping the child establish this sense of an experiencing self through the use of reflection (with the aid of instant photographs if necessary) in the way suggested by Powell and Jordan (1992).

### **Executive function deficit**

An executive function involves processes such as planning, monitoring and directing activities, reflecting on one's mental states, and achieving a goal by flexible means. Certainly, it is true that all of these functions are disturbed in autism (Ozonoff, 1995) although children with learning difficulties without autism may share at least some of these problems.

One particular consequence would be difficulty in modifying behaviour in relation to feedback. Thus, the child with autism persists in actions even though they are clearly seen to 'fail' or are punished in some way. This is just the kind of behaviour that is often attributed to willful disobedience, failure to attend or simple provocation. Once it is understood that the child's actions are simply triggered by the situation, then teachers should feel less frustrated and more able to plan to help the child overcome this difficulty.

### **Effects on Teaching**

Understanding this difficulty enables one to see the futility of aversive measures intended to punish behaviour or of nagging or cajoling the child. There will be only two ways of getting the child to change his or her behaviour. The first, and usually the best, way is to alter the situation so that a particular behaviour is no longer triggered.

For example, a six year old boy had developed a 'habit' of tearing his bedclothes every night. Scolding him, even hitting him, had no effect. A warm air heater was placed in his bedroom and all his bed linen was removed.

Now there was nothing to tear and nothing to trigger that particular behaviour, but to ensure success it was also necessary to alter the child's own state. A vigorous rough and tumble game with his father was introduced for half an hour before bedtime (to ensure he was tired), followed by a warm bath (to calm him down). He was also given a toy (not a soft toy that could be torn, but a plastic toy that produced a soothing tactile experience) to fiddle with in bed, and gentle music was played through a tape recorder. Bedtime was made an hour later than formerly. Almost immediately, the period of restless behaviour in bed prior to sleep ceased. After a few weeks, the boy had developed the new habit of going to bed to sleep. At that stage, the heating was reduced and gradually bed linen was re-introduced. The behaviour remained under control.

The second approach, to changing behaviour is to prevent the child from performing the undesired behaviour in that situation and to train an alternative to take its place. This is the method of choice when the situation cannot be changed. This was the method used

to prevent a little girl from sticking her hands in the steam from a boiling kettle. The priority was to find something she could do that would be satisfying for her but would not put her in danger nor too near the temptation of the steam. She enjoyed other activities involving perceptual distortions such as the steam provided, and, notably, she enjoyed blowing soap bubbles and popping them.

An intense programme was started whereby, whenever she saw a kettle begin to steam she was kept at a safe distance but physically guided to clap her hands loudly (to act as a signal but also to keep her from touching the steam). At this signal, staff would present her with a bowl of soapy water and she was instructed on using it to blow bubbles. In a short while she began using the steam as a signal that she could 'ask' for the bubbles. She began to ask for the bubbles by clapping when there was no steam and this was allowed to a limited extent. After several months her habit of putting her hands in the steam had gone so that she was no longer prompted to ask for the bubbles if she did not do so spontaneously. Even so, adults had to remain vigilant lest the habit re-appear.

## **Conclusion**

Teachers do not need to wait-for acceptance of a single theory of the nature of autism before using these psychological understandings of autism to inform their practice. Attempting to deal just with the behaviour as presented is liable to lead to misleading interpretations and ineffective teaching strategies. Attempting to understand the autism enables more effective practical approaches to be developed.

## **Chapter 3**

### **DEVELOPING SOCIAL SKILLS**

#### **Teaching social skills**

There is a difficulty in teaching social skills when the child with autism has little or no social understanding. What we call 'social behaviour' consists of the ability to share pleasure in the company of others and to respond to and initiate social behaviour in contexts that are, by their very nature, continually changing. Children with autism will experience difficulties in all these aspects and this will lead to further problems in teaching and learning.

Since education usually takes place in a social context, there will be management problems affecting pupils' access to all aspects of the curriculum. Direct teaching of social skills will also be required since there will be many aspects of social development that will not occur spontaneously and many compensatory strategies that will be needed. There is the further practical difficulty that teaching a social behaviour appropriate to a child at some point in her/his life (e.g. teaching her/him to accept and return embraces so that s/he no longer rebuffs her/his mother) may take so long that by the time it is achieved it is no longer appropriate (the child is a teenager).

#### **The range of social problems**

It can be misleading to think that children with autism will necessarily be withdrawn. There is a wide continuum of social behaviour that is associated with autism, and the classic passive, solitary, and withdrawn child is only typical of one kind of child with autism, and not necessarily throughout the development even of that child. The pre-school child who starts off very withdrawn may become more passive and tolerant of others in his or her middle school years and by the time adolescence is reached may have become very interested in social contact but may just not know how to get on with others and make friends.

Higher functioning children with autism do not necessarily start off being any less socially disabled than those with additional severe learning difficulties, although, clearly, the range of social behaviours (as for all behaviours) they exhibit will be greater. As they grow older, however, the more able do generally become less socially disabled although in the population without autism there is no correlation between general intellectual level and social ability. Autism seems to be a special case in that respect in that those who do learn social interactions, appear to do so by different methods to those employed by normally developing children (not as a part of the process of maturation but by 'rote').

## **Particular social difficulties**

### **Attention Getting Strategies**

Children with autism rarely attempt to share toys or direct an adult's attention by pointing or looking at objects. They may be physically aware of the presence of an adult but seem unable to share a focus of visual attention. They appear to understand the use of the other person as an 'agent', but fail to show any appreciation that the other person has a perspective that can be shared or directed. They are able to take note of another's visual perspective (what the other person can see), but this does not occur spontaneously and they cannot take the conceptual perspective of another (what the other person knows or understands). They do not understand about communication and so they may not realise that what they say or sign has to be directed to someone. Children with autism who speak may be found muttering to themselves or delivering messages to empty rooms. Children who sign may do so under the table, not realising that their 'communication' needs to be seen to be understood.

### **Teaching**

Children with autism, then, need to be taught to recognise attempts to gain their attention, to share the attention of others and to obtain and direct it where appropriate. It will be easier for the teacher or carer to join in with the child's focus of attention at first, rather than expect the child to join the attention of the adult. Just as a mother might with a young baby, the teacher needs to comment on the activity the child is engaged on, or, especially for the non-verbal child, to join in that activity. If the child is making a pot from clay, for example, the teacher might also make his or her own pot, sitting alongside the child, instead of merely directing the child with instructions. This makes it easier to gain the child's attention in a relevant way and has the added advantage of providing an ongoing model of what the child is to do without continually prompting or nagging the child to keep on task. The children will need to be taught directly that there always needs to be someone to receive their communications; spoken or signed communications will need someone to hear or see them and that someone will need to have his or her attention captured before the children start to communicate. Speaking children can be taught to use vocatives or the person's name before they begin to speak. Non-speaking children may need to be taught specific ways of gaining attention (such as a gentle touch on some- one's shoulder or arm) according to the social context.

### **Physical Withdrawal**

It is sometimes difficult to tell if children with autism are actively withdrawing from people or whether it appears that way because they do not know how to relate to others and they are engaged in self-absorbing stereotyped activities. Nor is it clear whether such stereotypes are engaged in for their own sakes (because they offer predictability in an unpredictable world, perhaps) or as a way of shutting oneself off from others. Certainly, it has been found that children's responsiveness to their environment increases if their ritualistic behaviours are reduced.

Teachers should also remember that children with autism are just as likely (and may be even more likely) to become depressed so that if a child in adolescence goes through a prolonged period of withdrawal when previously he or she had been much more sociable, treatment should be sought for the depression, just as one would for any child. Not all symptoms of disturbed behaviour should be put down to the autism.

## **Teaching**

Many approaches for working with children with autism do not let the child withdraw but insist on joining in with his or her chosen activity, albeit in a loving and accepting way. Some teachers take charge of the situation and also do not let the child withdraw, a method described as 'intrusive teaching'. Such methods form the basis of structured and directed approaches. There may be initial resistance on the part of the child to such contact but, if done regularly and consistently, it is usually accepted by the child who might even come in time to seek such regular contact from an adult.

Contact with peers may be an even greater problem since the behaviour of other children is likely to be more unpredictable and, therefore, frightening. It is a mistake to expect children with autism to join in with others in free or 'play' times. They will not understand the rules of these unstructured social situations and so the task of 'joining in' becomes even more difficult. It is easier to get social contact with peers if they are engaged in a structured activity (even if that activity is a game) together. The best strategy is to give the child with autism pre-training in the task or activity so what they learn from the group is how to do the task with others, while the others are learning to do the task itself.

## **Negativism**

If tasks are within a child's level of competence then less non-co-operative behaviours are observed. We also need to ensure that the child has understood the request or command (and has been given sufficient time to respond - which may be a lot longer than is normally the case), before we assume the child is being negative or non-compliant.

Nevertheless, one of the central features of autism is that the individual resists changes in routine and engages in repetitive stereotyped behaviours. The appearance of negativism, therefore, usually emerges when any new behaviour is introduced, although it is not always a form of resistance to the new; it may be a protest at the old and boring. Another feature of autism seems to be a reluctance to repeat things on demand (presumably because they do not see the point and have no desire to please) and so a failure to respond to a problem that has been successfully tackled in the past may just be a failure of motivation. There may rarely be genuine cases of negativism (in the sense of a deliberate refusal to comply) but such cases may arise and be maintained by the-interesting effects they produce in the teacher!

## **Teaching**

The teaching remedy for all these cases will depend on the initial detective work in isolating the 'cause' of the negativism. In most cases the actual remedy is obvious once this has been done. In general, children with autism usually respond best to positive situations where the teacher assumes compliance and the task is structured in such a way that the child understands what to do, where, when, how, and when to finish. We also need to think of the future and how to foster independence and self-assertiveness. To that end we should not make all situations ones where the child has to comply with the wishes or orders of others; we should allow opportunity for choice and for learning to direct the behaviour of others (including the teacher).

We also need to monitor our instructions to the child to make sure they have been understood and remembered. Written or pictorial instructions are usually better than spoken words, but, if we use the latter we must be careful to use short sentences with sufficient pauses in between. Even where individual words and phrases are understood, too long or fast a delivery may be beyond the child's capacity to process and so may be experienced as incomprehensible and increasingly loud. This may be frightening or disturbing or even painful and so will make the child more withdrawn and less likely to join in and co-operate.

## **Peer Relationships**

Few people with autism make personal friendships of any depth (though some develop a network of associates who share a similar interest). Lack of empathy also often results in increasing isolation as they get older. This may seem sad to us, but many people with autism are happy to be on their own. What teachers need to do is to ensure that the child acquires the skills and understanding to make and keep friends so that, if they then choose to be on their own, that is a real choice and not the result of fear or lack of ability.

## **Teaching**

There needs to be a two-pronged attack on this. One goal for teaching should be the building of friendships and the skills that enable a child to enter a group, maintain the group topic, share information with a group and recognise and talk about things that interest others as well as oneself. For the non-speaking child, this transfers into learning to act with others and to join in with others in co-operative play activities that involve the same kinds of skills.

The other prong to the teaching attack, however, needs to recognise that these skills are not going to be easy for the child to acquire and many may never be achieved at a functional level. Thus, it is necessary to ensure that academic skills are not held back by insistence on learning in collaborative groups and if is necessary to try to teach those aspects of development that would normally be 'picked up' in the course of friendship groups. This will include teaching the adolescent or young adult which rules are important to adhere to at all times (the rules of the land and safety regulations for example) and which can sometimes be bent or broken according to circumstances. This is very difficult to achieve but it is important that they learn, for example, that it may be necessary (in terms of maintaining a friendship) not to tell an adult about a misdemeanour of a friend (such as eating in class), as long as there are no serious

consequences for the individual him/herself.

When it comes to helping individuals with autism to mix and play with others, if not to truly form friendships, there have been some successes. There are good examples of 'reverse integration' where mainstream children come into the 'autistic' setting to play or work with those with autism, rather than expecting the children with autism to adjust to new settings as well as new people and expectations. Some schools have developed programmes that encourage reliance on peers rather than adults (by giving power and control to the peers) and teaches the outward signs of friendship behaviour at least. It may seem a sham to teach the outward show of friendship without the emotional attachment that usually underpins it, but to have even a superficial friend may serve a valuable function and be a gateway both to a wider social life and to further social understanding.

### **Teacher/Pupil Relationship**

The process of education is based on the notion that the teacher is a facilitator and mediator of the learning experience. Clearly, if the pupil is disturbed or confused by this social interaction, then this will have tremendous implications for teaching. Good teachers are used to developing a relationship with children as a first step in teaching them and using that relationship to stimulate and motivate the children to further academic learning. Yet in autism that relationship cannot be built in isolation, just through contact, and so teaching and learning cannot depend on its existence. In fact, it may be the case that it is by working regularly with the child on some academic task that the teacher has the best chance of developing that relationship. In other words, the normal teaching sequence may be reversed.

After a while, however, most children with autism will develop relationships with those who make themselves predictable and will learn best from such familiar people. Sometimes they become over dependent on teacher affirmation and approval, however. They may depend on the teacher for confirmation that their responses are appropriate, and to initiate the next stage in any problem-solving process. This sometimes reaches the point where they will not take any action, physical or intellectual, without prior approval. They seem to have no reference point in terms of their own experience (e.g. of problem solving), and therefore come to rely on someone else's ability in organising thoughts and subsequent actions.

### **Teaching**

There have been special curricular approaches that do not rely on this pupil teacher relationship, either because the teacher does not act in a social way with the child (standing silently behind each of the children and physically guiding them through a set of activities and actions) or is not part of the teaching situation (through the use of computer assisted learning for some aspects of the curriculum). This may be a necessary step in some instances to avoid holding back academic progress, but there should also be a parallel programme of teaching the child how to learn in social contexts. It may be, however, that the teaching situation needs to adjust as much as the child and that some teaching approaches are more facilitatory than others. Approaches that rely exclusively on behavioural techniques, for example, may foster this excessive dependency.

TEACCH (Schopler et al, 1981) is an approach developed specifically for pupils with autism. It is very structured and uses some behavioural methods but also includes a programme for independent learning. (independent of the adult, not of the structure). In this programme the child is put in charge of his/her own timetable that is coded in a way that indicates where a task is to be done and with what degree of supervision or help. The child is taught basic work skills as a matter of routine, where to start a task, how to proceed systematically, always to complete work started, to work left to right (or right to left, depending on the culture) and top to bottom and so on. It provides a good compensatory approach to autism, although there may also be a need to give the child ways of understanding that enable them to function in situations where this clear structure is not provided.

## **Conclusion**

Social difficulties are at the heart of autism so it is not surprising that they pervade every aspect of teaching and learning. They are also difficult to teach since the rules need to be so flexible and depend on particular contexts. The most fruitful approach for teaching is often to circumvent the difficulties by allowing the child to learn in non-social situations, while at the same time fostering social development through a variety of experiential situations which are carefully managed to control for stress and confusion. Normally developing peers can be useful 'teachers' in these contexts, but they will need some initial education about autism (not in a formal sense, but in terms of what to expect). This will help them to realise that the child with autism does not intend to be hurtful or rude, and to be more tolerant of someone who is often a very unsatisfactory playmate.

## Chapter 4

### ENABLING COMMUNICATION

#### Communication and language

There are considerable variations in language ability within the autistic population, with some remaining without language throughout life, while others appear to have very good structural language skills, speaking in full sentences, reading and writing well. Yet, regardless of the level of language ability, all children with autism will suffer from a communication disorder.

Language and communication are normally so totally bound together in development that it is hard to envisage the situation in autism, where they take different developmental paths. Whereas communication is the normal precursor to language development, in autism language may develop without the child having any idea of how to use it for communication or any understanding of how speakers can use it pragmatically to create a variety of meanings beyond the literal meaning of the words and sentences. Most children will pay more attention to what they think the speaker intends than to the literal meaning of the language used; children with autism are blind to that intention (a mental state) and focus on the literal meaning regardless of how absurd or unlikely that may appear to be to the onlooker.

Nor is it just the communicative uses and understanding of language that are affected; there are difficulties with all aspects of communication. They are able to hear intonation patterns in speech, for example, but they cannot attach pragmatic meaning to them and so they just become 'noise' that distracts from and interferes with the meaning of what is said, rather than adding to it. They have similar difficulty in using intonation patterns appropriately in their own speech, which then sounds either very monotonous or robot-like or has widely (but often, inappropriately) variable intonation patterns.

Similar difficulties are experienced in interpreting facial expressions, signs and gestures, body postures and even the regulation of personal space (how close you stand to people when communicating). Pointing in particular, whether through the index finger or through head or eye pointing, is affected. A failure to engage in spontaneous indicative pointing (pointing things out for the sake of a shared interest as if to say, for example, "Look! There's the moon", rather than because one wants to have something) is now considered one of the key indices of possible autism when the child is eighteen months old.

## **Language difficulties**

Structural aspects of language may only be a problem where there are additional learning or language difficulties. A significant number of individuals with autism remain mute and will need to be taught a means for communication. However, they will have difficulty in learning all language forms without an understanding of communication to support them, so that sign language may be almost as difficult as speech. For most children with autism (even those who have some speech) using pictures or written cards to communicate will be the most helpful strategy. Even children with severe learning difficulties may be able to learn to read in a functional way (to ask for things they want using a communication board, for example, and to recognise key words in their environment) and this may help them learn to speak as well as being a useful alternative way of communicating for those who remain mute. However good a child's language skills, autism always means there are at least some communication difficulties and such children may still have problems understanding language when it is too complex, when it is too fast or when there is too much else to take in at the same time. For a few children with autistic spectrum disorders (especially those with Asperger's syndrome), there may also be associated specific language problems such as dyslexia and this will obviously make it difficult in those cases to use reading and writing as an alternative to speech.

## **Literal language understanding and use**

Because of the failure to understand about communication, language tends to be used for a very narrow range of purposes, mainly to make requests and to talk obsessively about some aspect of especial interest. It is often non-productive in the sense that it does not build on what others have said nor does it relate to the context, but tends to reproduce familiar learned patterns of speech. The individual with autism will try to understand what the words mean rather than what the speaker means, s/he will interpret idioms or sarcasm literally and so may miss the point or even become distressed.

## **Teaching**

Teachers will need to address these problems by direct teaching of conversational skills such as turn taking, active listening, topic introduction, maintenance and change and attempting to make pragmatic knowledge explicit. Turn taking can start with very simple turn-taking games with objects and then, in the pre-verbal child, with games built around mutual imitation. This may start with the adult imitating the noises made by the child and, once the child has noticed this and is pausing to allow the adult turn, gradually changing the sounds made, to encourage the child to pay attention to adult sounds and imitate them.

A more able child with good spoken language will need to learn to turn take and to listen and take account of the turns of others in the context of groups. Passing round an object (like a 'conch') that signifies that the person holding the conch has the speaker's turn can help regulate turn-taking in a group, although older children will need 'additional practice in recognising the more natural ways that turn taking is regulated in groups (through sitting forward and making eye contact for example) if they are to generalise these skills.)

Getting the children to listen to what others say and take account of it in their own speech is more difficult. There are some games which can help with this process. The 'shopping' game has each child saying "I went to the shop and in my basket I put some . . .". The first child completes this phrase with his or her own choice ('biscuits' for example) but the next child must now complete the phrase by repeating what the first child said ('biscuits' in this case) and then adding his or her own choice. This goes on round the group with each child having to listen to what has gone before and take account of it in their own answer. Of course, group numbers will need to be small if the task is to be manageable and the game may have to be introduced by having picture cards to register what each child has said and to reduce the demands on memory.

More advanced games which increase the flexibility of the language used (so it is not just repetitious) have an object or picture presented to the group by the teacher and now each child must say something about that object or picture, but they have to say something different to the comments of all the other children. This is more sophisticated because it involves paying attention to the meaning of what is said rather than just repeating the actual words, but it is something that many children with autism can manage if it is introduced gradually and there is a clear structure which shows them what to do.

## **Reading and writing**

Some individuals with autism will exhibit what is known as 'hyperlexia' where they are able to read mechanically beyond their level of understanding. The individual with autism may find it easier to learn to read than to listen to stories or to tell them from picture books, so the normal stages in progression may not apply. However, those with associated dyslexia will need special techniques for learning to read.

## **Teaching**

For most children with autism, teachers will need to check for understanding of read texts and to look for opportunities to demonstrate the purpose of reading. This is most easily accomplished (as well as tapping into the individual's likely source of strength) if the individual is encouraged to read factual texts rather than fantasy stories. Giving children written instructions to complete familiar tasks has the dual function of helping them gain independence in completing the task and helping them learn to read.

The problems of teaching those with additional dyslexia are more complex. Using multi-sensory approaches to teach reading may help as will the use of computer assisted learning. Like many dyslexic children, children with autism may find it easier to remember movement patterns than auditory patterns or, in some cases, visual patterns. It is a good idea, then, to try to teach them proper keyboard skills from the start, rather than typing with one or two fingers as most children (and adults!) will do. This will enable them to learn to spell by repeating the movement pattern with their fingers.

## **Educational uses of language**

There may be failure to appreciate communicative intent so that 'common sense' is never applied to work out what is really meant. This difficulty is not easy to understand and the child's misinterpretation is often attributed to obstinacy or willfulness or a lack of motivation. For much the same reason it may be difficult for the child with autism to understand instructions, especially if these are expressed in indirect 'polite' forms.

Many questions asked in teaching contexts are not 'genuine' in the sense that they seek information that the questioner has not got; rather, they are asked to test the individuals' understanding, to encourage greater individual participation, or to issue instructions. Individuals with autism may mistake these educational uses for the proper use of questions and use it as a model for their own repetitive questioning.

## **Teaching**

Teachers will need to approach this range of difficulties in two ways. One aspect involves a conscious monitoring of the language they use in instruction to make sure its meaning is clear and does not require an appreciation of what people intend rather than what they say. Teachers will need to restrict their use of sarcasm or irony or even metaphor, although it will seldom be possible to eliminate these forms entirely, especially in mixed settings. Even if it were possible, it would leave the person with autism vulnerable to other people using such forms so teachers must also try to teach understanding at the same time as they restrict their use. In work on metaphors, for example, teachers can start with more transparent forms such the use of 'sunny' to mean happy. Pictures of the sun can be drawn with a happy face (as they often are in picture books for young children) and the teacher can explain that we often feel happy when the sun is shining so sometimes we just say 'sunny' when we mean someone is a generally happy person.

Where the metaphor is more obscure it is often best not to try to make sense of it in this way for the person with autism but simply to teach them the metaphorical meaning directly, somewhat as if it were a foreign language. In the same way we can get children to tolerate synonyms. Thus we would tell them directly that their outer garment may be called a 'coat' or a 'jacket' or an 'anorak' and that all these words may refer to the same object. Or we would tell a girl with autism that someone might call them an 'angel' or a 'girl' or 'you' or 'Amy' or 'Amy Smith' and that these would all mean her. But some of these words could be used to refer to other people and some (like Amy Smith) would be more specific to her. Also some would depend on circumstances and contexts so that 'you' would only be used when someone was talking directly to you and 'angel' when someone thought you were being very good. Of course, just telling the child about all these meanings would not help them very much; the teacher will need to show them how they are used in everyday contexts and to draw their attention to ways in which they can use such terms themselves to refer to others.

## **Pronouns**

Children with autism find it difficult to understand the way in which 'I' and 'you' are used to refer to conversational roles and particularly to the way in which 'you' varies according to the speaker's intention. They may muddle these pronouns or, more commonly, refer to themselves as 'you', 'he' or 'she' or by their proper name, mirroring the way they hear themselves addressed by others.

## **Teaching**

The first person pronoun only refers to the self as a conversational role, or an experienced agent of action ('I') or recipient of action ('me'). Individuals with autism will have little understanding of conversational role and, without a conscious sense of themselves may not express this agent or recipient role either. Thus general work to help the individual build up a sense of themselves performing actions through reflection, using video and instant photographs of their own role within activities, will help in the acquisition of this pronoun.

In a more direct way, children can be taught to label their own assertive acts, using the 'I' pronoun, even if this is only in imitation at first. They can be prompted to say "I jump" as they jump, "I sit" as they sit and so on. They may be helped to do this with photographs or with the written words on cards.

The understanding of 'you' can be fostered by helping the child attend to situations when 'you' is used to refer to people other than the child. The teacher must contrive situations in which the child is rewarded for recognising correctly the reference for you in each case. With children with general learning difficulties as well as autism, it might be better to allow the use of names instead of pronouns, to avoid confusion.

## **Echolalia**

Copying what is said by others either immediately or after an interval that may even be years (delayed echolalia) is a common problem in the language of children with autism who speak. It is seldom helpful just to try to eliminate it, because it often leads to more productive language and it usually has at least some communicative purpose. Thus, immediate and delayed echolalia may be interpreted as ways in which the child with autism is either trying to communicate or is 'playing' with language in the sense of analysing and recombining it; such an interpretation allows the teacher to try to find ways of using the echolalia as a way into establishing communication.

## **Teaching**

The first step in dealing with echolalia should be to determine exactly how the echolalia is being used and the form it is taking. This should include noting the situations in which the echolalia is occurring and how close it is to the echoed utterance. Of course, this is easier to accomplish for immediate echolalia where the 'model' utterance is directly observable. Analysis of delayed echolalia may need to infer the utterance being echoed, but it will still be helpful to analyse the communicative functions being served by the echolalia and make some deductions about the conditions that are triggering it.

The teacher needs to consider how far the echoed utterance is being used to communicate something? If so, what? At a minimum level, teachers should look for the fact that the child has recognised that there is a need to take a 'turn' in a conversation. At a more advanced level, look at whether the child persists in the echoed utterance until some end has been achieved, thus indicating the intent to achieve that purpose. Other questions are whether there are any changes in the form of the delayed echolalia over time or whether there is evidence of a failure to understand that may be triggering the echo?

Where there appears to be very little comprehension of what is being said and very little functional use of the echoing in a communicative sense, the priority would be to improve the child's understanding of spoken language, to increase the proportion of spontaneous utterances and to introduce planned variation of the echoed utterances that could be taught to the child specifically as functional ways of achieving particular communicative ends. Long pauses and the slowing of interaction have also been shown to be effective in increasing the proportion of spontaneous utterances compared to echolalic ones. If the atmosphere of such sessions is relaxed, with little overt pressure on the child to speak (i.e. with the interaction continuing, supported by the adult, regardless of the contribution of the child), then this too will increase the likelihood of spontaneous utterances. The third part of the programme for such a case would first involve imputing communicative intent to the delayed echolalic responses of the child. Once the child had begun to echo the phrase immediately following the teacher on a regular basis, then the teacher would make the echoing of that phrase conditional for the request (e.g. "Do you want a biscuit?"). Once the child is using this phrase readily with this communicative intent, the teacher would look for other situations where the child's needs were clear and where such a phrase might be adapted to fit a similar communicative intent (e.g. "Do you want go out now?"). Finally, the teacher might shape the child's 'comment' into a more conventional request form (e.g. "Can I go out now?").

## **Repetitive questioning**

Behavioural management may be necessary as a short term measure, but teachers should try to understand this in terms of what the child is trying to communicate. We all ask questions to test for knowledge (teachers' display questions) or to try to get the other to think of alternatives, or to seek reassurance (when the questions will require the same answer in order to be reassuring e.g. "Do you love me?" said a thousand times is still looking for the answer "Yes") or to express anxiety. There are also rhetorical questions, expecting no answer, so we should not act as if asking for information you do not have (the sincere question) is the only purpose.

Children with autism may not know about minds that can have different access to different kinds of information and so the 'sincere' purpose of questions is not perceived. Instead, they may copy the teacher and use questions as a device to further their own topic (looking for the answer that fits their own agenda, just as the teacher does) or they may often use questions to seek reassurance (seeking the same answer) or to express anxiety (keeping the topic up front). What is often different about individuals with autism is that they are made anxious about things that do not normally give rise to such feelings and so we are not alert to what they are communicating by their questions; nor, of course are they responsive to our irritation or boredom, which normally helps keep such repetitive questioning within bounds.

The teacher needs to look for the underlying meaning of the questioning and show the child explicitly that his/her needs have been recognised and then give an alternative to that way of expressing them. The more able child can also be taught how to use questions to ask for information, but this needs to be done in a very concrete way and when the child is not anxious (i.e. not during the bout of repetitive questioning). Thus, the boy who keeps asking when the taxi is coming, when you feel he knows very well when the taxi is due, is not helped by being told that he knows already or being forbidden to ask. The teacher may understand that he is anxious about the journey home because other children from another school also travel in the taxi and they tease him by tying his shoelaces together and laughing at him. Asking about something repetitively does not always mean that the child is looking forward to it; it often means the reverse. The teacher, then, instead of answering the same question over and over again, says something like "I know you are worried about the taxi and the journey home. Let's discuss what you can do if the children start to do things you don't like". And the teacher can go through and rehearse strategies for helping the child cope with this situation such as teaching him how to tell the escort (getting her attention first, for example) or how to defend himself from attack.

## **Developing language**

Approaches to teaching language in autism should have a functional and communicative bias. If language is taught in a rigidly behavioural way, divorced from a communicative context, then this makes it difficult for children to learn about communication. This is not to reject, out of hand, behavioural programmes, but rather to suggest that they may need adaptation to make them 'natural' and part of genuine communication.

The TEACCH programme (Watson, 1985) suggests that there are five dimensions that need to be taught in language:

- vocabulary
- context
- form
- semantic function.
- communicative function

Teaching language to individuals with autism needs to move away from the old techniques of teaching a vocabulary (whether of speech or sign) and then teaching more sophisticated linguistic expressions i.e. concentrating on teaching the forms and 'words' for communication only. The individual may need to be taught some means with which to communicate, but the more fundamental teaching priority is to teach about communication. Most specialist teaching, at least, does pay attention to the dimension of context as well as that of form and vocabulary in that it takes account of the fact that being taught something in one context does not mean that the child with autism will have that skill in another situation or with another person. Programmes cope with this either by teaching in the functional context where the behaviour will be used, or by specifically teaching generalisation of the skill. So, form, vocabulary and context are usually taught, but what of the other two dimensions - semantic and communicative functions? Many teachers find it very difficult to separate these two dimensions conceptually and in practice it is not essential to do so. Thus we are really only talking about one missing dimension but it is the one that defines the difficulty in autism i.e. the one concerned with communication itself. The reason this dimension is so often neglected in teaching may be that it is so much a natural part of normal social situations that it is difficult to isolate it as a dimension and even more difficult to think about teaching.

Another important teaching point to remember is that the teaching is unlikely to be successful if more than one dimension is taught at a time, This can be neglected as a factor, especially when one of the dimensions is 'communicative function' which comes so naturally to most of us.

**Example:** A young boy with autism, without speech or an effective sign or symbol system, had developed disruptive behaviour at lunch times at school. Careful observation showed that it seemed to occur when he had had enough to eat and that was the trigger for him to scream and throw his plate, if staff were busy elsewhere and did not immediately notice when he stopped eating. The behaviour was developing into a habit since it was rewarded by the removal of the food (which he wanted to be rid of, once he had had enough) and often his own escape from the dining room (which he didn't like because it was noisy and echoing).

A clear priority in this situation was to teach the boy to communicate the fact that he had had enough, without screaming and throwing his plate. Staff decided to teach him a new way of communicating this in a less fraught situation than the lunch-time one. The written word 'enough' was used (as a separate card at first, and then as part of a communication board) as being no more complex than other visual symbols that were available and having the advantage that it could be read by others without training. Staff sat near him when he was engaged in activities of which they knew, from experience, he would soon tire. As they saw the signs of restlessness that meant he would soon abandon that activity in favour of another, they prompted him to point to the word 'enough' before explicitly removing the old activity and letting him move onto a new one. This was extended to drinks in the classroom where drinks were poured for him until he indicated he had had 'enough'.

Only when he was secure in his understanding, that he could point to 'enough' and whatever was in front of him would be removed, was this transferred to the lunch situation. As might be expected in autism, transfer to this situation was not automatic but, after two days of prompting, he began to point to the card spontaneously. Disruptive behaviour disappeared at lunch and he even began to eat more of his lunch once he

could trust his method of communicating that he had had enough.

## **Alternatives to speech**

There are many children with autism and additional language and/or learning difficulties who will never acquire a spoken language and so need to be taught an alternative. There are others who will struggle to learn to speak and who need an augmentative system to help them to acquire speech and to have a means of communicating while they are doing so. For all these children, then, the teacher needs to choose a system to be taught.

### *Choosing a system of communication*

Early goals would be to improve spoken language skills as well as teaching for and about communication. Choosing the most appropriate system will depend to some extent on the individual and the context of the teaching. The teacher and parent (for decisions on the communication system to use should involve a joint view) cannot base the decision purely on the child's preferred medium (visual, for example) without taking the communicative environment into account. The very essence of communication is that it is a shared system and, while there can be some individual variation within a class or family group, there must be a system that is understood and used by all the adult members of the communicating group at least. As a general guide, the following points need to be considered when making a decision on the communicative system to use:

- intelligibility for the naive user i.e. will others be able to use and understand the system without the need for training?
- portability and ease of use i.e. will the system be able to be used in a variety of contexts (including the outdoors) without the need for elaborate or cumbersome equipment? This is obviously especially relevant for systems depending on the use of technological equipment, but also has implications for symbol and picture systems.
- compatibility with the user's level of linguistic, cognitive, sensory and physical functioning i.e. is the proposed system within the individual's capacity to acquire?
- usability within present or projected future environments i.e. does the system allow the individual to communicate with those who currently affect that individual's quality of life (and those who are likely to be significant in doing so in the future)?
- normalisation i.e. is the system one that encourages inclusion into society or does it increase the likelihood of further segregation and isolation? A part of this would be the consideration of whether the system could be used as augmentative to speech in the hope that speech development would be facilitated by its use, or whether the system was purely an alternative to speech.

## **Facilitated Communication**

This is a technique involving a particular form of prompting a child to point to letters or words either on a communication board or with a special computer (Biklen, 1990). The approach is based on the assumption that autism is really a motor disorder and that the person with autism knows what he or she wants to say but cannot execute the motor movements to speak or to type or point independently. A facilitator helps the child to do this by assisting the withdrawal of the pointing finger after it has made a point (or tapped a key) and re-positioning it for the next point. In this way, many remarkable texts have been 'written' by mute children with autism.

Although there is still a degree of controversy surrounding this approach, it has generated considerable research. There is some concern that facilitators unconsciously prompt the messages being written, but individuals (mainly parents) report positive results. Useful side effects from the use of FC in autism include confirming that many children with autism, even with severe learning difficulties, can be taught to read and type, thereby communicating, and reminding staff that many children with autism have additional motor problems and often need help in planning and executing movements. In addition, it provides a context in which staff and/or parents can sit with their child and enjoy a teaching task together. These aspects are positive but those applying the technique should be aware of the danger that unintentional guidance may produce misleading results.

## **Fostering communication**

Where there is little or no understanding of communication, it is not sufficient to teach language skills (whether these are a spoken language, a written language or a system of signs, symbols, pictures or objects). This will just give children the means with which to communicate but, in the case of autism, it will not ensure that they are able to do so. There are at least three essential components to the ability to communicate:

- something to communicate with (a language or a communication system)
- something to communicate about (involving an awareness of one's own needs, desires and intentions and a shared understanding of the world with others)
- something to communicate for (an environment that is responsive to expressed communication and where there is some manageable pressure to communicate)

In autism, there will be an additional need: that of teaching the child what communication is. This means in practical terms that we have to teach children with autism to use whatever means they have to communicate and we have to address all the forms of communication, including the earliest ones of facial expression and gesture. We also need to consider how we can encourage an understanding of communication that will lead to more spontaneous use of whatever language the child has.

## **Understanding Communicative Gestures**

Parents and teachers need to achieve the discipline of giving explicit instructions of what the child is actually to do, instead of relying on implicit understanding of communication. They will not only need to be told where to look to achieve joint attention but also that holding items up is a signal to direct attention to that object, as is pointing. Direct teaching of the meaning of certain gestures may also be helpful, especially to the more verbally able child.

### **Where to start ?**

One of the main difficulties facing teachers of children with autism is knowing how to start teaching them about communication. Because it is normally an intuitive process learnt in the early years of life, it is hard to know how it can be broken down into teachable 'steps'. Below are some suggestions.

### **Using the child's own responses**

Starting the communicative process, by imputing meaning to the child's non-communicative expressions, is the basis of normal language and communication development. Thus the young girl with autism may not have meant to tell anyone that she was hungry when she started to cry and hit herself each morning, but, if the teachers have worked out that that is probably what is wrong, they can treat her behaviour as if that were what it meant.

Each time she starts to cry they can say "Oh! You must be hungry!" and then offer food. After a while, the timing of this can be so the girl only just starts to cry before her need is met. Then she can be prompted to communicate that need in a different way (giving a card to the teacher with a picture of food on it, for example, or giving an 'object of reference' such as a spoon or plate). The success of this programme relies on the teachers working out accurately what it is that the child would want to be communicating in that situation at that time if she knew how.

Imitation of the child's spontaneous actions can also be another strategy for getting the child starting to communicate. It is effective in getting individuals with autism to pay attention to others and learning that they can modify their behaviour. The teacher or parent starts playing a game where- by they copy the child's noises or actions, timing the imitations and the pauses so that the child begins to notice and turn-taking is established. Some children with autism may resist this intrusion into their 'private' actions at first but in time most accept it and begin to like the fact that they have a way of controlling what the adult does. Once this is well established, the adult can begin to change the action or noise a little to see if the child can be persuaded to imitate that, and so begin to acquire the very useful skill of imitation.

For more able pupils who may have some degree of language skills but are still very communicatively impaired, we should look for any communicative intent that might be there (in echolalia or apparently non communicative uses of language) or might sensibly be imputed. Where the child is apparently lacking in all attempts at communication, the easiest communicative function to start with is that of request, for this can most readily be demonstrated and it is the first (and sometimes the only) communicative function to

develop in autism. But even here teachers and parents must beware of just teaching a 'ritual' that must be gone through first, or just polite conformity.

The individual may be at the stage where outbursts are a simple reaction to need, without communicative intent at all. However, the teacher can use such outbursts to impute the communicative intent of a request and teach the individual to grab; if the individual already tries to grab (or grabs the teacher's hand and 'throws' it at the desired item) then the communication training starts there. Teaching the individual to stop and look at the teacher, by interrupting the 'grab' sharply with a restraining hand (and thus causing a momentary glance at the person causing the obstruction, in most individuals, even with autism) can be built on until the individual is coming to give that checking look spontaneously as s/he reaches for the item. This can be extended to a variety of contexts and, once it is secure, the grabbing hand can be gradually shaped into a point until the individual has the communicative act of pointing and looking. Teaching pointing, without these preliminaries to teach the meaning, will only lead to meaningless pointing, even when there is no-one in the room to see the point.

## **Communication problems in autism**

### **Conversational skills**

Conversation requires spontaneity not only in the production of utterances but in keeping track of the discourse to monitor its progress and actively listen to the contributions of others in order to match one's own utterance in terms of topic relevance, style and timing. This is a complex array of skills which is difficult for children with autism, even when their language skills are apparently good.

### **Teaching**

Some of the outward forms of conversational behaviour can be taught. Children can be taught to take turns, the rules for entering conversations, ways of changing topic politely and even ways of closing conversations, although that is more difficult. It may even be possible to get children with autism to pay attention to what others are saying but it is far more difficult to teach appropriate timing for these behaviours or the very subtle responsiveness to different circumstances which is the hallmark of fluent behaviour. One way of tackling the problem is to teach sufficient skills to enable the person to begin to participate in conversations with others. It is only through active participation that these more subtle behaviours will ever be acquired.

## **Understanding and telling stories**

This is not just a difficulty in understanding imaginary characters and events, but includes difficulties in remembering the gist of what they hear (as opposed to memorising and being able to reproduce chunks of it) and telling people about personal events in a meaningful way. Fictional stories that are read are difficult because it is even harder to understand why people do things if you cannot see the very cues that you have been learning painfully are associated with certain feelings (the smile indicating happiness, for example).

Yet some children with autism can become very obsessional about particular stories, especially cartoons, or videos and demand to have the same ones told over and over again. It is not clear what the fascination of these particular ones are ('Thomas the Tank Engine' videos seem popular with children with autism the world over, for example) but it may be that the characters are simplified humans who do predictable things and have definite characters (one is always 'naughty', another 'trustworthy') so that they are less confusing than stories that relate to real people or which are ambiguous about people's motives and beliefs. A more mundane difficulty with story time in school is that it may involve sitting and listening to verbal information at a speed and of a length that the child with autism cannot follow. Nor is the child very clear about what is meant by 'listening' and they will see it as the same as 'hearing', rather than realising that it involves an active process of trying to make sense of what is heard. Where there are additional problems of hyperactivity, as there often are, it is of little use to exhort the child to 'sit still and listen'; they may need something to do or at least fiddle with, if they are to be able to listen.

## **Teaching**

Helping children understand that listening is an active process and helping them tolerate sitting to listen to a story can start with being given toy characters or puppets and being taught to act out the main themes of the story being told. For children with written language skills, the structure of a story can be made more explicit by being taught to pick out all the words that refer to the main character (e.g. Tom, he, his, him) and underline or highlight them in a certain colour. Then other characters can be highlighted using their own colour. Yet another separate colour can be used to highlight the actions of the main character and so on.

Helping children with autism talk about what has happened to them and what they have been doing needs to be tackled in a slightly different way. We can borrow from the techniques of normal child rearing and mimic (and emphasise and adapt) the way in which parents normally help their children learn to talk about themselves through a process of first going over events in a structured way and then prompting them to talk about it in a structured way to others. The structure used consists of questions that help the child see that one needs to talk about a character (who?), an event (what?), a time (when?), a consequence (what then?) and an emotional/experiential reaction (how?). The child is helped to build up this topic-comment structure of a narrative through a careful scaffolding of this kind. For children with autism the scaffolding may need to be more emphatic.

## **Conclusion**

Many children with autism will have some difficulties in acquiring language and understanding at least some aspects of it, but the main problem in autism is communication. Teachers need to monitor and modify their own use of language and to foster both language and communication skills in the children. For some, an alternative mode of communication will need to be taught; visual systems will generally be most useful but the actual system chosen will depend on an analysis of the child's strengths and weaknesses and the characteristics of the situation. Whatever is taught needs to be taken one dimension at a time and to take into account the child's difficulties in understanding what communication is about. Specific problems that arise in language or communication are best dealt with not by trying to suppress them but by understanding their function for the child and teaching an alternative mode of expression for that same function.

## **Chapter 5**

### **ENCOURAGING FLEXIBILITY IN THINKING AND BEHAVIOUR**

#### **Lack of flexibility in thinking and behaviour**

Children with autism are often characterised as having behaviour that is 'ritualistic'. They often develop routines on which they then come to rely, so that disturbances in those routines may lead to stress and even challenging behaviour. Another very noticeable feature of rigidity is that children with autism often seem unable to transfer what they have learnt in one situation to another and much of their learning is habitual; they rely on the same cues being present in order to remember and 'trigger' the response.

It is important here to make the distinction between those with different levels of intelligence, and in particular, to the difference that possession of good language skills can make. The rigidity of thought and behaviour is still apparent in high functioning children with autism, although it will manifest itself in more complex ways than in the pupil with autism and additional learning difficulties. Obsessional interests are more a feature of the high functioning group than simple repetitive actions or stereotypes although these too may appear at times of stress. The more profound the additional learning difficulties, the more likely are stereotyped and self-stimulatory activities and this is even more so when there are additional sensory disabilities. Teachers, then, need to adjust their own behaviours so as to make themselves more predictable, to reduce stress and enable a relationship to be established, but they also need to look for ways of helping the children make predictions and learn in less structured situations.

#### **Learning and behaviour**

Children with autism can be taught procedural habits or automatic skills through behavioural methods of training, but real education involves deep learning in which the individual's cognitive structures (the way s/he thinks and learns) are altered, and this is the only way in which truly independent learning can be achieved. For children with autism who do not have language, and/or who have additional severe learning difficulties, such independent learning may be difficult to achieve, but this should be an aim, albeit a long-term one.

Children with autism have difficulties in reading the intentions of others but they also have difficulty in developing intentions of their own. It is as hard for them to project themselves forward to make their behaviour goal-directed as it is for them to remember personal events (projecting themselves backwards). It is noticeable that it is only when their own obsessional interest is involved that this can serve to make their behaviour focused towards achieving certain ends; it is cognitively difficult for them (i.e. it is not just a matter of lack of motivation) to direct their behaviour towards some 'other-defined' goal.

Non-autistic children learn what it is to have intentions through early interactions in which they notice and respond to the effects they have on others and direct their behaviour towards producing those effects and collaborating in joint intentions. From those joint intentions comes not only awareness of how to direct one's own behaviour towards ends, but also that this is a feature of the behaviour of others also.

So, children with autism will tend to learn in a habitual kind of way without any real awareness of, or ability to monitor, that learning. This means they become dependent on others (or the environment) to cue or prompt them and the behaviour pattern is disrupted if any part of it is changed or interrupted. This explains why more able youngsters with autism who are interrupted in a long monologue about an obsessional interest or in the process of a routine, will have to start again from the beginning, rather than being able to take it up again from the interrupted point. It also explains why less able children with autism will have no idea how to clean their teeth in their grandmother's house, for example, if they have only been taught to do so in their own home. The performance of the skill is dependent on the right cues to trigger it, and, once triggered, it has to run its course.

### **Intuitive versus learned behaviours**

As with so much in autism, however, it is not so much that the child with autism cannot do things as that play and interests do not develop spontaneously and, if they are directly 'taught', they tend to remain limited to the kinds of play and interests that have been demonstrated. Again, the more able child may display imagination, but it is likely to be of a limited kind, and there may be difficulty then in distinguishing imagination from reality. With some individuals it is as if there is no basis for distinguishing mental images from images produced directly from the environment.

### **The nature of the cognitive difficulties in autism**

#### **Perception**

There are many reports of inconsistency or fluctuating perception in autism and many high functioning individuals writing personal accounts of autism attribute their difficulties to a mixture of perceptual or sensory integration difficulties. It may be difficult to distinguish cause and effect in thinking of the nature of these difficulties. Is it a problem in processing rapid information that leads to difficulties in interpreting social meaning, or difficulties in 'tuning in' emotionally to others that leads to social isolation and consequently to a failure to categorise and understand the world?

At a practical level, understanding that a child may be over or undersensitive to particular forms of stimulation can be helpful in explaining extreme reactions (to certain noises, for example, that may appear as painful) or indeed lack of reaction (to pain, in particular where staff cannot rely on pupils to inform them when they are hurt). It also helps the member of staff to realise that perceptions may vary from one extreme to the other even within the course of a day, although it may then be more difficult to find a solution. It is also important for teachers to be aware that integration of stimuli may not only be difficult of itself but may require extra time.

## **Teaching**

If children with autism are oversensitive to general stimulation, then a low intrusion approach to their learning environment and teaching approach will be of benefit. Bright lights may need to be reduced (even sun- light may need to be reduced for some children with a light curtain or blind), noises deadened with soft flooring, visual displays all but removed and the teacher will need to speak minimally in a low or even whispered voice. Such an extreme environment will not be necessary for all children with autism and even those who start in such a way may be gradually re-introduced to a more natural environment through a process of desensitisation (gradually introducing the stimulation into a situation where the child is secure in steps so small that the increase is not noticed). Reducing stimulation can have a dramatic effect in reducing the child's stress and making him or her more receptive to learning.

However, if the problem is one of variable sensitivity rather than just over-sensitivity, it is difficult to deal with simply in this way. Carers or teachers would need to give some proximal control device to the individual such as ear plugs (or a 'Walkman' radio) or coloured lenses so that the child can use them as and when needed. Just having control can do a lot to reduce the fear and anxiety provoked by over stimulation and consequently can have a marked effect on behaviour. Sensory integration may be tackled through sensory integration programmes and allowing the child to use proximal senses such as touch for exploration of objects. This can apply even to the most able whose verbal and academic skills may mask this underlying confusion in interpreting the world. There is also the need to give the child time to process his or her environment and teaching styles and curriculum delivery must allow for this.

## **Attention**

When teachers describe a child with autism as having a 'short attention span' they usually mean that the child will fail to concentrate on the tasks the teacher has set. In some cases this may be a problem of motivation where the child does not understand the purpose of the task nor see the need to 'please the teacher'. However, attentional problems in autism are not all due to this kind of motivational problem and there may be genuine difficulties in sustaining attention, especially when the child is young. It is also clear that children with autism have problems in switching attention and may take a long time to do so; the danger is that the teacher will not wait long enough for a response and may re-phrase the instruction, giving another processing task on top of the first.

There are many reports in the literature of people with autism attending to detail but not being able to see the whole. This is undeniably true in some instances but it appears to relate to what is seen as meaningful rather than an invariable feature of cognitive style. It was also thought that individuals with autism were unable to attend to more than one stimulus at a time, but this is probably a developmental delay rather than a deficit. Many individuals with autism will be unable to attend to two sources of information at the same time which means that instructions or commands only serve to enhance (rather than direct) the actions the individual is already performing; unless this is understood, the individual may be seen as 'disobedient' rather than having a problem with processing.

The most well-documented attentional problem in autism, however, is that relating to 'joint attention' which is at the heart of the inter-personal difficulties. It is not that children with autism are unable to follow where someone is looking if they are instructed to do so, but rather that they do not do so spontaneously and so they miss out on all the shared referencing that is the foundation for social, cognitive and cultural development. It may also be that this failure to attend to social and cultural meanings leads to greater attention being devoted to proximal senses than is normally the case, so that responses to others may be very dependent on how others smell, feel or taste more than how they look or what they say.

## **Teaching**

One lesson for teachers is to ensure that the intended focus of attention must be made meaningful to the individual with autism. This can be done by drawing attention to the child's natural activity, rather than always expecting the child to pay attention to the topic the teacher has chosen. Sharing activities, whether this is working together at a computer or playing an imitation game involving one of the child's stereotypic actions, may also be effective. When it is important to gain the child's attention, staff will need to make sure the child is not doing anything else and to give sufficient time for the child to switch attention. Joint attention cannot be assumed and so instructions to "Look at what I am holding/ pointing to/ looking at" will need to be given explicitly.

A failure to appreciate social and emotional meaning may also help explain the difficulty in focusing attention on some aspects of the stimulation being received while ignoring others. This means the child may not be able to attend selectively to the teacher talking when there is other competing noise or may not be able to sit still if the feel of the clothes on the skin or the chair on the bottom makes it hard for them to think of anything else. In the visual domain also, it means that the child may need a relatively (if not completely) display-free area in which to work, at least for new or concentrated learning. It also means that 'talking a child through a task', as is common practice in schools, may make it more difficult for the individual with autism to concentrate on that task. Teachers may need to look for ways of structuring the task so that the child knows what to do, when and how without the need for additional instruction. Good practice will draw the child's attention to the way in which things are related in a very deliberate way and try to help the child see the patterns.

## **Memory**

There are often very good rote memories and amazing recall of detail alongside an inability to give the gist of a story or event and an apparent failure to remember what happened to themselves even a short while before. Memories need to be cued or prompted in some way and there appears to be no way in which individuals with autism can search and produce memories spontaneously. Thus, it is not that they have completely 'forgotten', or that they are deliberately not co-operating; they just do not find it easy to retrieve memories, especially related to general prompts concerning what they have done in the past.

Children with autism may be able to recall facts about themselves (where they live, where they have lived in the past, any facts they have been 'told' about themselves), and episodes that do not include a personal element (the exact date and time when a visitor last came to the school, for instance, even when that was over a year ago). They may also be able to recall particular episodes when they are cued by particular words or phrases or by being in exactly the same situation again. In fact, such memories may not be under conscious control and may be triggered by the environment at inopportune moments leading to inappropriate behaviour and delayed echolalia. Children with autism may also have little difficulty in remembering particular aspects of 'general knowledge', especially related to their own particular interests.

They are also likely to have good procedural knowledge for skills, such as bicycle riding or playing a musical instrument. But at the same time as all of this they may be unable to remember themselves performing actions, participating in events or possessing knowledge and strategies. This means that they are dependent on others providing them with the right cues to get them started and any disruption of a learned way of tackling a task will mean the child is completely at a loss as to how to proceed.

## **Teaching**

Awareness of these difficulties will help the teacher draw the individual's attention to relevant features at the time of learning which can serve as cues at the time of recall. They will also need to be taught how to use semantic strategies (relating what has to be remembered to something that is important and makes sense to them) to memorise rather than relying on remembering 'snatches' of events. For example, music is often important to children with autism so a musical phrase can be used to describe an event at the time (e.g. "Johnny's making a cake. ..with eggs and butter and sugar and flour...beat, beat beat..Johnny's making a cake") so that the rhythm mirrors the actions and the key words to remember are emphasised in the musical stress. Then, when asked to recall later what he had made in cookery, the music can be played or hummed as a trigger for him to sing the song and so recall the event.

A child with more language skills might be taught to use the scaffolding questions that were suggested in the communication chapter for building up story-telling ability. Instead of waiting for the teacher to prompt with "who?, what? when? how?" questions, the child can be taught to use them him or herself to cue the structure of the event and aid memory. In trying to get a child to tell about a past event shared with others, it may also be helpful (at least as a first step) to ask the child what others did or what happened to others, as this seems to be easier for them to recall, from the 'outside' as it were, rather than trying to retrieve personal memories.

Teachers also need to use the natural environmental cues to aid memory. After a task has been completed, for example, the child has painted a picture, the child should be asked to recall the event while there are still clues to trigger the memory. In that case the clues might come from paint on the child's hands, from the apron used, and so on. This initial discussion before the child has cleared up can be reinforced later after clearing up (either verbally or by selecting symbols or pictures that describe the activity) so that the child's memories begin to be triggered by internal cues, but this needs to be managed slowly. At first, the teacher may still need to jog the memory by re-introducing the painting apron, for example, even though the child is no longer wearing it.

## **Problem Solving**

In common with many others with learning difficulties and especially those with poor language skills, children with autism display poor metacognitive skills (being able to think about their own thinking and so plan, monitor and control it). These difficulties mean that children with autism often learn in a rote way, adhere to learned responses in certain situations and are at a loss if the response does not work. They find it very difficult to inhibit their actions and will persist with habitual responses even when these are known to be wrong or when they are punished. They cannot model their own intentions, which leads to apparent motivational problems and they rely on others or the situation to cue their actions. It also means they will have difficulty making choices or even understanding what a choice is (since that depends on modelling alternative actions) and an inability to benefit from “incidental learning” where particular responses have not been trained.

## **Teaching**

If it is important that the child achieves a certain skill or performs a certain activity (as it may well be with certain life skills) then it is important to structure them in such a way that the problem-solving element is reduced to a minimum. A goal of long-term independence, however, requires consistent attempts to teach the child to become aware of the process of learning and the stages of problem solving.

Choice should be introduced into as many situations as possible in ways that are meaningful to the child (a choice of snacks, meals, activities etc.) and which offer structured alternatives to begin with. Thus, a child may be taught to use pictures to indicate a choice so that the choosing situation can be one of selecting from an array of pictures, rather than being confronted with real items. The advantage of this is that, in the real situation, the child may only notice the item wanted and may point to that (or ask for it) without being aware of the alternatives, and so is not really aware of making a choice at all. It may also be difficult for children to inhibit their responses to items and so using a distal stimulus (like a picture) may help them make a real choice.

All teaching should involve a period of planning where the child is taught to intend by selecting what is needed for the task and having a clear idea (expressed in words, or pictures or a model) of the goal to be aimed at. At one level, the child with severe learning difficulties and no speech, who is asked to lay the table, will need a photograph (later, schematised as a drawing and then a plan) of how the table will look when finished. This will not only make the goal clear and specific, and help keep the child on task, but it can be used at the planning stage to help the child plan the task by first counting and assembling all the items needed (e.g. six forks, six mats, six glasses etc.) before arranging them.

## **Concept Acquisition**

Children with autism do not seem able to see the meaningful patterns in the world around them and have difficulty analysing stimulation and abstracting the features that lead to concepts being formed. More able individuals (even when they have been very successful academically) will talk about their problems in thinking in conceptual terms. Sometimes this is described in the literature as a difficulty with abstract concepts but, if we listen to what people with autism tell us, we find that they are having just as much difficulty in thinking about a 'chair', or a 'cat' as they have thinking about 'old' or even 'peace' or 'justice'.

They have to think in terms of particular experiences, thinking about a particular chair or cat, an old man, a peaceful scene, a judge in a wig and gown. Of course the effect will be more noticeable when it comes to abstract concepts since a judge in a wig and gown is more misleading about the concept of justice than a particular chair is about the concept of a chair. Yet all these rigid concepts will inhibit thinking and will be harder to elaborate and link together than would be more flexible concepts.

## **Teaching**

Although we do not normally acquire concepts by a logical analysis of their features this may be one step forward in helping some more able children with autism extend their concepts. For less able children, however, and for all children with autism in the early years, we need to adopt a particular teaching approach. The child is not taught about a particular object or procedure, and then has to 'unlearn' its particularity while learning a more general concept, e.g. learn that a particular cup is 'a cup' and then learn that there are, in fact, lots of kinds of cup. Instead, the broader concept would be introduced from the beginning, teaching the child to pay attention to 'meaning' from the start, e.g. the child would learn that various shapes and sizes of cup can be used for drinking from, and only then, that they are all called 'cup', as was discussed in an earlier chapter.

## **Generalisation**

There is a well-established difficulty in transferring knowledge and skills to new situations. Those with spoken language will find it easier to learn a generalised 'idea' of the task which can help that transfer; others may have to have more specific cues (photographs of them doing the task, for example or some object of reference that comes to signify that task). Whether this 'bridge' from one task to another is through a language or a symbol system, it cannot be assumed that it will occur naturally, even in the most able.

## Teaching

Important life skills are often taught in a functional context (i.e. where the skill is used meaningfully) to by-pass this problem of generalisation. Tackling it may be at different levels. Behavioural strategies do not attack the underlying problems but can be used to encourage transfer, with the child being taught to generalise in a structured way:

- the task is taught with the criterion for success being accuracy.
- there is a period of 'overlearning' where the child learns to do the same task in the same situation with the same materials but with the criteria of success being speed and fluency, while retaining accuracy
- variation is gradually introduced along a range of dimensions (one at a time): different materials, different settings, different times, with different teachers, with different peers, and so on, while retaining the previous criteria of success.

More fundamental gain in this area, however, can only really occur if children are taught to become aware of their own learning strategies, i.e. through self-reflection. With spoken language children can be taught specifically to label what they are doing, both in terms of the overall 'idea' (e.g. "I am making a sandwich" "I am doing a calculation") and the steps in the process (e.g. "I am spreading the butter, spreading the filling" etc. "I am writing down the numbers to be added in columns, adding the columns starting from the right" etc.). They can also be taught to 'rehearse' some of the other contexts in which the task can be generalised ("I could use brown bread instead of white" "I could make a sandwich for lunch at the weekends when I am home" "I can add up the price of my shopping to check that I have been charged correctly" etc.).

This is more difficult without language but children can have their photographs taken (where there is access to an instant camera) at every stage in the task and these can be used both to structure the performance of the task, but also to aid memory of it and transfer it to other situations.

Drawings may help, where a camera is not available, but there may need to be training to help the child make the connection between the task or the step in the task and the picture.

## **Learning about thinking**

A difficulty with mental states and being aware of one's own thinking does not just mean a difficulty in understanding people but also problems in understanding thinking at all. Thus, children with autism are often unaware that tasks require an 'attitudinal stance' in that they have to make an effort to learn or remember.

## **Retaining a mental image**

Teachers need to be aware of the difficulty experienced even by the most able in holding onto a mental image while faced with competing stimuli. This means that even a simple task such as copying a sequence of coloured pegs will often be attempted by the child picking up a handful of pegs and putting them in on an ad hoc matching basis. This may be interpreted as a difficulty in maintaining left to right sequencing, but is more likely to be because the task requires the child to hold the concept of the particular colour next in sequence while searching through a box of pegs with distracters of many different colours.

The teacher may need to give the child some more concrete way of retaining the mental image, appropriate to the child's ability. In the peg sequencing task above, for example, this might be simply to repeat the name of the colour being sought during the searching, or to write it down or to have a symbol card to refer to when searching the box. The number of distracters in the box can also be manipulated so that, to begin with, there may be only one (or even none) and then distracters are added as the child shows understanding of the task.

## **Integrating thinking**

Children with autistic spectrum disorders do not seem to set up models or schema of events they are engaged in or of stories they are told. They do not attend to overall meaning or see the pattern through which things are related. This means that learning becomes fragmented and tied to contexts since the overall meaning is missed and not related to other aspects of the child's knowledge or understanding.

## **Teaching**

Helping the child understand about thinking can be tackled at one level by teaching the child to follow the main events of a story by acting them out with puppets as the story progresses. This also helps the child tolerate 'story time' since it now has structure and a beginning and an end that can be predicted. A more able child may be taught how events in a narrative relate together by highlighting written texts or giving systematic training in the structure of narratives.

General teaching tasks will need to be analysed to see where children are being asked to reflect on their own mental images (for example, being asked to think about a situation when they were frightened as the basis of writing an essay), and to see if this is then a barrier to learning. Ways of making the implicit thinking explicit will need to be developed. One attempt at this might be through familiar songs or rhymes in which words are substituted with pauses and the song is rejoined at the correct point, showing that others, like oneself, can be 'thinking' (i.e. saying the missing words silently 'in one's

head') the same things.

## **Developing creativity**

The kind of rigidity of thought that we see in autism seems to run contrary to any notion of creativity. We know that individual children may sometimes produce works (e.g. in art or music) that are 'pleasing', but we need to ask if those works are productive or merely reproductive. The distinction that we need to make is whether or not original stimuli have been extended, elaborated or changed by the individual. If they have not, then the work is 'parasitic' in that it derives directly from the original without any intervention at the cognitive level. That is not to decry the achievement inherent in such works or their beauty, but we should not confuse a remarkable ability to recreate what is seen (often from a single viewing) with the creative imagination needed for a more abstract or symbolic form of art.

If we shift the focus beyond 'creative works' to the creative aspects of everyday life, then it seems that children with autism are seldom creative in the sense given above. In every aspect of their lives from their use of language to the way in which they go about activities they will tend to operate within fairly constrained repetitive cycles. If they say or do something that appears to be 'new' or 'inventive' then one needs to check back to sources. Typically, it may be that they are reproducing faithfully chunks of remembered dialogue or actions from a source such as a television programme.

Some individuals with autism, however, do 'create' by devising their own patterns, usually within an obsessional interest. Computer programmes, mathematics or musical compositions may offer a context in which this is possible. In the main, however, the autistic way of thinking is one in which faithful reproduction is the dominant mode whereas the creative production of ideas is not.

## **Conclusion**

Difficulties in being flexible in thinking and learning have fundamental effects in education. This is not so much to do with missing skills and understandings (although there may be such gaps in development) as a different style of thinking and understanding. For the teacher this will not just mean trying to access steps to learning certain processes but trying to understand this difference.

We can get some ideas from normal development, from the writings of those with autism, and from observation, of the way children with autism actually learn. The teacher will need to be creative and flexible in the presentation of curriculum content, in the teaching approach used and in the outcomes demanded. Rigid methods may offer more control of the child's behaviour and a seemingly faster route to skill acquisition but if we want those with autism to develop more flexible problem solving approaches to their learning, we will have to enable the children to take control of their own learning and increase their understanding as well as their skills.

## Chapter 6

### MANAGING BEHAVIOUR

#### Setting priorities

The behaviour of children with autism may be so disturbing that teachers may feel that they must gain control of the behaviour before any teaching or learning can occur. Yet it is a mistake to think that behaviour can be managed without understanding the causes of that behaviour and without teaching alternatives. It is both ineffective and potentially cruel just to try to prevent or stop children with autism behaving in certain ways, without teaching them how to behave (in that situation and in response to the same emotion) in more acceptable ways. Behaviours may be suppressed for a while, but they will recur, or the child may replace the unwanted behaviour with an even more undesirable one. More commonly, the child with autism will continue with the unwanted behaviour no matter how much it is 'punished' because it has become habitual in that situation.

There is another risk in placing behavioural conformity before teaching and learning, in that this is liable to increase a dependent style of learning. The child may become more passive and withdrawn and less able to engage with the environment, or with others, spontaneously or to exercise any meaningful choice. Some degree of conformity is necessary, of course, if the child is to live in, and be accepted by, the community. Yet this will not be successful in the long run if it is not accompanied by some understanding of the world and the meaning behind the 'rules' that must be obeyed.

Teachers need to ensure that conformity is in the child's interests and not just those of the teacher or the institution. Even where control or suppression is thought necessary or desirable, the teacher needs to think of ways of achieving the same ends through a positive approach rather than centring on 'getting rid of' certain behaviours. In general it is true that behaviour problems and frustrations will be eased if the child is taught communication and social skills, for example, and if something is done to improve the child's understanding of the world. Yet, if the child's behaviour is so disruptive that s/he cannot be approached, then that will need to be a priority.

In the early years difficult behaviour is less disturbing and more easily controlled because the child is smaller and the behaviour is more acceptable in a young child. The problem, however, is that the children with autism will not have had the opportunity to learn any of the things (social / cognitive understanding, communication), that other young children learn naturally through an inborn intuitive route, but which they have to work out painfully and laboriously for themselves. The main advantage of starting early is that we can help in this process by making the learning task clearer and providing more structured opportunities for the learning to take place.

## Disruptive behaviour as communication

One of the most useful ways of looking at disruptive behaviour is to treat it 'as if' it were communication and to try to work out what communicative function the behaviour is serving. Is it intended to indicate that the child is bored/frustrated/unable to complete the task/distressed by some noise etc.? Clearly the first step is to conduct a functional analysis of the behaviour to suggest some hypotheses about the causes and thus the communicative intent that it is useful to impute. The question the teacher needs to ask is "What would the child want to tell me, if he or she knew how?" This applies whether or not the child has spoken language because the child may still not know how to do use it for communication.

Once it is decided what the child would want to say, then he or she can be taught an alternative form of communication to achieve the same ends. However, the child who is engaging in disruptive or aggressive behaviour is likely to be upset and so not necessarily amenable to producing high level behaviours. The aim should be to find an alternative which is at the same kind of developmental level as the one being replaced.

**An example:** Peter is a six year old child with autism who regularly screams and bites (mainly other children, but sometimes the teacher or assistant).

**Functional analysis:** Observation of the behaviour suggests the function of the behaviour for Peter is that it gets him out of doing work tasks in the classroom. He displays the behaviour over a range of tasks, times and situations but always when he is having to do something at a table next to someone and the task has been set by someone else (i.e. he has not chosen it himself). What is needed, if this is correct, is another way for Peter to get out of such situations.

**Communication as priority:** Communication should be given a priority. The teacher cannot 'win' in the sense of making the child conform and complete the task at the same time as teaching him another way of indicating that he does not want to do it. The teacher must decide whether completing that particular task, or conforming in that particular situation, is more important than learning another more acceptable way of communicating the fact that he does not want to conform and complete the task. Sometimes conforming will be the priority, but more often it will not, and it will be in the child's long term interests to give the communication priority.

**Selecting an alternative:** Having decided to teach a new skill, the next step is to select one to teach. Since Peter is screaming and biting, it is tempting to think of an alternative involving the mouth (asking to be released, for example) but Peter has no speech and, in any case, it is difficult to train speech to order, especially when a child is upset. A communicative gesture would be an alternative and would be at the right developmental level. Pushing away the teacher as the task is presented is decided upon. It is better to train pushing the teacher rather than the task because the teacher can (through resistance) modify the strength and effect of the child's action whereas the task materials could be thrown with vehemence. Pushing is chosen because, although not appropriate in the long term, its meaning is clear, it is developmentally primitive and it can be prompted and controlled.

**Training:** Timing is important in that the unwanted behaviour (the screaming and the biting) must not be allowed to occur or the removal of the task will just reward that behaviour and it will not decrease. Thus, the teacher must be very clear about the actual trigger (in this case, the presentation of a task in a classroom situation) and time it so that as the trigger occurs (i.e. as the task is presented) the child is immediately prompted with the alternative response. In this case, then, as the teacher presents a task with one hand, she uses the other to physically prompt Peter to push her away saying, at the same time, "Oh! I see. You do not want to do this now" and immediately removes the task. After a short interval (1 minute perhaps), the task is re-presented and the same procedure of prompting the push and removing the task is gone through. This is repeated until eventually the child comes to trust the fact that he has another way of getting the task removed and is spontaneously pushing the teacher away each time the task is presented.

At this stage, the teacher can choose to begin to modify the response being trained towards a more appropriate form of communication for a teacher. This might mean prompting or shaping a pushing gesture whereby the teacher is not touched and this can be gradually fashioned into a dismissive wave or a blocking movement with the hand. The child might even be taught a sign or a symbol or a word to mean this rejection of the task.

Or the teacher's priority might not be the actual gesture used but rather. Getting the child to perform some of the rejected task, because it is valuable educationally or because the child must learn to conform to some extent. This can be taught at this stage because now the child already has a way of communicating. The teacher must indicate that this way is still effective (or the child's trust will go and he may begin to scream and bite again as a more reliable way of getting his own way) but now must negotiate a compromise. The teacher might say something like: "I know you don't want to do this Peter but I want you to do just this one bit (or to do it for just a minute until this timer pings, as appropriate) and then I will remove the task (drawing the child's attention to his visual schedule which shows him performing the task and then shows him having access to his twiddle)".

### **Problematic points**

This is a technique that can work even with long established behaviour problems, but there are several stages which may give rise to problems of one kind or another.

**Different functions:** The same behaviour may serve more than one function for the child; this is especially likely to be the case where additional severe learning difficulties mean there is a limited repertoire of behaviours at his or her disposal. A programme may appear unsuccessful because the unwanted behaviour is still occurring (although it may be reduced in frequency); in the example above, for example, Peter may continue to bite and scream on occasions. This may not mean that the original functional analysis was wrong, but only that it was not the whole picture. Peter may have been doing it to get rid of unwanted tasks but he may also have found that it produced interesting and predictable results (people getting hurt, upset or angry) and so have started using it as a strategy to get attention and provide stimulation when bored. Or he might also do it when-he hears a sound he does not like simply because it is his habitual response to stress.

The answer is not to give up on the first communication programme but to build in others to meet each of the communication needs identified. Peter might be taught, other ways of getting attention and predictable stimulation. There could be a play programme started to develop his ability to explore his environment and he might be given access to a wider range of interesting materials. In the second situation hypothesised, Peter would need to be given another way of controlling or shutting out unwanted stimulation or he could be taught other ways of coping with his stress. Thus, he might be given free access to headphones or a 'Walkman' radio so he could block out any sounds that worried him at will. He could be taught standard relaxation techniques (training to tense and relax his muscles in turn, to take deep slow breaths, to adopt relaxed postures and head position). Each 'solution' follows the same principle of identifying the function and then finding and teaching a more acceptable way of achieving that same end.

**The 'last straw' phenomenon:** Another source of difficulty is that there may be no clear function for the unwanted behaviour. It appears to 'come out of the blue' with the child reacting violently to something or some situation which had been well tolerated on other occasions. It is hard, then, to see what has caused the behaviour or what the child is getting out of it. This is usually because there is no common trigger or goal in these situations other than the fact that the child's stress levels have reached such a pitch that the smallest extra pressure is just too much and the child erupts. When stress is lower they may not be bothered by a particular sound, they may be able to face a challenge in tackling a new or more difficult task or they may be able to tolerate sitting next to someone else. But when stress is high any one of those things can be sufficient to provoke the outburst. In such cases, the basis of any programme must be stress reduction and alternative ways of managing the stress.

## **Causes of unwanted behaviour**

### **Failures to understand**

Many of the problem behaviours seen in autism stem from the difficulties people with autism experience in making sense of the world.

- **Others' intentions:** Appreciating that others have intentions and that behaviour has meaning, rather than being random, is very difficult when you have little or no awareness of mental states. Teachers, therefore, need to think about ways of making that meaning explicit for the child. In some cases this may just mean voicing one's intentions instead of assuming the child can pick them up intuitively. In other cases, where, for example, the child does not understand verbal language very well, the teacher will need to be more inventive.
- **Prediction:** Part of appreciating the intentions of others and being aware of one's own, is being able to predict future behaviour and the outcomes of current behaviour. Children with autism will need lots of practice in making these kinds of predictions. Teachers should start by creating pauses in familiar routines, where future actions and outcomes are well known, and encouraging the child to 'fill in' or 'close' the routine. Once this has been established move towards slightly less routinised, but still familiar, activities with the same procedures and gradually move towards making predictions in novel situations. This last stage is unlikely to be reached unless the child also has a parallel programme of teaching about the cues one needs to attend

to in order to make predictions and which features are relevant to which predictions and which are not. Clearly this is very complex, for both the child and the teacher, but it needs to be tackled if learning is to be truly flexible and stress reduced.

Children with autism will need positive and explicit help in predicting the behaviour of others, especially other children. Open-plan classrooms where children are free to run around or move from one area of activity to another are a particular nightmare for the child who does not understand what they are doing or what they might do next. The child may sit terrified and cowed at the table or desk, flinching as others approach and carefully ordering and arranging his or her material (books, pens, rulers and so on) to try to establish some order in what seems a chaotic world. It will help if the areas of activity (the large toy play area, the book corner, the place for individual study, the place to work one to one with the teacher and so on) are all clearly labelled and the child with autism understands the 'proper' place for everything and the purpose in moving from one place to another. It will also help if the daily schedule (for that child as well as for the class as a whole) is readily available for the child to consult, usually in a visual form; this might be objects of reference on a peg, pictures in plastic pockets or attached to velcro in sequence, or a written list in a notebook, according to the level of ability.

A further cause of difficulty, however, can come from the violation of predictions based on routines. A failure to make predictions, based on an understanding of people and what they are likely to do in certain situations and a reading of the social and emotional messages they give through their facial expressions, eye contact and body posture, leads the child with autism to rely on unchanging routines as the source of security. Distress and difficult behaviour can arise whenever these routines are disturbed because there is then a concomitant failure in prediction. The long-term solution may be to increase the child's understanding of others but in the short term there needs to be a strategy for making the 'unpredictability' predictable, or at least able to be tolerated.

## **Bizarre behaviours**

Individuals with autism often behave in ways which seem bizarre. Yet behaviour only becomes bizarre when it falls outside what we 'normally' expect and it may seem less bizarre once we understand the function it is serving for the child. That is not to say that such behaviours in those with autism should be encouraged or necessarily tolerated. It is important that teachers seek to enable children with autism to manage their behaviours without using these particular strategies if, for example, they are self-damaging or antisocial. Even here, though, attempts to modify or eliminate such behaviour are likely to be more effective if they are informed by an understanding of the function of that behaviour for the child.

All children feel anxious at times and may then produce unusual or even bizarre behaviours. What sets pupils with autism apart are the kinds of events that lead to anxiety and the fact that they do not inhibit their responses in the light of other people's reactions. A child with autism may, for example, jump up and down and flap wildly when excited or anxious and, while others might feel like behaving similarly, they will not do so for fear of being ridiculed or because they realise that this may alarm others. It is this that makes the behaviour of those with autism appear unpredictable and abnormal, when in fact they are reacting in typical ways in response to extreme anxiety.

A functional analysis of the situation is the best initial step, to determine what is triggering the behaviour and what is maintaining it. This then gives a clue to the situations that are causing stress and to the functional value of the response to that individual. It is important not to ignore this functional aspect of the behaviour, nor to just classify it as deviant and attempt to eliminate it, especially not through the use of blanket aversive techniques. Aversive techniques (the use of punishers) are now seen as both unethical in themselves and ineffective in the long term so that even the most behavioural of approaches will usually look first at training and rewarding incompatible activities, or removing the triggering stimuli.

The unwanted behaviour needs to be tackled on a number of fronts, but long-lasting effects can only be gained by tackling root causes not symptoms; symptom suppression will only provide a short-term solution and in the long term may make the problem worse. At the simplest level the behaviour may be bizarre simply because it is a low level response that is all the child has in his/her repertoire e.g. the child may twirl the wheels of a car partly because s/he does not understand the symbolic significance of 'playing cars', or the child may sniff people because information from olfactory senses is easier for the child to interpret than that from vision or auditory channels. If this is understood, the behaviour may no longer seem so bizarre and the problem may 'go away' or at least be redefined as a need to help the child achieve a higher level of functioning.

If the trigger is identified as a particular noise or level of noise (or colour, or social situation etc.) then a reasonable hypothesis might be that this is an aversive stimulus for the child who is either signalling that by his/her behaviour (in other words the behaviour is a primitive form of communication, which would be a very encouraging sign) or using the behaviour to block the stimulus. This could indicate removal of the aversive stimulus either directly or by giving the child a proximal block such as ear plugs, but this is not always possible or desirable. In such a situation one would also want to give the child an alternative way of communicating distress other than through the bizarre behaviour and to try to desensitise the child to the stimulus.

Some bizarre behaviours can be tackled by teaching the child to rely less on the proximal senses of smell and touch and more on sight and sound, which are more socially acceptable. It is arguably very cruel to block a child's main way of making sense of the world and force him/her to use information from senses that s/he may find distorted and confusing. Thus, rather than just forbidding the child or preventing the child from licking or sniffing others, the teacher (having ascertained that the function of this behaviour is identification of the person) develops a programme whereby the child is taught to pay attention to the visual and auditory features by which people can be distinguished and gives the child plenty of practice in making those distinctions through those senses. Only when this way of identifying is secured, should the licking or smelling be tackled directly, if they are still used.

## **Changing behaviour**

Perhaps the first question a teacher needs to ask him or herself, then, is 'Does the behaviour need to be changed?' and then, if it does, 'Is this the right time, or should I teach something else first?'. We must always ensure that we are changing behaviour in the child's best interests (for long-term quality of life) and not just because we (or someone else) finds the behaviour disturbing.

## Reasons for changing behaviour

The teacher might consider the following reasons for deciding to change the child's behaviour, although individual circumstances will always need to be taken into account.

- **Danger:** The clearest reason for deciding to change a behaviour is where that behaviour is a danger to the child or to others. This will include severe forms of self mutilation (including a diet that is so restricted that it is a danger to health) and aggressive out- bursts such as biting, hitting and kicking. It will also include running away or climbing in dangerous places.
- **Interference:** If the behaviour is engaged in obsessively to the extent that it interferes with the child learning anything else, then this may also suggest that it needs to be controlled or changed.
- **Restriction:** In many cases, the way the child reacts to certain sit- uations means that parents or teachers end up keeping the child away from those situations and so the life of the child (and often of the family as well) becomes intolerably restricted. . Intolerable inconvenience to others: This does not mean that the teacher is just inconvenienced but that the inconvenience is so severe that the quality of life of the person is affected. It might include a child who does nothing but ask the same question repetitively at school or someone who is up all night rampaging through the house and keeping every one else awake.
- **Destruction:** There may be behaviour such as throwing things around, shredding clothes and furniture or tearing paper, which is not of itself a danger nor of direct inconvenience to others, but for which it is impossible that an institution or a home bear the continual costs.
- **Extreme social bizarreness:** The kind of behaviour considered in this category is behaviour that other people find disgusting or offensive and which might lead not only to social ostracism but even to arrest. It will vary from one society to another, but will include immodest behaviour (e.g. not wearing clothes, touching genitals in public), unhygienic behaviour (e.g. picking one's nose over food, urinating or defecating in the street, spitting) or embarrassing behaviour (e.g. sniffing someone's armpit or bot- tom, commenting aloud on someone's appearance in a derogatory way).

## Ways of changing behaviour

The habitual nature of learning in children with autism and the difficulties they experience in planning, monitoring and, above all, inhibiting their own actions places restrictions on the ways in which their behaviour can be modified or changed. In effect, there are only two broad approaches that will be effective in the long term. First is to change the setting conditions that are triggering the behaviour. Second is to prevent the child from doing the unwanted behaviour in that set situation and to train the child to do something else instead. This latter behaviour will have to be consistently rewarded in that situation until it too becomes habitual. It will be more effective in replacing the unwanted behaviour if it is very unlike it and yet involves the same body part to carry it out (e.g. the hands in the case of replacing hitting, the mouth in the case of spitting).

### Changing the setting

This is usually the easiest option to pursue in that behaviour, especially if it is well established, can be very resistant to change. It is clearest where the behaviour is limited to one particular setting. For example, if a child attacks other children only at playtimes, it would be sensible to look first for the features in that particular situation that were provoking that behaviour.

- Is the child stressed by the lack of structure?
- Is the unpredictability of the 'free play' activities of the children frightening?
- Is the sheer number and complexity of the social interactions occurring at this time simply too much?
- Are there particular triggers for the behaviour?

### Altering the behaviour

People with autism cannot alter their behaviour simply by being exhorted to do so; they need positive supports for change. Some of these may involve altering the consequences of the behaviour, but punishing the behaviour is only ever a short-term solution and may not even be that. A better approach, as indicated above, is firm prevention of the unwanted behaviour while at the same time strongly rewarding an alternative behaviour which, one hopes, will fulfil the same function and which will be incompatible (in terms of its ability to be performed) with the unwanted behaviour.

**For example**, let us take the problem of running away which can be a very common worry for parents and teachers alike when the young child with autism may expose themselves to all manner of dangers and when, as they get older, it becomes increasingly difficult to ensure that they stay by the adult's side or in the class or family group. Such behaviour is often sustained because it is difficult to prevent in all situations (except through physical restraint which becomes less acceptable as the child gets older) and may even be rewarded by adults chasing after the child since many children with autism enjoy being chased.

Two adults are needed to tackle this behaviour, plus something that will serve as a powerful reward for that child. If it is difficult to think of a reward in a form that is easily transported when out shopping or on a walk, for example, the child can first be taught to associate a rewarding activity (being able to play with water in the sink, for example, or

having a swing) with a photograph or picture of the activity and then this photo or picture can be used to stand for that reward. The child is prompted to return (on the command of the first adult) by a second adult strategically placed in a contained situation where the behaviour normally occurs. Thus, the child would be taken to a field where there was a single exit, or the end of a safe cul-de-sac. The point is that the second adult is so positioned as to prompt the child to return without chasing after him or her. The first adult then rewards the child for returning.

### **Changing the consequence**

It is seldom sufficient just to work on consequences of behaviour because children with autism find it difficult to inhibit their habitual responses to situations, even if they are being punished. Consequences are most sensibly used in changing behaviour by rewarding other incompatible behaviours that are being trained in the same situation. Nevertheless, it is important to recognise the rewards for the undesirable behaviour that may (usually unintentionally) be helping to maintain that behaviour. In the running away example used above, for example, the adult chasing after the child when he or she starts to run may be very rewarding. It is also likely that the adult will be angry and shout at the child, once the child is caught and, again, this may serve as a reward for the whole episode. Teachers need to remember that it is not the adult's intention that counts (to punish the child for running away) but the actual effect. Many children with autism will perform actions deliberately just to get the predictable effect of someone displaying anger. This usually produces a more interesting and considerably more predictable response than trying to please, so it is not surprising if children with autism (in their effort to keep control) often do things that will provoke an angry response.

### **Conclusion**

Behaviour problems can often seem the most pressing issue in trying to teach children with autism. However, just as with all other aspects of teaching these children, the behaviour cannot be tackled effectively without an understanding of its causes and the functions it serves for the child. The most useful approach is to try to treat the unwanted behaviour as a form of communication and to teach the child a more acceptable way of communicating whatever it is that has been identified as the purpose of the behaviour.

Difficulties in inhibiting behaviour mean that approaches based on punishment are seldom effective and, even if they work initially, the behaviour is likely to return. Settings may be easier to change than behaviour and the teacher always needs first to assure themselves of the necessity for change. In a world that is largely confusing, it is not surprising if the child acts in ways that produce predictable responses, regardless of the nature of those responses. Teachers need to try to understand how the child is perceiving the situation in order to understand the causes of the behaviour and the approach to modification that is likely to work best.

## Chapter 7

### WORKING WITH EMOTIONS

#### Basic difficulty with emotions

Since Kanner's original description (1943), emotional difficulties have been seen as at the heart of autism. It is not just that children with autism have difficulties in reading the emotions of others and in reflecting on their own, but that the emotional link with perception and thinking is disturbed. Thus, there are difficulties in understanding and dealing with emotions but also in attaching personal meaning to what is perceived. It is this latter problem that leads to a range of learning difficulties in the classroom.

#### Recognition of Emotional Cues

Children with autism, to a greater or lesser extent, fail to appreciate or respond to the feelings and emotions expressed by others or, if they do, the response may be unusual and lacking in empathy. This makes it difficult for the child with autism to develop friendships and may lead to the child performing actions which appear cruel but in reality reflect a lack of understanding. For example, the sound of someone crying may appear peculiar to the child with autism and cause him or her to laugh.

#### Teaching

Systematic teaching about emotions tends to concentrate on outward forms and children with autism can be taught to identify stereotypical facial expressions for the more visible emotions such as 'happy', 'sad', 'surprised' and 'angry'. However, this does not help them to identify these emotions in themselves, nor more subtle emotions not tied to an obvious facial expression (such as embarrassment) nor such subtleties as 'a brave/false smile' or someone 'crying with joy'.

Behavioural programmes can be used initially just to draw the child's attention to people's facial expressions in social situations and some have been successful in getting the child to self reward for identifying certain expressions such as greetings through smiles. Once the child has begun to notice such expressions this is an important step towards teaching the social and emotional meaning but real understanding has to come from identifying real emotions in themselves and in others.

Naturally occurring unambiguous emotional events can be used to teach about emotions by drawing the children's attention to their physical manifestations of the emotions in situations that are meaningful. This may be done by making them aware of how they look (immediately, through mirrors and in reflection through photos or a video), how their body is reacting (sweating palms, trembling legs, pounding heart, for example, when fearful) and the context that further refines the meaning of the emotion.

## **Physical withdrawal**

There are many reports of aloofness and avoidance of physical contact among children with autism, although it is not true that all will behave in this way; some may respond to the initiations of others and some may seek contact constantly, although they are not sensitive to the reactions of others. In fact, although children with autism rarely initiate social encounters some can tolerate a fair degree of proximity and close physical contact while most may need specific teaching and desensitisation for this. Even in those who have learnt to socialise to some extent, however, there may be a danger in underestimating the stress social contact causes for individuals with autism who, on the surface, seem to be coping. They may cope in one situation under extreme pressure but then explode when the pressure is released (often at home).

## **Teaching**

Some approaches allow the child space to withdraw initially but then encroach on this through a structured and graded programme. Other approaches adopt the reverse strategy of not allowing the child to withdraw and insisting on joining in with the chosen activity, albeit in a loving and accepting way. Structured and directed approaches have been found to be more effective than a laissez-faire style of teaching but a varied programme may be best. Some periods of allowing the child to set the pace and offering low intrusion should help improve spontaneous social overtures whereas a more forceful elicitation from time to time may result in more pro-social behaviour being learnt, which in turn increases the amount of social interaction occurring.

Teachers may well be confused about whether the children should be persuaded or even coerced to join a social group if they do not spontaneously do so. It is a matter of establishing that the child has a genuine informed choice. Thus, the child should only be left undisturbed in a withdrawn state if it is clear that that child:

- is not frightened or confused by others
- knows how to join a group and to maintain group interaction
- has chosen to be alone in a positive sense.

## **Attending to meaning**

One less obvious difficulty with emotions lies in appraising events for personal significance and thus attaching meaning to them. Failures in the initial socialisation process also mean that children with autism have difficulty in attending to the same social and cultural meanings as other people. Part of the educational goal, therefore, will need to be directed towards helping the child decipher social meanings and understand the world about them in the same way as others do (or at least be aware that others have alternative interpretations to their own).

However, it will be even more difficult for them to learn to appreciate the way in which others see the world than it is for us to appreciate their perspective and way of seeing. We need, therefore, to start by following their interests and levels of understanding because this will be the only way they have of seeing meaning. Just as we do, children with autism will respond to meaningless tasks with increased rigidity.

## Teaching

We can give them ways of coping with meaninglessness through the visual structure of the TEACCH approach, for example (Peeters, 1997) but we should also try to give them some experience of learning through their own sense of meaning. Thus, we can join with them in favourite activities such as spinning or rocking or in rough and tumble play or we can work with them on the computer or constructing things. Rather than expect them to direct their interest to activities we have chosen and directed, we can direct our attention to their focus and so begin the experience of shared interest.

- **Motivation:** For the same kinds of reasons given above, much of what children with autism will be required to do in school will not be intrinsically motivating. Nor will they be able to access social motivation by doing things with their friends, nor build on the relationship with the teacher that is the foundation for most learning in school. The social-cognitive problem then leads to an apparent lack of motivation in the autistic individual, which can be interpreted by the adult as 'laziness' or 'awkwardness'. Often it seems that children with autism are not motivated to learn. In fact, the problem is largely a social one in as much as what they lack is motivation towards 'other-directed' or 'socially meaningful' tasks. If we can latch onto the motivation the child already has, this is liable to be more effective in the long run than relying on adding in additional external rewards to try to increase motivation.
- **Stress:** Continually being faced with work that you do not understand and which has no meaning or pleasure for you is a recognised source of stress. The child with autism is likely to be suffering from a high degree of stress already and this will further interfere with the capacity to learn and to be flexible in that learning. Building on what the child can already do and is interested in will help reduce the stress and thus improve the child's potential to learn.
- **Planning:** One of the difficulties experienced by pupils with autism in their learning is in being aware of their own intentions and using that sense of purpose to monitor and guide behaviour. Teaching, therefore, should seek to compensate for this difficulty by providing compensatory strategies that help the child focus on the goal. The visual medium is usually the medium of choice for this in children with autism and pictures of the desired end state (and a set of pictures of stages in the task which the child can sequence before starting the task) will help develop this planning process. More able, and more verbally able, children will be able to use verbal (written or spoken) means to plan explicitly, but they need to be taught how to do this and they need an explicit programme to do so.

## Managing emotions

The most obvious emotional difficulty in autism is often the uninhibited and inappropriate way they are expressed. Full control of emotional expression will probably only come from understanding about emotions and developing the ability to monitor them, but this is a long term goal that will not be achievable for many with autism. In order to create a situation in which the child with autism and his or her peers can learn, therefore, there needs to be direct teaching of strategies for managing emotions.

### Teaching

**Alternative means:** Where the child is expressing an emotion in an inappropriate or unacceptable way, a priority is to teach an alternative mode of expression. For example, frustration is an emotion that often provokes the child with autism to show self mutilation (biting themselves, head-banging, pulling out their hair) or aggression to others. As indicated in an earlier chapter, it is seldom effective to try to prevent the emotion through exhortation or punishment and nor is it desirable to do so. It is better to show the children that you recognise their emotion (in words, by labelling it for them and in a mirror perhaps to show them what they look like when they are frustrated) and to show them an alternative way of expressing it. Depending on the circumstances, this might be hitting a cushion, banging a drum, going outside to run round the playground, counting to ten in order to calm down and so on.

**Increasing understanding and monitoring:** The more the child is able to reflect on his or her own emotions, the easier they will be to control. However, this is a key difficulty in autism and is likely to need teaching over a number of years. As in the example above, teaching opportunities should be taken whenever the child is clearly expressing an emotion. The teacher needs to label that emotion for the child, point out for them the physical manifestations and the triggers that can be identified in that situation e.g. "You made a mistake in your sum and that made you frustrated" or "It is someone else's turn to be first in the queue and you are frustrated because you can't be first".

The teacher should observe situations closely where past experience indicates that certain emotions will be provoked and seek to identify the earliest signs of emotional arousal in the child. The next step is to teach the child to identify these same early signs in him or herself and to teach a strategy for preventing the full blown escalation of the emotion. For example, the early signs of frustration or anger might be an increase in heart-rate and restlessness. These can be used as signs that the child needs to have a turn running around a field or pedalling on a bicycle or retreating to a quiet corner with a cushion where they can learn to calm down.

**Calming techniques:** Teachers can drill young children into certain postures that help them control their own reactions and can be used by teachers to prevent or stop an emotional outburst. The signal for such postures should be clear and definite and might be a word or short phrase (e.g. "Hands by side!" or "Sit!") or even a whistle. Older children with greater verbal ability can be taught to talk themselves into a calmer state through the use of a repetitive phrase (e.g. "Keep calm!" or "It's all right now") or counting.

## **Sexuality**

Many people with autism will not be aware of themselves as sexual beings at all and for this group, in consultation with parents, it is probably better that sexual interest is not explicitly developed; sex education will centre, then, on dealing with issues of hygiene, safety and privacy only. These are difficult enough to teach, where there is little understanding but further problems arise with those who have no interest in others sexually but do have clear sexual needs. Then it is the teacher's (and/or parent's) role to ensure they have a means of expressing those needs.

In effect this means teaching adolescents and young adults how to masturbate and this presents both practical and moral problems. Some of the more able will have an apparent sexual interest in others but often this has more to do with wanting to be like other people and copy the behaviour they see around them, than a genuine interest in a relationship. All these issues will be closely bound up with the cultural and ethical values of the society in which they live, but the fundamental issues of coming to terms with their own sexuality need to be faced, whatever the mores of the culture.

## **Coping with bodily changes and feelings**

The minimum that all individuals with autism will need to learn is how to follow (if not always fully understanding) the social rules of any society for privacy and discretion. This will apply to dealing with menstruation but it will also apply to masturbatory behaviour in those who have the need. It may be appropriate (according to the rules of the society) to teach 'waiting' for an appropriate time and place by teaching distracting or sublimating behaviour. Whether such behaviour can ever permanently take the place of sexual expression is doubtful, but that is an issue that will need to be faced in societies where masturbation is against ethical or religious codes.

Teaching the notion of 'private' usually begins in relation to toileting and hygiene, long before puberty. Children should be taught to perform toileting functions in private and to make sure their clothing is properly adjusted before leaving the toilet area. Those with speech will also need to be taught that this idea of privacy applies to talking about toilet issues or menstruation and that girls should look for a female adult (preferably her key worker when at school, but a variety of females according to who is available) and tell her about starting menstruating in a quiet voice. All this will need many weeks of practice both as a form of role play before the event and then with prompting and modelling after the event. Boys will need to be taught about wet dreams in the same practical way so they are not upset by thinking they have 'wet the bed' or feeling out of control of their bodies.

It is important that the training concerns what to do rather than what not to do. If the training had centred on the negative, this would not only make it more difficult to learn the correct behaviour, but there would also be the danger that the child might realise that this is a behaviour with which he or she can control the adults. This might then have resulted in an increase in the 'embarrassing' behaviour simply because of its effect.

## **Sex education**

Where there appears a need for full sex education, ethical problems arise in that the teacher may have to come to terms with the fact that some individuals may never develop caring relationships with others and yet may want to have a sexual relationship. The problem is, then, whether one should teach practice that would enhance the quality of life of the individual and be in line with accepted norms in some societies at least but which may be against the moral principles of the teacher and the values laid down by that same society (and possibly the law) for schools to inculcate.

Each school should, in collaboration with parents, work out its own policy for sex education. It is important to remember the difficulties people with autism will have in understanding their own needs and the needs of others and how their behaviour, in its naivete, may well make them vulnerable to abuse. There will also be rarer cases where they may abuse others, due to lack of understanding rather than evil intent.

Keeping children safe from sexual abuse must be a high priority in the teaching about sexual behaviour. Many schemes and packages for education in this area involve getting children to be assertive and say "No!" whenever they are made to feel uncomfortable about what someone asks them to do. This is difficult to achieve in autism where children have little insight into the way they are feeling and even greater difficulty in expressing it. Nor is it desirable to teach a general fear of strangers because this would counter all the teaching undertaken to make the children more sociable and still leave them vulnerable to abuse from relatives or familiar adults.

However, the notion of privacy as applied to bodily functions can be used to give children a clue to the kinds of behaviour to which they should say "No!" and refuse to comply. This is again problematic because the teacher may have spent a lot of time in other contexts teaching the child to obey commands and be compliant. It is difficult to get children to discriminate the situations to which these different responses are required. Since safety has high priority, these confusions must be risked and children taught that if people (other than a specified group to include same-sex parent, key worker, doctor and nurse) try to touch them in personal areas or talk about doing so they should say "No" and tell a relevant adult (key worker/parent). This can be accomplished through various role play scenarios, although results are variable, depending on the ability of the child to learn in this way.

In practice, it is also desirable, in order to retain the benefits from the child's increasing affectionate contact that may have been developed over the years, to teach the kinds of touching and affectionate contact that are permissible with anyone and those that must only be allowed with a few restricted others. The problem of identifying intimates can be tackled with an initial list as indicated above. Later, children can be taught that when they have known someone for a long time (defined as more than ten visits) they can discuss with their key worker or parent whether such a person might become an intimate.

## **Bereavement**

Bereavement presents two kinds of problem in autism. One is concerned with how children can be helped to deal with their emotions and their lack of understanding when someone dies. The other is how teachers may better understand the reactions of children with autism to the loss of an object or routine.

## **Coping with death**

Children with autism are often attached to familiar people in their own way but their way of expressing this attachment may be unusual and so others may not appreciate the degree of their loss when someone dies. Their feelings of loss may be made worse by their lack of understanding, not just of death (common to most children) but also of their own emotional state and that of others. The difficulties are compounded where the child does not understand or use speech, but even those with speech may find the euphemistic language confusing and misleading.

One child, for example, started a habit of insisting on going up into people's attics whenever the family was visiting, following his grand- father's death. This bizarre behaviour was only explained when his brother revealed that he had told his brother that his grandfather had gone 'up there', pointing to the sky. The nearest tangible space to the sky, in the view of the child with autism, was an attic so he was looking for his grandfather in every attic he came across. Once this was realised, his parents had to talk to him about what it means to die (using plants, insects, family pets and other people as examples) and how his grandfather would not be coming back, but could be remembered and thought about by looking at photographs and talking about what he used to do. Children with autism will need to have these ways of remembering spelled out for them rather than just being told misleading things like "Your grandad will live on in our memories".

Yet the very difficulties inherent in autism can be used in helping the child come to terms with the loss. To some extent, we all miss people in relation to the activities we used to do together and the more of our lives we shared, the greater will be our sense of loss. This is even more so in autism where a person's identity is even more closely bound up with what they do rather than who they are. If we recognise then, that it is the dead person's behaviour that is the main focus of the child's distress, we can think of ways of replacing that behaviour with someone else and so help the child get over what is, nevertheless, genuine grief.

## **Loss of objects and routines**

Our normal categorisation of an attachment to objects or routines is that of 'obsession' and so we do not always recognise or allow for the very real sense of bereavement that the child with autism may feel when such an object is lost or such a routine disrupted or prevented. It is uncomfortable for teachers, and even more so for parents, to realise that such objects and routines may mean more to the child than other people do, but, until that is accepted, the loss in these situations will be trivi- alised and not dealt with effectively. Recognising what such a loss means for the child, helps us to think of solutions, and

makes us more cautious about removing items to control behaviour. In the case of a genuinely lost object, teachers should try to identify the root of the attachment for the child. Is it to do with the way the object, looked/ tasted/ felt./ sounded, or what the object did or could be made to do? Then the teacher can look for other objects that share those properties, although this will require trying to see the object from the child's perspective. Even when a close match has been found, it will not necessarily be accepted as a substitute and the teacher may need to institute a specific training programme to reveal these desirable properties to the child (prompting and rewarding the child for holding the new object, for example, to experience what it feels like).

## **Conclusion**

Emotional difficulties are at the heart of autism and they do not just affect the individual's relationships with others but also the way people with autism relate to the world and establish meaning within it. Teachers need to address this difficulty directly by using emotionally charged situations to teach about emotions but they also need to help pupils control their own emotional outbursts and to use their emotions more constructively in the emotional appraisal that is so essential to attributing meaning. Dealing with bereavement and the problems that come from sexual development needs to include an appreciation of the particular perspective stemming from autism.

## **Chapter 8**

### **DEVELOPING LIFE AND LEISURE SKILLS AND EXPERIENCES**

#### **Education for life**

People with autism continue to learn and develop through life and education has a role in all areas of development because they will need to be taught so much that others will learn naturally. Whether or not individuals with autism will be able to have paid employment in adult life will depend on the vocational and social skills they acquire and the cultural context of the work situation. In industrial areas with complex social conditions it may be impossible for the person with autism to have a job because they cannot manage the social and cultural environment that is part of the work situation. In rural areas the pace of life and the fewer social pressures may make it easier to have a job but there may be fewer jobs to be had. Teachers need to develop each child's academic and special skills as far as possible to increase employment opportunities, but it also needs to be remembered that a lack of appropriate social skills and understanding is likely to be a greater barrier to getting a job than any skill deficiency.

Whether or not people with autism have a job, they will still need to be taught how to manage their lives as independently as possible and to occupy themselves in their leisure periods. The problem of occupation starts in the school years as parents find the need for continual 'entertainment' and vigilance increasingly burdensome and the child reacts to being bored by engaging in unwanted or even disturbing behaviours. One recognised cause of self mutilation, for example, is boredom. It is not just a matter of having things available for the child to do; the child needs to be taught how to do them and when.

Education then has an important role beyond the teaching of academic skills; it must teach skills and understandings as a preparation for life. It will be easier to see this where the child has additional general learning difficulties, but even those with good intellectual and academic ability will need this kind of education if they are to lead a full life. Education, then, should include programmes to develop leisure interests, improve job opportunities, develop new skills and knowledge, to help them express themselves in new ways and for sheer enjoyment.

#### **Functional life skills**

Those providing services and care for children with autism are necessarily involved in the teaching of functional life skills or the management of those skills, no matter whether they are teachers or carers. Because of the difficulties in transferring learning and in making sense of what they are taught, it will be best if these skills can be taught in the context where they will be used. This will mean that the home context is often the most effective one for teaching domestic and self care skills but it must be remembered that this is a skilled teaching job and it cannot be expected that parents or other carers will necessarily be able to manage this without help and guidance. Home school

collaboration is even more important in autism than in other areas of education. In spite of this there may be some situations where it is better if educational sessions take place at school, at least at first. Thus toilet training, for example, could be tackled first at school and only introduced into the home once the child has established some control and seems to understand the process. This is because it may be difficult for parents to keep accurate records to determine when would be a good time to try the child on the potty and to remain calm in the face of 'accidents' in the home. The reverse might be true for teaching the child to go to bed to sleep, for example, since this is artificial in the school context and has more chance of success at the end of the day.

### **Examples of life skills programmes:**

**Getting dressed in the morning:** Many children with autism have very set ideas about what they will wear and/or find many kinds of clothing uncomfortable. They may also have problems with visual spatial orientation in relation to their own body and with sequencing in time so the actual act of dressing is problematic. Added to this may be difficulties in timing actions, in being motivated to achieve an end they cannot visualise and to a time constraint that has no meaning for them. All this can add up to a severe problem when it comes to getting dressed in the morning in time to go to school. Many a day starts with nagging and frustration on the part of the parent (often conveyed to the child) or the parent simply gives up and forcefully dresses the child.

In such a scenario, the first step, as always, is to identify the sources of difficulty for the child. It may also be sensible to start to train dressing skills at school when an open-ended period of time can be devoted to it and when there is not the emotional tension of needing the child to be ready in time for school. Then the following possible sources of difficulty need to be checked:

- **reluctance to wear clothes:** look for button thread, labels, clothes that are tight that are wrinkled, or consider the child's skin condition.
- **problems in left right orientation:** use body awareness exercises in PE and/or self massage with oils. Then use backward chaining whereby the adult physically helps the child perform the action right up to the last stage and then the child is rewarded strongly for simply performing the last bit. As each step is mastered, the adult stops at the one before until eventually the child is doing it for him or herself.
- **panic in getting things over the head:** use wide necks with fastenings and/or give children practice at closing their eyes and a programme of desensitisation to the use of blindfolds.
- **the skill is too advanced:** change the goal from self dressing to one of cooperation during dressing. This involves a desensitisation programme so that contact is tolerated, then movement together, then physically guided movement and finally allowing oneself to be dressed.
- **sequencing in time:** teach an invariant order at first and then the rule about clothes that are worn next to the body going on first.
- **no goal directedness:** the child may start dressing but then stop half way. Photographs of the child at different stages in the process of getting dressed and when fully dressed can help, if the final picture is used as a token for a reward (time on the swings, a favourite piece of music, a special drink, for example).
- **no sense of time:** do not allow the state of undress to let the child 'get out of or

delay an unwanted activity. Arrange some set period of a pleasurable activity (such as watching a favourite video, listening to music, rocking in a chair, eating a special treat) that can only be indulged in when fully dressed before it is time to go to the activity.

**Toilet training:** There is nothing autism-specific about toilet training except that associated motor difficulties or a difficulty in digesting foods may lead to problems of constipation or diarrhea and this can cause problems. There is also the problem that the child will not be motivated to 'grow up' or be aware of the social stigma of being in nappies or wetting oneself. A toilet training programme for a young boy with autism, then, might have the following steps: Check regularly and look for patterns in wetting and soiling.

- If he uses a nappy, use the most frequent times to sit him on the potty (in the nappy).
- Take off his nappy at such times and place it in the bottom of the potty. Give additional specific rewards when he performs.
- Take away his nappy and reward him in the same way for using the potty.
- If he does not use his nappy, introduce the pot in a favourite place for performing. Prompt or encourage sitting on the potty for a few seconds, reward him and continue until he is sitting successfully for a reasonable period. Then reward him for performing in the same way as indicated above.
- Reward him for emptying his potty into the toilet.
- Move the potty next to the toilet.
- Encourage or prompt the child to use the toilet.

## **Leisure Skills and Activities**

The main difficulty with leisure activities for the child with autism is that they are usually unstructured. It is this that is often the hallmark of a leisure or play activity - that it is open ended, with no set goal and no set agenda. These very attributes, that make leisure so attractive and different from work for most of us, will lead to difficulties and stress in children with autism. This major source of difficulty also suggests one solution for making leisure activities more accessible to children with autism: these activities can also be structured just as one might a task to be done.

### **Structure**

This reduces stress by showing the child exactly where, when and what to do as well as how to do it. This can be done most effectively through the use of visual cues such as pictures and the use of room dividers (bookcases or desks arranged appropriately will suffice) to separate different activity areas. Just as the child may have a visual schedule for the daily programme at school, so teachers will need to help parents devise a similar schedule for leisure time in the evenings and at weekends. Where there are household tasks to be done, parents should be assisted in training the child to perform these tasks in an ordered way. This enables the child to have a role in the family similar to his or her siblings and may be more enjoyable for the child, who has something concrete to do, than trying to occupy him or herself at play.

## **Buddies**

Having a 'friend' can help the child with autism mix with other children and engage in a range of leisure pursuits that would not otherwise be accessible. The problem is that children with autism do not know how to make friends or to keep them and this initial difficulty deprives them of the very experiences they need in order to foster friendship and develop interests that are shared by others. Where children are in mixed settings (whether this is in mainstream or with other children with different special needs) or have access to them, other children can be encouraged to be their 'friends' and to help introduce them to others and activities.

This cannot be left to chance for children with autism are not always attractive playmates and other children may be cautious or even frightened of them. The teacher needs to establish some kind of buddy scheme whereby other children (usually on a rote basis, since it is a big responsibility for one child to handle on a daily basis) are told about the 'specialness' of the child with autism and how to react to some of the behaviours they may experience. They then 'look after' the child with autism during school breaks, protect him or her from bullying and help to explain and interpret the social world. Some schemes have formalised the buddy system by having normally developing children sign up for a special scheme where they have a badge and where their community efforts are noted on their own record of achievement. Other schemes have been just as successful by relying on children's natural good nature and eagerness to help, once they understand that the child has a problem and is not just being nasty to them.

## **Building on strengths**

If the child has a particular skill or a strong interest, then it is sensible to build on this in his or her leisure activities. The social situation will be hard enough for the child with autism to cope with without also learning a new skill so it makes sense to use what the child already has. Some teachers, however, are worried that if they let the children pursue their obsessive interest freely in their leisure time then they will become increasingly obsessed by it and it will be difficult to get them to do anything else. Parents too may worry and feel guilty when they see their child engaged in what seems to them a mindless activity and feel that they ought to be occupying him or her with something more productive. There are several issues here.

## **Should obsessions be indulged?**

It is true that children with autism do not seem to tire of obsessive activities in the way that other children do and it certainly does not often reduce a behaviour by trying to satiate it (e.g. giving the child an end- less supply of paper to tear does not seem to have any effect on that child's motivation and ability to tear other paper, from precious files, or off the walls). Obsessions do sometimes go but they seem to go abruptly rather than just fade away and they are often replaced by another one. Occasionally they may return as abruptly as they were discarded.

It seems, therefore, that obsessive behaviour is relatively independent of people's reactions to it; it appears to serve the internal needs of the child, although it too becomes habitual and triggered by certain situations. Since there is no evidence that allowing the child to engage in an obsessive behaviour either increases or decreases the likelihood of

that behaviour occurring, it would be cruel to prevent a favourite activity as long as it was not hurting anyone or restricting the child's opportunities to learn. Thus, it is reasonable to limit obsessive behaviour at school, when the child should be more profitably engaged and parents may forbid it during times when they wish to do something else with their child. But at the end of a long hard day, most people need to relax with a familiar routine and the child with autism may be more in need of that kind of relaxation than anyone.

### **How can obsessions be used?**

Rather than attempting to prevent or restrict an obsessive activity, a teacher or parent may decide to use it to further the child's development. The adult may join in the obsessive act, imitating the child and indicating through his or her actions that whatever the child does is going to be taken as a signal for playing this imitation and turn-taking game. If this is done with enthusiasm and a sense of fun, as in joining in a game, then mutual enjoyment often ensues and this can be a valuable way of building relationships. Imitating the child will lead to an increase in eye gaze and an awareness of turn taking and the social timing that goes with it. Imitation of the child also puts the child in control and makes the adult more predictable so social interaction is no longer fearful (at least with that adult) and may even be sought.

Obsessions may also be used in a more behavioural way by using them as rewards for less favoured activities. The child with autism will not understand words like 'later' or 'after work', however, nor will he or she trust the activity to return once it is removed. For such a strategy to succeed, therefore, there needs to be a pictorial representation of the activity to be performed and then the obsessive 'reward'. Once the pattern of 'work then play' has been established, the work period may be extended to more than one activity (in stages) but there will still need to be a visual reminder of when it can be indulged in again, for most children with autism.

The third way of using obsessions productively is to build on them to form more productive behaviour which may eventually be used as the basis for a career. Thus, some talented individuals with autism have learnt to use their talent to make a living as artists, as musicians, as cartographers or even as engineers. For those without a special talent that can be built upon in this way, there may still be creative ways to incorporate an obsessive behaviour into a more useful activity. Obsessive lining up, for example has been converted into sorting and grading which eventually led to a job packing cutlery for a catering firm. Twiddling threads was converted (after skilled teaching for many years) into spinning and helping to make items for a craft shop.

## **Play**

Children with autism typically show impoverished play behaviour and a failure to learn by imitation. A failure to learn to play socially is also important in adding to the social and emotional difficulties of the child. Without such play, the child with autism will find it even more difficult to learn about social roles, about sharing interests and activities, and will not be able to practise and rehearse the emotional dramas of life. Early lap play is the context for mutual arousal in joint routines whereby children learn to explore the emotional reactions of others and to use these in their own reactions to novel or created situations. Again, this early play seems to be disturbed in autism.

### **Sensorimotor Play**

If there is any play behaviour at all in autism, then it tends to be where the child manipulates an object in a way that explores its physical properties but does not necessarily take account of its function. Such play is often repetitious, involving simple actions such as mouthing, hitting or banging. Children with autism may even become fixated on just one mode of exploration or one object to explore. Those with additional profound and/or multiple learning difficulties are likely to withdraw into a self-stimulatory world wherein, they can impose their own of regularity by, for example, spinning the wheels of a toy car round and round or twiddling a bit of fluff. It may be that attempts by others to intrude into this world may be met by aggression, if intrusion means the introduction of the unpredictable into the predictability that the individual has managed to create for him/herself. On the other hand, sharing in the child's activities in a predictable way can lead to shared experience of pleasure which is a good basis for further learning and development.

Play without objects is even more primitive and will include rocking, and typical rough and tumble play, such as being tossed in the air, being swung round and being tickled. Some children with autism will only enjoy this kind of play and will continually seek it out, jumping on adults or peers, pulling at hands or placing hands on their own bodies in order to be tickled. Such behaviour is liable to frighten peers and may result in even greater isolation. Other children with autism, however, far from seeking this activity, are fearful of being lifted or being off the ground in any way, or are not able to tolerate touch. They will resist any attempts by others to engage them in such play and may feel that others are attacking them (and so strike back) even though the other children are trying to include them in their games.

Teachers should be aware that these primitive forms of interacting with the world often provide comfort and pleasure for the child with autism, even when they have developed other ways of playing. This is especially likely to be the case in stressful situations or when there is little else to do.

## Teaching

If the play is very limited, so that the children are not even using different objects in their play nor varying the actions with them, then teaching will be needed to extend this play. As with all other ways of modifying behaviour, the child needs to be taught other ways of behaving first, before limiting the old way. Thus new toys can be introduced and the child rewarded for playing with them, before the old obsessional toys are removed or restricted.

Another way of developing flexibility in play and extending it beyond simple perseverative routines is through a step by step approach, changing one element of a task at a time. In this way, there is enough predictability for the child to accept the change, but the play is gradually extended. One might start with making a small change in the materials being used (colour or size change, for example) and when significant variations in that dimension have been accepted, move on to other changes both in the materials and then in the actions engaged in. This is more difficult to change but may be done through joining in with the child's actions in an enthusiastic way and then making small modifications, which the child is encouraged to imitate in turn.

Helping the child form relationships through early forms of lap play can be valuable but needs to be structured and supported; it is not simply a matter of re-exposing them to supposedly 'missed' opportunities for interaction. We need to slow the interactions and make the structure more emphatic and accessible for them. This can be done by dramatic accentuation of the normal interactive routines, but more common are approaches that use music to accentuate the structure and help engage the child emotionally in the activity. In one approach, live music is used to emphasise and make predictable the interactive moves between the child and the caregiver or teacher.

Group or class sessions are also used where there are singing or musical games involving closure, structuring the interactions between a child and an adult, two children or even a group of children. Similar approaches use techniques of imitating the child to build up interactive routines and help the adult share the child's focus of attention and emotional involvement. Rough and tumble play or chasing games are usually appreciated by the child with autism and can be structured by the teacher to involve training in turn-taking, eye contact and sharing pleasure.

Where children with autism are inappropriately boisterous in their attempts to join in with others, teaching will just involve control of this so that they do not frighten or hurt other children plus the use of such play as the context for learning. It can, for example, be used to help the child learn to ask for 'more', to learn to take turns and to learn about the self and others. Forms of rough and tumble play may also provide a context for coping with the stress of social situations, structuring them and offering enjoyment for all, especially in a more exciting context as, for example, play on a large inflatable.

On the contrary, children who are fearful of others will need to be taught play only as a form of desensitisation and a way of making contact with others. Training for coping with mixed settings, for example might include special sessions in which the teenage boys with autism are taught to 'jostle' one another when sitting together on a form or standing in a queue and to tolerate being jostled. This helps them to participate in integrated settings and to avoid them being distressed when jostled in such settings. Under stress,

it is common for us all to revert to more primitive forms of behaviour. This is true of those with autism also, and so the older child with autism may still need periods of a calming activity (perhaps a turn on the swing, perhaps a rock in the rocking chair) following a period of stress.

## **Exploratory Play**

This kind of play involves piling objects up (e.g. stacking bricks), placing objects inside each other (e.g. nesting beakers) screwing and unscrewing lids, turning handles or locks and so on. Through such play the child learns to understand, and assert control over, the environment, and to develop a sense of self agency.

Some children with autism do explore the world in a purposeful way but others, especially those with additional learning difficulties, do not. In this latter group, their play may be dominated by sensorimotor behaviour or there may be perceptual abnormalities that interfere with this exploration.

## **Teaching**

There may be an increase in exploratory behaviour in children with autism if sensory play can be suppressed but this needs to be supported by attempts to train alternative novel or creative, as opposed to stereotyped, play behaviours and then to use differential reinforcement to encourage the kind of play wanted. However, there is a danger that there is a lack of generalisation, and all the child learns to do is perform the specific trained acts in specific (rewarded) situations. The teacher will need to look for opportunities outside the training sessions to cue and reward examples of exploratory behaviour.

Children can also be encouraged to play in new ways by hiding favourite items inside containers which have different ways of opening (a lid that needs to be turned, a lock and key, a push-button opening etc.) in front of the child. This can become a game so that the hiding and finding is of itself rewarding and then the child can be prompted to hide things from the adult, who must then retrieve them. In the process the child will learn more about how to place things in things, behind things and under things; they will, in fact, be learning how to relate objects to one another in space as well as learning valuable turn-taking and social skills with the adult.

## **Pretend Play**

Pretend play involves both functional and symbolic play. Functional play is the ability to treat an object as it's function denotes even if it is a toy version of this object (e.g. doll play, play with toy cars). Symbolic play, on the other hand, shows the capacity to treat objects or situations as if they are something else. This would mean for example treating a stick as if it were a baby or a stone as if it were a car. Children with autism do not spontaneously engage in pretend play with others, although they may learn to perform certain actions from peers or from direct teaching.

## **Teaching**

Pretend play can be developed in children with autism through behaviour modification techniques and this can be useful in that it may help the child engage with other children. This can prevent some of the secondary problems that arise from social isolation as well as giving the child the chance to learn about pretence through experience. It should not be dismissed because it does not lead to full understanding initially.

In one integrated setting, a child with autism was 'playing' in the home corner with his peers. At one point a child picks up the toy telephone, holds it to his ear and then gives it to the child with autism, saying "It's your mum". It is clear that, as the child with autism takes the phone, he has forgotten about 'pretence' (about which he has been having lessons in his 1 to 1 sessions with his teacher) and expects to hear his mother on the phone. There is a moment's bemusement and then the light dawns and he asks his 'friends' "Is this pretend?". A few moments later his playmates announce that they are all going to feed the birds and again there is a moment of puzzlement but he quickly smiles and asks again "Is this pretend?" Thus, he is learning about pretence in an experiential way and with continual opportunities to check his growing understanding and gain reassurance.

Children with autism may also engage in pretend play if their initial involvement is cued and the sessions are given structure. They need to know what to do, where, when and with whom, and picture sequences of little play scenarios (putting a dolly to bed, having a pretend tea party etc.) can be worked on in 1:1 sessions with an adult before helping the child transfer these skills to play with other children. However, it is important that the 1:1 sessions with the adult include some adult involvement or the children will just learn to perform the routines mechanically on their own and then will not be able to adjust to include other children in the play situation.

## **Playing games**

Children with autism have some considerable difficulty with team games (like football) where there needs to be some social and cultural understanding. Thus football involves knowing that you are part of a team, understanding both competition and collaboration, processing rapidly changing information, reacting quickly and so on. All of these skills will be problematic in autism.

Some board games (e.g. chess) are more to do with logic, spatial awareness and maths than with understanding people and these will often be grasped by the child with autism. It can also help the child learn to play with others if the children themselves make up the rules of the game. Personal involvement and meaning make tasks easy to remember and this can be an effective strategy, especially for the more able children. The child with autism may need help in making the rules explicit, however, so that other children can participate.

## **Conclusion**

The distinction between school-based and home-based programmes cannot be maintained and most teaching and learning has to cross both contexts if it is to be effective in improving the child's quality of life, both currently and in the future. Teachers will need to help parents devise effective programmes for daily life skills as well as play and leisure activities. Parents may share the strategies they have found effective in working with their child at home. Whatever programmes are adopted cannot be merely concerned with altering behaviour (although behavioural techniques may form part of the programme); they must include an understanding of the particular difficulties the child is experiencing related to his or her autism and to any additional learning difficulties. However, this area, more than any other, also allows the teacher to focus on the child's strengths as well as weaknesses and to devise programmes that both enhance skills and social interaction. 1

## Chapter 9

### MODELS OF PRACTICE

#### Introduction

Although this book has attempted to be aware of different cultural perspectives, it is clearly rooted in the context of a country which led the world in the establishment of services for children with autism and has a well developed educational framework for children with special needs. However, children with autism are found in all countries in the world with different cultural expectations, different attitudes to education and disability and very different levels of resources. In this chapter some contrasting perspectives are given of the educational provision for children with autism in four different countries.

These have been chosen because they represent examples of good practice in very different situations. From the Basque area of Spain there is a well developed and resourced service based on a parents' organization and following principles of integrated services. In France, there is the perspective of someone who has established a service for the diagnosis and education of people with autism and the training of professional staff to work with them. This has been pioneering work asserting the value of education in treating autism against a background cultural view of autism as an emotional illness requiring psychotherapy.

From Hungary is the equally remarkable story of someone who has set up comprehensive services from scratch and where funding has also had to be raised. The services provided have been diagnosis, family support, education, adult day care and finally the training of professionals. Finally, is the story from one of the longest established schools in South Africa. Here there are all the problems of a developing country plus the difficulties that have arisen as a long established service supports children and their families through a period of enormous political change. None of these are intended as models to copy, but rather as models of hope. From a variety of very different situations, all four have believed that one can make a tremendous difference to the lives of children with autism and their families through education. None claim\* to cure, but to educate in the fullest sense, which goes beyond the mere training of skills or modifications of behaviour.

# **Developing integrated services for people with autism (Spain)**

by Joaquin Fuentes, MD

(Medical Advisor, GAUTENA, San Sebastian)

This section will cover some issues related to the development of services for persons with autism in a pre-determined geographical area. What can be appropriate and feasible in one part of the world may prove unrealistic or even totally mistaken in another part. One has to “transplant” the ideas, the basic concepts, and adapt them to local culture and conditions. In order to develop sound integrated services for people with autism the following four aspects should be considered.

## **Recognition of autism in the primary community services and agencies**

Autism is a relatively infrequent disorder and is also an invisible one, so that professionals may fail to recognise the few cases they are exposed to. A complicating factor is the great diversity of autistic spectrum disorders. Autism awareness, therefore, is the first thing that has to be considered. This awareness training needs to address four groups of people.

### **The general public**

It is necessary to plan publicity carefully to make it cost-effective. Each country and each community has different systems and in some areas the radio may be the best vehicle, while in other countries television, newspaper ads or leaflets may be better options. The message should clarify the basic facts and correct any misconceptions about autism. People with autism should be presented in a positive manner, doing something that is age appropriate, culturally valued and performed alongside people without disabilities. The community capacity to support people with disabilities, such as autism, should be stressed as well as the positive contribution made by parents, professionals and volunteers.

### **Public authorities**

Politicians and community leaders need information in reference to the scope and magnitude of the problems produced by autism in the given region or area considered. It is often better to produce lists of real people with real needs, rather than to merely reflect prevalence figures or estimated future demands. The presentation of these needs (as well as the suggestion of cost-effective, internationally contrasted, locally adapted alternatives to meet them) can be done in brief meetings involving representatives from both parents and professionals. A written report covering the data presented can be left for subsequent study. Public authorities in all countries prefer to deal with organised bodies, rather than with individuals. Thus, it has proven essential to develop a local Autism Society. There are different models in different countries and perhaps the key aspect lies, not in the dimension of the membership or the amount of successful projects developed (although a minimum critical mass of both is necessary), but rather in the

capacity to retain a balance of power and responsibility between parents and supporting professionals. This principle of responsible collaboration is also the golden rule when considering the relationship between local Societies and national Societies. There are international bodies, such as the International Association Autism Europe (I.A.A.E.), located in Brussels (Belgium) which can provide invaluable information for new Societies.

### **Specialised agencies**

There is general agreement on the need for an early diagnosis. Therefore, it is crucial to incorporate valuable information on autism in the basic education of students in the medical and nursing professions, child care specialists, speech and language therapists, specialised and ordinary teachers and social workers. Nevertheless, where this varied array of professionals is not available, community health workers and ordinary teachers should be the targets for information.

In general, autism is scarcely regarded in the general basic education of health, education and social services workers. Thus, it is safer to anticipate a tremendous need for information in all professionals working in any community. An effective way to use the informative materials is to handle them personally or to mail them to key professionals in the community, along with a standing offer to facilitate more training materials if necessary.

### **Families and persons with Autism**

Very often the families themselves are the main vehicle for information to professionals. Parents will also have to function as effective advocates and therefore need to remain as informed partners. The World Wide Web in INTERNET will be (and has already begun to be) a growing tool for exchange and information, since several autism home pages in different languages can be visited and represent a useful resource for parents and professionals, specially for those located in more remote areas where access to information is more difficult.

### **Development of integrated opportunities for people with autism**

The aim of programmes for autism should be to help both the people with autism, and their surrounding community, to decrease the handicaps presented by the former and the ignorance presented by the latter. In this way we should be able to increase the capacity for participation in people with autism and the potential for acceptance and support by the community in which they belong.

There is a close relationship between the respect and rights awarded to disabled citizens and the ones awarded to the non-disabled people. Thus, a positive attitude towards the human and civil rights of all citizens is automatically paralleled with a recognition of the rights of the weaker members who cannot stand up for themselves. In a generally uncaring society, then, there is a need to implement the changes that would lead to both more justice and integration. However, this does not equate with development status and many poor communities share a positive attitude toward their disabled members along with a strong familial support network, while in many of the big cities of the richest nations, people with psychiatric and social problems have a marginal life on the streets.

From a practical view, nevertheless, we will have to reconcile, in the majority of our countries, the coexistence of integrative efforts and the provision of sheltered places for many of our citizens, including those with autism.

We know now that many people with autism (if not all) learn to enjoy the presence of others and become, with time and age, more socially oriented. There are studies from several countries showing that this phenomenon is fostered by participating in integrated settings. Also, the amount of social initiations depends not only on the person with autism, but on many other external aspects (such as, the amount of structure provided, the availability of visual support or alternative means of communication, the familiarity with the communicative partner, the opportunity to choose and so forth).

There will, however, still be a need to respect the reasonable demand for time alone, which should be incorporated as an option in any schedule, and the typically solitary lifestyle of some high-functioning adults. Therefore, development of services should involve placement in a comprehensive caring community, where diversity is accepted and compensatory support given to those who face challenges in becoming valued participants.

Sharing this orientation, in June 1994, under the auspices of UNESCO, representatives of 92 governments and 25 international organisations formed the World Conference on Special Needs Education, held in Salamanca, Spain. They agreed a dynamic new Statement on the education of all disabled children, which called for inclusion to be the norm. In addition, the Conference adopted a new Framework for Action, the guiding principle of which is that ordinary schools should accommodate all children, regardless of their physical, intellectual, social, emotional, linguistic or other conditions.

Inclusive education is based on ideas such as a sense of school community, shared vision, development of problem solving teams (typically consisting of principal, special education teacher, regular education teacher, parent, paraprofessionals and specific resource people), parents as valued partners, use of students as problem solvers (peer mediator, peer tutoring, cross-age tutoring and buddy systems), community involvement, curriculum adaptation, learning in the least restrictive environment, co-teaching, staff development, and so forth.

## **The case of autism**

Students with autism require specialised instructional techniques that are not easily provided in ordinary classrooms (at least in non-inclusive classrooms). The practice of inclusion is complex and requires significant change in the attitudes, beliefs and knowledge of everyone involved. We started 15 years ago transplanting students and teachers from our special school to ordinary community schools. Our move had little to do with the ideology of integration, but more a concern about the poverty of our social environment in our special school as it pertained to our pupils and the belief that the special teaching approach could be transmitted to interested partners. In other words, we were driven by the individual needs of the students. We need diversity, as we have a diverse group of students, as well as flexible access to a wide array of opportunities.

This diversity means that there are children with autism that are being educated in ordinary classes, with different types of support provided, children that split their school time between the regular classroom and the typical non-categorical resource classroom, children that attend our GAUTENA run special classrooms and share activities with the rest of the students and, finally, and most importantly, youngsters that spend less and less time on school premises and learn functional skills in the community or in developing transitional programmes to wherever they will go after twenty years of age. After years of hard work we enjoy now in our Province a zero-rejection policy, which means that all disabled children are part of the educational system and an inclusive policy which has led to having 100% of these children with special needs below 14 (around 2.4% of the school population) placed in ordinary schools.

Gipuzkoa is a Province of the Spanish Basque Country. It has a relatively dense population, with 700.000 inhabitants and a size of 60 by 40 kilometres. The majority of people live close to its capital, San Sebastian In our program, GAUTENA, 130 staff meet the needs of around 200 families from the Province.

There are twelve GAUTENA classrooms dispersed throughout the Province, but not all pupils with autism will attend these classrooms. The pupils in them may have autism or related disorders that require special curriculum adaptations. A small team of peripatetic educational consultants from GAUTENA provide support to all teachers in the Province, and the Department of Education also has support teams as well as providing other measures such as downsizing classrooms, assigning extra-teachers, etc..

### **Integration in the family and integration of the family in its community**

Families all over the world are the main social reference for us, including people with autism. In many countries, people with disabilities are not supported by the state and their families have to take full responsibility for what happens to them. In general, neither governments nor societies at large, recognise the basic role played by families, and this is clearly reflected in budgets. Helping families of people with autism would be the most cost-effective intervention for the vast majority of countries.

### **Services for families**

- information, referral to experienced people
- practical advice and follow-up
- financial support
- respite possibilities
- legal advice
- accessing programmes

Families do not adapt passively to the inherent stress of having a member with autism. Each one has its own way of coping with the situation, depending on many factors. Some relate to the person with autism (the level of functioning, age, associated problems, etc.) and some depend on the family (number of relatives, marital accord, health and age, economic situation, life cycle moment, etc.). Our role, as professionals, is to respect their coping strategies and to promote two fundamental goals, to help them

integrate the person with autism in the family and to support the normalisation of the living conditions of the whole family.

In GAUTENA we offer every newly diagnosed case a free programme, providing emotional support to families and helping develop a home programme. Normally children with autism and their parents come once a week for three or four years, to work with a specialist psychologist who remains as the case manager for that child. Our approach is psycho-educational and we insist that we will learn from each family much in the same way they will be learning from us, and that partnership is what it is all about. To complement this treatment, we facilitate families meeting experienced parents as soon as they feel ready, and with older children and adults we offer diverse opportunities of respite care. The goal of respite care is to foster a less restricted life for families. We never question their need for a break; if we can give it, we do it, and very often we encourage it. A day programme is a good starter for respite and it would be the very first thing to try to develop but there are other complementary services to consider. Respite care includes home aid, baby-sitters, family to family respite care, a temporary foster family, use of leisure community resources, rotating respite beds in group homes and a weekend hostel. These services continue to be available for adults with autism.

### **Integration of the services for persons with autism in the wider array of human community services**

If one looks at how many of the programmes around the world for persons with autism started, it can be seen that there is always an initial effort to stress the differences between these persons and the rest of people with disabilities. The reasons for this are clear. To begin with, these persons were normally rejected by existing services because of their peculiarities, and secondly, if relatives did not stress their need for special provision no new programmes would be generated. People with autism require specific support, but they also have the same needs as others (for love, stimulation, enjoyment, activity, health, money, company, etc.) What is special about people with autism is that they need special support and understanding to meet those common needs. This support may be given in a variety of settings, including those with non-autistic persons (disabled or not). If there are limited resources, it will work much better if a collaborative model is followed, involving families of children with other disabilities, but recognising individual needs.

# **The development of services for people with autism and training for professionals (France)**

by Bernadette Rogé

(Unité de diagnostic et évaluation de l'autisme. Toulouse hospital)

The training of professionals working with people with severe developmental disorders is an urgent problem in France at the present time. The inertia which was a striking feature of the attitude to new knowledge in this field has largely contributed to the present situation. It must be remembered that the psychoanalytical model is still very dominant in France and that the explanatory theories which arise from it have largely stressed the psychogenesis of autism, thus giving a privileged place to psychotherapy to the detriment of educational approaches.

Whatever the speciality, the number of professionals who have received proper training and who are already operational, is very limited. This lack is felt in all areas, in diagnosis, assessment, medical follow-up, practical educational management and the supervision of workers. Development of services for people with autism In spite of a considerable accumulation of shortcomings, there has been a definite evolution in the services available to people with autism, in response to the demand by families for an approach to management and education which is adapted to their needs. Projects involving new facilities, or existing institutions which modify their admission criteria to extend their scope to autistic people, are under way in all regions of France to cater for children, adolescents or adults with serious developmental and communication disorders.

Various formulae have been developed during recent years to provide facilities adapted to the needs of children. Following the model which has proved its worth in other countries, integrated classes have opened in normal schools, both state-run and private. They have the advantage of offering an individualised teaching programme while enabling the children to become socially integrated. Such classes have a limited number of pupils and are run by two members of staff, a teacher and a teaching assistant. Other facilities catering for children with autism have been set up in institutions belonging to the health and social sectors. These are usually medico-educational institutes or day hospitals which have opened a special unit run on the lines of a classroom. The team in charge has generally received, or is receiving, specific training in the educational approach.

However, problems remain concerning this type of structure:

- staff are not always sufficiently numerous for optimal adaptation to the needs of people with autism
- staff are sometimes inadequately trained, which makes it difficult to set up high-quality projects and fulfil the initial goals,
- another frequent problem is continuity in the follow-up of the children. In regions where educational facilities for adolescents and adults are as yet non-existent, there may be no suitable solution for children who have previously benefited from

an educational approach, or they may be redirected to facilities which are not suited to their needs.

### **The problem of training for professionals**

With growing awareness of the educational needs of people with autism, and under pressure from parental associations, new facilities have been created and institutions have redeployed some of the means at their disposal so to be able to cater for them. Efforts in this direction have been insufficient, however, the places available are too few to meet the need, and it is still not possible to recruit enough competent personnel who have received formal training. Some institutions have opened and are functioning with inadequately trained and sometimes underqualified staff. The need is great and can at present be only partially satisfied, but high-quality training programmes have been set up.

### **The work of the associations**

The primary impetus for professionals trained in autism came from parental associations, who invited professionals from other countries to conduct training courses. Both theoretical and practical courses were set up. These broad-based courses were progressively complemented by more specialised courses, on assessment for example. In-house courses to train teams already working in an institution were also provided. The scope of the training offered thus widened to respond to the needs expressed. Within certain associations, speakers also became more diversified and experienced French professionals took over.

E.D.I. Formation was the first association founded with the purpose of setting up programmes aimed at those working in the field. PRO-AID Autisme has also been taking in trainees for some years in the facilities under its charge. In addition, this association runs an annual practical training course conducted by a team from the TEACCH programme. Post-session support is available to the professionals who have taken part.

Other associations, of professionals only, or of both parents and professionals, have been set up as training organisms (E.P.I.C.E.A., A.F.F.E.E., A.I.R.) and run theoretical or practical sessions. The Opleidingscentrum Autisme in Antwerp, directed by Theo Peeters, runs training sessions, takes in trainees, and can also send out teachers to do in-house training on request from institutions. This team is much sought after in France because of its considerable experience.

A.R.T. (Autisme-Recherche-Toulouse) first organised theoretical and practical sessions as a preliminary to taking over this function by the University, which has now been accomplished. A.R.A.P.I. (Association pour la Recherche sur l'Autisme et la Prevention des Inadaptations) first started running international colloquiums and seminars in the eighties. In 1989, the Universite Internationale d'Aussois was established and now brings together researchers of international status and students at doctorate level. It is held every two years and will congregate for the fifth time in October 1997. It is organised in collaboration with the Universite Francois Rabelais of Tours and the Universities of Toulouse-II and Toulouse-III (Science and Medicine : Universite Paul-Sabatier; Letters and the Humanities : Universite du Mirail).

## Universities

Teaching focused on autism is rarely included in the basic university syllabus. It depends above all on the proximity of a specialised centre for the diagnosis of autism. Students in such universities can attend lectures given by speakers from a hospital and university background or by specialised academic staff as part of a diploma in psychiatry (Paris, Tours, Toulouse), keeping them up to date with current knowledge in the field. Such modules, forming part of the basic syllabus, cover only a limited number of hours. On the other hand, students from a variety of disciplines who enter specialised departments can acquire in-depth training and go on to take part in research.

Complementary education programmes have also been set up; in Tours, annual study days serve to spread information on clinical practice and on the latest developments in research. Similar study days are also held in Paris. In Toulouse, there is a European training programme combining 120 hours of theoretical teaching with periods of practical training. In other universities, developmental disorders are dealt with but in a more limited fashion in courses such as university diplomas.

## European collaboration: the Educautisme Programme

This project, which aimed to create a European training module for all professionals working with people with autism was launched under the impetus of A.R.A.P.I. The programme then developed through collaboration with the C.N.E.F.E.I. (Centre National d'Etudes et de Formation pour l'Enfance Inadaptee). The countries taking part are Belgium, France, Greece, Portugal, Spain and the United Kingdom. Basic support materials and illustrative aids (overheads, slides, video tapes) together with assessment of the knowledge acquired (questionnaires) were prepared. Experimental modules were developed and led to the continuation of this education programme in two forms:

- the European training programme "Autisme and other developmental disorders", has been set up in Toulouse as part of the Etudes et Actions Experimentales of the Ministere de l'Education Nationale and was part of the experimental phase of the Educautisme programme.
- the C.N.E.F.E.I., has been running since 1995 a module on developmental and communication disorders. This module is linked with training at Toulouse University.

The first phase of the Educautisme programme was also complemented by a second phase, Educautisme Part 11, which concentrates on the training and employment of adults with a handicap linked with developmental disorders.

Thanks to the efforts of associations which provide theoretical and practical training and of the universities which have organised specialised courses, some of the gaps in the field of training have been filled. In spite of high-quality achievements which help those working with people with autism to update their knowledge and to acquire new techniques, much remains to be done to develop further the structures that exist and to complete the training possibilities available so that the needs may be met.

# **Establishing services from scratch (Hungary)**

**by Anna Balzs**

(Autism Research Group and Foundation, Budapest, Hungary)

## **A short history**

The organisation and development related here, and covering the last ten years (1987-1996) was initiated by two professionals. One had met autism-specific services before in the US. and, when facing the poor state of the field within the medical and educational field in Hungary, (and spending a study tour in Holland, England, and Belgium) launched a two year project, supported by the Soros Foundation (Budapest).

## **The background**

None of the basic elements necessary for successful services, for a population of people with autism and their families, were present in Hungary. This stood against the background of large, nation-wide systems of services for other groups of handicapped people, including some that were long established and some that were new. But no colleges or universities, not even postgraduate clinical specialisation, had given (nor gives today) proper training for future professionals, doctors, psychologists, teachers, health- or social workers on pervasive developmental disorders (PDD) or autism. There were no special services, no special institutions, nor the necessary legal framework nor even a moderate level of information, nor tolerant support in the community (which is possible only on the basis of this information).

Financially and politically it may not have been the best period to start a new kind of service-development: with a declining economy and shrinking social, educational and health budget, with a growing social gap between populations, rising unemployment (unknown before - and so more shocking), and the tremendous need for social support by big or growing, helpless groups, like the elderly and the poor. But the public sector was growing, and there was only one instance when we got direct refusal of help from any official. The management and financing burden meant and still means more work for those who are also involved with the professional side of the work, and it limited our capacity seriously.

## **The original project**

This was only meant to be a preparation for the realistic planning of services, and of future clinical, and research work. The project was financed by the SOROS Foundation, which remained by far the most important supporter through all the financial crises of the years 1989-1994, before and beside the Hungarian state. The work was realised with the help of students (some of whom later became the core staff) from the College for the Teachers of the Handicapped, where the clinical work and teaching started. We considered the necessary elements of proper services and fruitful activity in a field like this:

- to be as clear as possible about the nature of the problem
- to gain information about the population involved: number, situation, difficulties, possibilities
- to involve interest groups among professionals for the evaluation of the situation, service planning and provision, etc.
- to involve parents and establish voluntary groups
- to develop trained professionals
- to learn from specialists in this field
- to provide up-to-date, organised special services in health, educational, and social fields for children, adolescents and adults,
- to support families
- to collaborate with special institutions in the same field
- to develop vocational training and working opportunities
- to work towards a legal framework for the provision of services for people with autism
- to campaign for social security coverage, and the same social conditions for all children
- to seek to develop an informed, tolerant, and supportive attitude from the general population

There were four major goals set to prepare for the training of professionals, the planning of services, and the social aspects of professional work:

1. adaptation of up-to-date scientific information, diagnostic, therapeutic, and educational methodology,
2. starting a data bank,
3. making a social study on the situation of families with autistic children in a small sample,
4. organising a pressure-group in the form of a parent-association (a new kind of organisation here)

### **The first year (1988)**

This started peacefully: The collected information found its way directly into our own curriculum of child-psychiatry in the College for the Teachers of the Handicapped. An informal autism-clinic began to take shape as well, within the clinic there. In both, we based our thinking on Rutter and Schopler (1978), and on the principles of ICD-9 (WHO, 1978), on the TEACCH program learned through Theo Peeters, behaviour therapy from Laura Schreibman, and a wealth of information collected at the IAAE conference at Hamburg, where we met Loma Wing and Rita Jordan, and the helpful offices of the National Autistic Society (UK). The first pedagogical trial begun in September 1988, with one high functioning child with autism and Duchenne-type muscular dystrophy, whom we integrated into a small class of children with mild learning difficulties and social problems, with two special teachers. The class was a joy, with very supportive six-year olds, but lasted only one year, as a consequence of an intolerant reaction from some of the school staff. Teachers and pupil moved to the new class of children with autism in 1989.

The sociological survey was on its way. The students made very detailed semi-

structured interviews (provided by, and adapted from Elisabeth Newson, UK) with parents of autistic children, that yielded a wealth of (expected, but still moving) information, and much to think about. After regular, monthly meetings and discussions with a growing number of parents known from clinical settings, and a few professionals, the parent-association was officially established in December, with a basic document stating an agreement about the nature of autism, and the goals set before the Association by the membership, both prepared mainly in line with similar documents by e.g. IAAE.

But real needs interacted with the original plans. By the end of the year it was apparent that we could not remain idle with appropriate methods in our hands. The families we met and diagnosed were left without any teaching, training, or therapy. We had to use the collected methods to be able either to teach them or to teach other professionals.

### **1989: from project into organisation**

At the beginning of 1989, in an empty wing of a daycare centre, we opened one special kindergarten group for young children, and in the autumn a school group beside it for five high functioning seven-year olds. The project received financial support from the Ministry of Education, which gradually, became an almost permanent state-contribution. This small unit was the core of the present school. The methods used there combined early social and preverbal communication training, with limited musical interaction type therapy (from Elisabeth Newson, Nottingham), elements of early training seen in the Netherlands (from Ina van Bercelaer Oonnes), much from the TEACCH-program, cognitive and behaviour therapy, and ideas put forward for example by Patricia Howlin and Michael Rutter (1987), or by the members of ATHACA (1985) on the special curricular needs of autistic children.

In the clinical setting there was a fast growing number of families, and a very limited number of colleagues and rooms. We made some of the assessments in the corridors of the clinic and in the waiting area. But the biggest problem was explaining everything in one or two settings, and giving advice about what to do and how to proceed in the future without having any specially trained professional background to help the families. The need created the solution: we suggested the families try and bring with them on the second occasion, a professional (a teacher) or any helper from their region, who planned to work with the child. We offered explanations, literature, demonstration in the classes, and consultations in the future.

This has been one of the most important steps in our history: the families did bring kindergarten and schoolteachers, special teachers and assistants, psychologists (a few times), and occasionally even their doctors. We began to have a growing number of colleagues around the country, all sorts of people, who were using our information, coming back for more, or for consultation about the child, and working with him or her and bringing the results and the problems. More and more it happened that a family came from somewhere faraway, and we could say: "Go and ask this person to work with your child, she already has some experience". And we began to suggest to the family or the parent- teacher pair that they go to the local government, to tell them that this child needs special care, and that there are more similar children in the area. If they want to know how many, to ask us (naturally we knew only those who turned to us), and if they would do anything to organise a class, we were ready to assess the children, train, help

and advise the teachers.

This offer often got us into roles and conflicts totally out of our sphere of competence, such as in local clashes of interest between town and county authorities, school and class, teacher and teacher and we were called upon to help convince people, solve conflicts, or finance the service. The first special educational groups for children with autism were created as early as 1989, within health or educational institutions (most often schools for the mentally handicapped). That was the beginning of our National Network.

One more very significant event took place in the spring of 1989; to secure the financial background for our expanding work (after the Soros-support) we created our Autism Foundation. This legal entity is not a classical foundation but is able to collect and manage donations and contributions. By the end of the second year (the planned end of the original project) almost the whole basic structure of our present Centre and activity was set up.

### **1990 onwards**

The end of the next year, 1990, brought independence. Growing out of our physical space, we finally acquired a large, worn down, but empty kindergarten-building to rent. We moved there with the 22 children-school, the outpatient clinic, and all the other functions, with about 30 members of staff. It was not easy for anyone, but had the quality of a heroic and happy beginning. While once in a while special teachers, angry or merry, but always spirited, had to go up to fix the roof or break the ice themselves, we did try to proceed in our aim of organising small, model units or projects, like the weekly evening club for adolescents and adults, the regular weekly discussions with our own colleagues about methodology, and about materials under development, like the special evaluation sheets used after each semester about each child, or monthly meetings with the headteachers of the special groups of the National Network from all over the country.

We also began publishing with a translation of Uta Frith's book: (1989). But there were problems still to be solved. Our building was in an outer district, and our first time patients and visitors often simply got lost, and never found us. Also, we wanted to get closer to possible co-operative partners, like the Semmelweis University Medical School. Two years later (Christmas-time, 1992) we succeeded in moving to our present, and hopefully final place: two rented, and later bought, small townhouses, in a quiet, but central district.

These years were characterised by a qualitative and quantitative development in all fields, and a hectic activity - a race to keep pace with very different kinds of demands. It did overburden the staff, as every-body had to carry more, and often more qualified work, than they were prepared for, or could. Some left with angry feelings, which shows that we may have imposed on people.

## Present situation and activities

### The Centre

With very intensive activity, this has a basically similar structure to the early one, but with a 60 member strong staff working, and outgrowing its three small buildings.

**1. The Child-and Adolescent-Psychiatry Outpatient Clinic:** Adults with autism are accepted, but rarely show up. So far 1200 children or people have been assessed, 60% diagnosed as having autism, and 15% as having some other diagnosis behind their problems. The remaining 24% of cases are unfinished, or waiting for further evaluations. There is an average of 100- 120 families constantly on the waiting list, with an expected waiting time of seven months. This is a major stress for our staff.

#### Activity:

- Diagnostic evaluation, assessment, and counselling is offered and treatment plans and methods for home training, early treatment, social-cognitive training, behaviour therapy, and school-placement,
- The parents are assisted in finding a professional (mostly teachers), special group, tolerant daycare-centre or school to turn to in the family's area, and an informal instruction with future counselling is offered for the professional there. The network has an increasing role in providing this.
- Patients are seen once a year, and if really needed, more often.

**2. The Experimental School:** This has five groups, and 27 children from 5 to 20 years old. About the same number of adults work with them in shifts, among them about 25% with a college or university degree, but all trained in this special field within our Centre. There is one extra group: a kindergarten for the children of the staff. Sometimes it is used also for integration, sometimes to observe a child from the Clinic in a peer-group. The pupils represent practically all types and mental levels of children with autism, some with additional difficulties. There are two part-time pupils undergoing partial integration.

#### Activity:

The school, as all other units, has multiple roles. It:

- serves the pupils and their families
- is an experimental field to try out educational methodology
- is a teaching ground for training professionals
- models and demonstrates possibilities for the outpatient clinic in counselling families, teachers, and home-trainers
- provides a model for new groups under organization
- serves as a model or demonstration to journalists and television people to inform the public

**3. The Adolescent House and Adolescent Club:** The Club has a long history of weekly meetings, open to new families, but the members and the programme have become too static. The 8-14 participants are partly adults (from 15 to 46 y.). Some live in the House, and some come for the Club only, and the parents accompanying have a group discussion with one of our psychiatrist colleagues. After a separate social program of discussion or a communication game for the higher and lower functioning group respectively, there is a snack (prepared by two young men with help), some table-top

activity or game for the rest, and a dance for everyone.

The House is organised, as a transition to final home-type arrangements (there is no place to go to yet) for high functioning adolescents and adults. It has some boarding capacity, but financial constraints mean it has been closed so far at weekends and holidays. It is free for the families. Its programme consists of vocational, social, communication, free-time, self-help and household skills training, teaching academic skills for some, and programmes in the community. It can draw on the support of the Psychiatric Clinic of the Medical School.

**4. The Methodological Centre:** This is only a few rooms, and most of its staff have other major tasks (headteachers in classes, staff of the outpatient clinic), with an extensive range of activities:

- management of the Foundation's 'KAPOCS' publishing house.
- managing the educational experiment, financed for ten years by the Ministry of Education. In the framework of this we try to help the groups of our Network to use new methods and unusual teaching conditions (e.g. teacher-pupil ratio) with children with autism. The final achievement has been a special curriculum for pupils with autism which is on its way to being enacted in law.
- a very limited amount of basic psychological research
- continuous improvement of diagnostic and assessment methodology.
- supervision and development of educational methods and materials for children and adolescents with autism
- planning and preparation of training materials for professionals
- training professionals.

Organised professional courses for our own staff were and are held regularly with invited international lecturers. Senior staff (13 colleagues) were enrolled in the Birmingham University (UK) Distance Education Course in Autism to improve our training for professionals, and with the hope of creating higher educational possibilities in this field within Hungary as well in the future. There are many visitors, including students, asking for information and help. The Network has to be supported and finances have to be raised.

Our principles and strategies for the future:

- long term planning, allowing for new needs and plans,
- securing regular funding
- adapting the most advanced methods and systems possible
- interdisciplinary thinking and collaboration
- the work-roles in our centre are generalist. The expectation is not only to be a specialist in one field of activity, but to work in others as need dictates, from management to diagnosis.
- satellite service-organisation (groups and individuals) as a mode of expanding services.
- avoid becoming part of a larger institute or university to keep professional autonomy
- attempt not to overburden or underpay staff
- to try to secure funding for projects before, rather than after, they are started

- to lobby the state to undertake its responsibility
- to be proactive in giving views on proposals or legislation
- to use fortunate occurrences (e.g. the film Rainman) for propaganda purposes
- making no, or very few, professional compromises, not even for funding

## **Relevant conclusions, important factors**

There are a few failures and difficulties worth mentioning as there are conclusions to be drawn, or at least to be learnt from.

- There is still a lot to do in the organisation of formal training for parents where the western model is not fully applicable.
- There were unresolved difficulties from the professional jealousy of colleagues working in this field before us, and from the different points of view of professionals and a parents' association.
- The schism between organisations representing the field makes it more difficult for the state and local government to make proper and positive decisions.
- The controversies between professionals are probably to be expected but are difficult to prevent.
- We should have been more tolerant (not compromising) with the standpoint of the Association, for example in advertising healers or acupuncturists to the membership.

## **Conclusions**

There were some indispensable conditions of our existence:

- the professional support from abroad, coming free, and without any reservation from almost every colleague we asked, and a friendly, supporting attitude everywhere we went.
- at least one financial supporter with relevant sized funds: in our case, Mr George Soros. The help of many state officials, and ultimately the Hungarian state was similarly essential, but came only after the help to start, and to stabilise ourselves from the Soros Foundations.

Our financial instability meant and means permanent insecurity. There was the loss of constantly overburdened staff, frustrated in their wish for learning, for research, or in their self-confidence and satisfaction with their own performance.

Thus we have reached a few important conclusions:

- we have to concentrate our efforts on training professionals, to improve the country's and our own situation.
- reluctantly we have to offer training in the future only with tuition fees for professionals and parents.
- we need to cooperate with organisations in the Central and Eastern European Region, to make our efforts for development in our field more cost effective. We want to establish a Central European Educational Centre for Autism, in which we plan to offer training courses and counselling in organisational tasks for professionals.

# **Working with parents of children with autism in the context of a developing country (South Africa)**

by Christine Koudstaal

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## **Introduction**

The changed political situation in South Africa has been accompanied by changes at the social level, which include the provision of health, education and welfare services to persons with disabilities. In the case of autism the available services are located in only two urban areas (1600 km apart) and the development of services for individuals throughout the country is therefore an urgent necessity. It would appear that, where educational and training programmes exist, and where a diagnosis of autism has been made, the role played by South African parents in the development of their children, does not differ much from that in other countries. As in other parts of the world, it was in the late sixties that parents began looking to the education and welfare of the individual with autism. However, it seems that although diagnostic and educational services have been established, the development of extended services and adult services have lagged behind, compared to certain countries and states in Europe and America. Services and facilities in respect of diagnosis and the provision of education have, since their establishment, remained virtually unchanged. Change can, however, be seen in the increase in the number of referrals and the resultant increase in the number of admissions to schools. As a result, more parents are receiving help. At present, provision has been made for a very limited number of individuals whereas the majority of cases are as yet undiagnosed. There are, therefore, thousands of parents who are unaware, that the peculiar behaviour displayed by their children, could possibly be attributed to autism. The parents worst affected are those resident in remote under-developed areas where primary health care, welfare, appropriate education and support are sadly virtually non-existent. There are still no facilities or programmes catering for the needs of adults with autism. Although comparable to other countries on the African continent as well as abroad, one has to distinguish between the privileged and the marginalised groups in South Africa.

## Diagnosis and assessment

### *Aggravating circumstances*

- Language: at present there are eleven official languages in South Africa. Although English is most widely used, many parents of children with autism are fluent in only one language.
- Culture: due to the ethnic diversity in South Africa, attitudes towards children with autism differ vastly from one culture to another. Interestingly, it has been found that amongst some ethnic groups, the extended family of a child with autism tends to take on the responsibility for such a child in an extremely positive way.
- Socio-economic status: poverty, unemployment and domestic violence is not uncommon in many South African homes. The impact of these factors on the parents is often so great, that caring for a child with autism tends to be neglected or sometimes ignored. It is often virtually impossible to include such parents in a home-based programme.
- Violence: as stated above, many children with autism reside in remote rural areas where no facilities exist. Professionals who in principle, are willing to assist parents in these areas, are unfortunately neither prepared nor equipped to venture into highly volatile and potentially life-threatening areas. Police are also often regarded in a hostile light.
- Ignorance: lack of knowledge and appropriate training, not only amongst parents but also professionals and para-professionals, contribute to the fact that many children with autism and their parents remain without much needed assistance.

Even if parents realise that their child needs intervention, they may be unaware of where such services can be obtained. Also, financial constraints and poor public transport to and from remote areas inhibit many parents from seeking help. It is clear that, especially in remote areas, little or no services for families of a child with autism are provided.

Although a pretty bleak picture has been described above, there are also many children with autism who have been diagnosed correctly and are receiving appropriate intervention and education. The pioneer work on diagnosis in the sixties can be attributed to child psychiatrists working in child and family units attached to Provincial Hospitals in Cape Town. In the early seventies and eighties similar diagnostic services spread to Johannesburg and Pretoria respectively. At present these services are also being developed in Port Elizabeth. Of the nine provinces in South Africa, only three are involved in the identification, diagnosis and specialised education of individuals with autism.

## **Assessment procedure**

Doctors, psychologists, therapists and even parents who suspect that a child could be classified as autistic, refer parent and child to an existing child and family clinic at an academic provincial hospital with specific diagnostic and evaluation facilities or to one of the existing schools for further referral and follow-up.

Full-time personnel attached to specialised schools catering for learners with autism, especially the psychologist, speech and occupational therapists, as well as the school principal and a member of the teaching staff, form a trans-disciplinary diagnostic and support team under the leadership of the child psychiatrist. Parents are also actively involved in the team effort.

Assessments are carried out at Child and Family Units of Provincial Hospitals (see Appendix B) or one of the schools. Internationally accepted diagnostic criteria as well as assessment procedures and techniques are implemented when evaluating an individual. Parents pay for this service according to approved hospital tariffs and sliding scale benefits. Provision is also made for indigent cases. When the diagnosis is made, the child is admitted to the school, should a vacancy in an appropriate class exist. As a pupil of a school specifically geared to provide appropriate individualised education, the child also qualifies for speech and occupational group therapy. In some instances there are no school vacancies, or transport problems prevent the child attending school.

## **Empowerment of parents**

Most of the services, i.e. psychiatric, psychological or other therapeutic interventions, are to be found at, or provided by, the different schools. The first step to empowerment is knowledge. Information is provided by different role-players either by means of individual or small group sessions with parents, supplemented by written documents, recent literature or video material. The nature of autism, its implications and treatment programmes are dealt with.

Every parent experiences hope that their child may become 'normal', verbal, scholastically proficient and an independent adult. While hope is the cornerstone of all parental efforts, realistic expectations as to the prognosis of the child have to be established over a period of time. Parents are guided through the confusions they experience as well as the grieving process, which seems to repeat itself whenever an envisaged milestone is not successfully reached. The parents are made aware of their options and rights and are guided in the choices. Empowered parents are able and eager to participate actively in the planning, management, delivery, monitoring and evaluation of services for their children.

## **Learners admitted to schools**

Parents are viewed as partners and thus as co-workers in the education of their children. They are drawn in when new aims and objectives are formulated. Consensus is reached concerning the method of implementation as well as the evaluation period allowing for adaptations, if necessary. Members of the school, supported by a visiting child psychiatrist together with the parents, are involved in regular discussions concerning the pupil. Contact between home and school is maintained by means of a daily diary

wherein daily events, behaviour and unusual occurrences are exchanged. Under certain circumstances such as crises, telephone contact is commonly used by both parents and staff. Home visits are carried out on a regular basis by the teachers, where distance allows. The aim of these visits is observation of the child's behaviour in his or her home environment and adaptation of existing programmes, as well as emotional support. Parents from long distances are expected to pay at least one visit to the school per year, whilst further contact is maintained by means of letter writing and the telephone. Parents are further empowered through self help support groups which are organised either by themselves or in conjunction with members of the multidisciplinary team. Regular parent evenings are held at the school where parents can visit their child's class, meet socially and listen to speakers on relevant topics requested by the parents themselves e.g. behaviour, communication, perceptual development, management of sexual problems, alternative treatment strategies and programmes. Sibling groups as well as a group for grandparents are held at least twice per term. In-service-training sessions are arranged for domestic assistants if the need should arise.

### **Home-based programmes**

As stated earlier, some learners with autism cannot be immediately accommodated in a school for varying reasons. Parents who care for their child with autism at home, visit the school closest to them on a regular basis in order to receive training regarding the management of their child. The most common workshops are on augmentative and alternative communication systems, sensory integration training and the management of challenging behaviour. Children who are treated on an out-patient basis are re-assessed annually by the school's assessment team, to ensure appropriate intervention. Some children with autism are placed in schools for the mentally disadvantaged, should such a school be closer to the home of the child. In these instances the psychologist, occupational therapist, speech therapist and/or a teacher visit the school to assist the parent or staff in coping with the special needs posed by having a child with autism either at home or in the classroom.

### **Education**

The five existing schools owe their existence to these determined parents and interested professionals who, in the early seventies, realised the urgent need for the establishment of specialised educational facilities, tailored to the specific needs of their children. These schools had their origins in a single class of three or more pupils. Initially, parents were solely responsible for the funding of the class or school which included the building and salaries. The schools were run as private schools because the then Department of National Education did not make provision for education of persons with autism since the nature of the disability and the implications thereof were totally unknown.

A Committee of Enquiry was appointed to look into the Treatment, Education and Training of Children with Early Childhood Autism. Their report was published in 1970. After the acceptance of this report the Department decided to acknowledge and support schools for pupils with autism. However, the schools had to prove that they had the support of a sponsoring body as well and the association for autism fulfilled this role for each school.

From 1994 new policies have been formulated and the new Education Bill of 1996 proposes the inclusion of children with disabilities within the regular classroom. Parents, however, will have a choice regarding the placement of their child. Thus, although the need for the development of at least one centre of expertise per province exists, the lack of overall financial resources necessary to supply education to all in South Africa, including the individual with autism, will probably hamper this. Without financial support and the backing of the relevant authorities, parents as well as the individual with autism will unfortunately not be reached by appropriate educational, support or care programmes.

## **Establishment of associations for autism**

Parents whose children were diagnosed during the late sixties, and early seventies came to the sobering realisation that there was total ignorance concerning autism as a disability, and that schools were not prepared to admit their children. Parents, on the other hand, were not prepared to admit their children to a psychiatric or mental institution. It was important to them that their children be given an opportunity to attain their full potential whilst they, themselves, had a need for support and understanding. It was at this stage that parents in Cape Town, Pretoria and Johannesburg founded associations for autism, thereby enabling them to legally raise funds. In this way they could begin to look to the education and welfare of their children, as well as make the general public more aware of autism whilst also supporting one another, especially in respect of acceptance and management techniques. Membership of these associations consists mainly of parents and interested staff members and to a lesser degree other interested professionals from the community (see Appendix C for list of Schools and Associations).

## **Marketing of autism**

In order to make the wider community more aware of autism and related disorders, members of staff, together with parents, and members of the various associations, are constantly involved in the preparation and distribution of information in the form of articles, pamphlets, newsletters or magazines. Some parents give lectures to interested groups or welfare organisations and also take part in radio and television programmes.

## **Adults with autism**

There are, as yet, no suitable facilities for the adult with autism and most of them are placed in facilities not designed to meet their needs. Parents are once again involved in investigating possible options and solutions.

## **Autism South Africa**

Whilst the various associations diligently look after the interests of the individual and his or her parents at local level, it soon became evident that co-operation on a national level was essential. This led to the founding of a national umbrella organisation viz. Autism South Africa. Through this, parents, assisted by various professionals and other interested parties, have a greater bargaining platform.

## **Conclusion**

As this perplexing disability has become better known and professionals acquire more expertise in this field, the available resources are being optimally utilised. Lack of funds, physical facilities and manpower are impairing the quality of an outstanding service which has been built up over several decades. All in need, albeit the parents, family, or the individual with autism, do not always receive the services to which they are entitled. Some people are on the waiting list for more than a year before being suitably placed. It is evident that the state cannot assume sole responsibility for these persons. Therefore, parents will still have to be actively involved in fundraising and lobbying for the rights of, and services for, the family member with autism.

Since persons with autism are generally unable to represent themselves, their parents, and the parent bodies who speak for them, will probably always be their only voice.

## **Making the Best of the Current Situation**

Effective education for pupils with autism depends on understanding the child's needs and the particular strategies that will help. In other words, even in mainstream classes, specialist knowledge of the condition is essential for effective teaching. If the teaching in the early years is going to benefit children with autism, rather than create further problems leading to eventual exclusion, it needs to be based on understanding of autism and knowledge of effective strategies to use to help them develop and learn.

Recognition of needs, then, should lead to the provision of 'prosthetic environments' for autism that favour normalisation. Prosthetic devices are ones that prevent disabilities from becoming handicaps. While recognising the very profound nature of the difficulties faced by people with autism in living in our socially dominated and culturally biased world, it is fundamentally 'uneducational' to always talk of 'deficits' with their images of irreversible damage or absences. It is seldom, if ever, the case that an individual with autism has a complete deficit in any area of development. Rather, it is the case that they do not do things spontaneously or naturally or intuitively (e.g. joint attention, spontaneous play,) but they can do so (or they can perform with very similar behaviour) if prompted, or cued or taught.

The real deficit may be a much more basic one that does not allow this development to proceed naturally without intervention, but practitioners need to move from a situation where they are 'allowing' for these deficits in their teaching to one where they recognise the 'challenge' that these difficulties present to the individual's learning but they also try to identify ways of helping the individual meet and overcome those challenges. We know many able individuals with autism overcome or meet these challenge more or less unaided, so we know that autism itself is not a barrier to it being done, although the presence of additional difficulties, such as general learning difficulties, will make an already difficult task far more difficult. If we succeed in our teaching, we will not have 'cured' autism because the original difficulty or deficit remains and so the many ordinary everyday aspects of living which are accomplished by us without effort or thought will require considerable amounts of both by the individual with: autism and his or her 'teacher'.

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