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Prognosis in autism: do specialist treatments affect long-term outcome?

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Abstract Many different treatments have been claimed to have a dramatic impact on children with autism. This paper reviews what is known about the outcome in adult life and examines the limitations and advantages of a variety of intervention approaches. It concludes that there is little evidence of any

"cure" for autism, but appropriately structured programmes for education and management in the early years can play a significant role in enhancing functioning in later life.

Key words Autism –prognosis – follow-up – interventions

Introduction

The parents of children with autism are faced by bewildering and often conflicting claims about the merits of different interventions. As one parent writes, "We weren't searching for a miracle... we were just looking for something- anything- because to do nothing had become intolerable... each time I hear of something new... a little spark inside my brain briefly ignites and I wonder once again, what if...:?" (106). This paper explores recent findings on the outcome for children with autism, and attempts to evaluate the potential benefits, or hazards, of a variety of treatment approaches.

Follow-up studies of individuals with autism

Early reports of adults with autism were largely anecdotal (33, 39) but towards the end of the 1960's Michael Rutter and his colleagues conducted a detailed follow-up of 63 autistic individuals initially diagnosed during the 1950's and early 1960's. Amongst those who had reached adulthood, over half were in long stay hospitals, eleven were still living with their parents and three were placed in special autistic communities; only three were in paid employment (87, 137, 138).

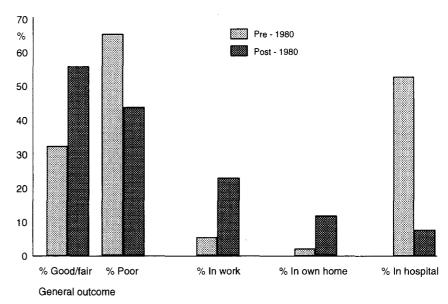
In a subsequent study, (90, 91) Lotter followed up 29 young people with autism aged over 16. His findings were similar to those of Rutter although by the 1970's many more had received full-time education. Nevertheless, only one individual had a job and almost half the sample was in long stay hospital provision; 2 individuals were living at home and 5 were attending day training centres.

Throughout the 1980's and 1990's there have continued to be a small number of reports of outcome in adulthood. These include the follow up study by Chung et al. (28) in Hong Kong, Gillberg and Steffenburg in Sweden (47), Kobayashi and colleagues (83) in Japan, Goode et al. (49) in England. A follow-up in France has been carried out by Fombonne et al. (46), although this involves a more heterogeneous group of subjects.

There have also been several studies that have focused more specifically on higher functioning individuals with autism or Asperger syndrome (134, 139, 150, 152, 158) all in the U.S. or Canada and in Britain.

Using the composite ratings of overall outcome employed by Rutter and Lotter in the earlier studies, together with information on jobs and living arrangements, Fig. 1 attempts to summarise the major findings from reports on outcome in adult life. The analysis is split into those studies that appeared between 1950 and the end of the 1970's and those completed during the 1980's and 1990's. Howlin and Goode (66) provide de-

Fig. 1 Outcome in studies published pre- and post 1980



Outcome data based only on those studies with suffient Information to rate. % for Good / Fair & Poor outcomes do not necessarily total 100% because not all studies provided figures on each of these variables.

tails of all the studies involved and the way in which results are summarised.

Although, direct comparisons between studies are complicated, because of differences in methodology, in the subjects involved, and in data analysis, the overall results indicate that, over the years, there have been improvements in the levels of functioning attained by people with autism. More people are living independently; more are in jobs and far fewer spend their lives in hospitals or similar forms of institutional care. Obviously, these changes cannot be directly attributed to better treatment and education – the decrease in hospital care, for example, is mostly due to the widespread closure of large institutions – but they are encouraging.

Factors related to outcome

These studies also suggest that there are a number of factors related to early development that appear to be associated with later outcome. These include the development of at least simple communicative language by the age of 5 or 6 years; the ability to score within the mildly retarded range or above on nonverbal tests of ability; and in many cases, the presence of additional skills or interests (such as specialised knowledge in particular areas or competence in mathematics, music or computing) which make it easier for individuals to find their own "niche" in life Kanner and Rutter et al. (76, 77 (p. 187), 138) and Lotter (90, 91) also note the importance of appropriate education. The influence of other factors, such as the severity of autistic symptomatology, early behavioural difficulties, family factors, or the sex of the child remains uncertain. On the whole,

women tend to do less well than men, although this is probably related to IQ differences (89). There are no individual symptoms (other than lack of speech) that are related to outcome, although the greater the number of social and behavioural problems, the worse the ultimate outcome. And, although some studies indicate that socio-economic factors and ratings of family adequacy may be *correlated* with outcome (90, 91), there is little evidence of any direct causal relationships.

The impact of early intervention on outcome in adult life

In his account of over 90 young adults who had first been diagnosed in childhood, Kanner (77) noted that 11% to 12% of the group had done relatively well, despite receiving little in the way of specialist intervention or support. This led him to speculate that prognosis might well improve in future years as recognition of the disorder, and the provision of appropriate educational and therapeutic facilities increased.

However, despite some improvements in outcome over the past two decades, the majority of adults with autism still remain highly dependant. Despite claims appearing from time to time in the media that particular treatments can have a dramatic impact on outcome, there is little evidence to substantiate such optimism. Indeed, on the whole, the more extravagant the promises, the more limited are the data on which they are based. Moreover, even when there is evidence of short-term gains, information about later adult functioning is generally nonexistent.

The following sections explore a number of treatments that have risen to prominence over recent years. The first section covers therapies that offer parents the hope of "miracles" or "cures". The second reviews approaches that are more cautious in their claims, but which may be able to bring about major improvements in children's behaviour. It is not feasible to include all possible models of treatment, and instead the article focuses on therapies that have received particular publicity. It is by no means all inclusive and no doubt, even by the time this article appears, new therapies will have hit the head-lines.

The "sounds of miracles"

Auditory integration training (AIT)

The title for this section is taken from Annabel Stehli's book "The Sound of a Miracle: A Child's Triumph over Autism" (148). In this she describes her daughter Georgie's response to auditory integration training, based on the theories of Dr. Berard, a French ear, nose and throat specialist. He postulated that sound sensitivity, and hence behavioural disturbance in autism, could result from distortions in hearing. Such distortions can be identified by peaks in the child's audiogram, and treatment involves the use of filters to eliminate these peaks. If the child cannot tolerate audiometric testing, a standardised program of Auditory Integration Training is given. This involves listening to electronically processed music through headphones for a total of 10 hours, (usually in 2×30 minute sessions over a 10 day period). Similar procedures, but using rather different equipment and requiring 200 hours of listening have been developed by Tomatis in Paris.

Most of the evidence in support of this approach is based on subjective and unsystematic parental reports although not all of these are positive (8). However, Rimland and Edelson (130, 131) compared 8 children receiving 20 sessions of AIT with 8 who did not. Following treatment there was no evidence of any decrease in sound sensitivity, and although it is claimed that the experimental group showed significant improvements on the Aberrant Behaviour Checklist (ABC), the change is, in fact, negligible (a difference between initial and final scores of less than half a point, on a scale of 58 items). In a further study, (summarised in Rimland and Edelson (130, 131)) the authors report on outcome in 445 children and adults with autism with an age range of 4 to 41 years. Again the average ABC score improved by around 0.4 points and there was a small but significant reduction in parental reports of sound sensitivity. Slight improvements in hearing acuity and a reduction in variability on audiogram measures were also

recorded. But, there was no difference in results according to the different types of AIT device used, nor according to whether or not filters were used and the authors found that most change occurred in the first 5 sessions of treatment.

57

There are no studies of the longer term effects of this approach, and even the short term findings raise questions. Firstly, it is important to be aware that results that are statistically significant are not necessarily of any practical value; thus, the reported decrease of less than one point on the ABC is hardly an indication of marked behavioural change. Moreover, reliance on measures that are based on the accounts of parents who have invested considerable money, time and emotional energy in the treatment, must also be questioned. The most puzzling finding, however, is the fact that whether or not filtering was used had no impact on outcome, although the whole rationale of AIT is supposedly based on the removal of frequencies to which the individual is sensitive Bettison (14), found that structured listening had as much impact on children's behaviour as auditory integration training. It is possible, therefore, that the main value of this technique lies in encouraging children to sit quietly for two half hour periods a day. Learning to attend and to co-operate to this extent is a major achievement, and once established such behaviours may open the door to new learning and greater behavioural change.

The Option method

Within the field of autism, the Option method is based on the premise that the child finds the world confusing and distressing and hence attempts to shut it out. This then starves the brain of the stimuli needed to develop social interaction skills, thereby further increasing confusion and reinforcing the desire for isolation. The essential principle underlying treatment is to make social interactions pleasurable for the child. The approach also emphasises the importance of acceptance and recognising that the children's behaviours are not deviant or inappropriate, but an understandable reaction to their difficulties in making sense of or controlling their world (78, 79). In order to "reach" the child with autism, adults must be prepared to join in with and enjoy the activities that the child finds pleasurable (very often his or her obsessional activities). Once the child's confidence has been developed in this way other activities may be encouraged.

Training at the Option Institute is expensive and involves a week's course, during which parents sleep, eat and work in the same room as the child (57). Subsequently, families are encouraged to continue the process at home, and this can mean adapting the house to ensure that they have a distraction free area in which to

work. Intensive, one to one interaction lies at the heart of the Option Method although the amount of time required for this seems to be variable, with some families managing to fit therapy around other activities, and others spending many hours a day with their child and requiring additional assistance from volunteers (75, 95). After 9,000 hours of such treatment the Kaufmans' own son is said to have progressed from being "a severely autistic child... with an IQ of about 30" to a completely normal young man with "a near genius IQ" (57). Parents' own accounts suggest that their children became more co-operative, calmer and happier as a result of therapy. "He now asks us to join in his obsessions, where previously they were exclusive" (95). The Kaufmans are said to make no untoward promises about the effectiveness of their approach but the book titles (e.g., A Miracle to Believe In (79)); the fact that children in treatment wear T-shirts proclaiming "Miracle in Progress", and the statement in the brochures that this is 'A place for miracles" rather belie this claim.

Although some observers have concluded that this is "an unproven but hopeful method that is unlikely to do harm" (75), anecdotal reports from teachers indicate that some children returning from the Institute have considerable difficulties in adapting to school routines again, and that their ritualistic behaviours have, if anything, become more difficult to deal with. There are no controlled investigations of this form of treatment, and apart from the Kaufmans' own writings, no reports of the long term effects of intervention.

Scotopic sensitivity training

Abnormal sensitivity to certain wave lengths of light is said to result in the Scotopic Sensitivity Syndrome. This produces a variety of symptoms, including dyslexia, and deficits in recognition and attention (69). Specially designed spectacles, incorporating lenses of different colours, can provide the "optimum" tint for each individual, thereby improving reading skills, body and spatial awareness, eye contact, communication and self control.

The spectacles are claimed to provide great help to people with autism: "We are still at the beginning stages (but)... we are amazed by the results. All the senses are connected so that visual perception can affect thought processes which influences auditory perception and, in turn, language" (69). Donna Williams, a young woman with autism whose autobiographical writings are well known (162, 163) is said to have found the results "close to miraculous... she was able to listen and concentrate better; her speech became more fluent and spontaneous". However, other than reports from a small number of individuals who have worn the spectacles, and the writings of Irlen herself, little is known about

the relative merits of this form of treatment, and nothing about its long term effectiveness.

Holding therapy

In their book Autism - A New Hope for a Cure the Tinbergens (154) suggested that the condition is caused not by genetic or neurological factors, but by "an anxiety dominated emotional imbalance, which leads to social withdrawal and ... a failure to learn from social interaction". This imbalance was said to result from a lack of bonding between mother and infant, which could be ameliorated by Holding Therapy. "Holding" was initially promoted in the U.S. by Martha Welch (160), who claimed it could be effective for an astonishing range of problems from autism to marital difficulties. It was also publicised widely in Germany (115), Italy (167) and the U.K. (123). The process involves holding the child tightly, to ensure eye-contact, with the aim of deliberately provoking distress, until he or she needs and accepts comfort. Richer and Zappella (123), reviewing research into Holding Therapy, claimed that it had "a major contribution to make to the treatment of autistic children" and that it could result in children becoming "entirely normal". Wimpory and Cochrane (164) severely criticised this review, noting that the authors do not properly report on the nature of the studies involved (many were not research articles, as claimed; others involved a combination of different strategies), on the subjects used (many were not actually autistic), or on the results (the percentages of children who were said to have improved were lower than the figures given in the source articles, and reports of adverse effects were considerably higher than cited).

Holding therapy generated a great deal of controversy in the late 1980's and was taken up by large numbers of parents. Promised evaluative studies never emerged and there is no adequate information about either long or short term effectiveness.

Facilitated Communication

Facilitated Communication involves a facilitator supporting the client's hand, wrist or arm whilst the individual uses a key- or letter board to spell out words, phrases or sentences. Its use with people with autism is based on the theory that many of their difficulties result from a movement disorder, rather than social or communication deficits. The facilitator should presume that the client possesses unrecognised literacy skills; the provision of physical support can then lead to "Communication Unbound" (18).

It was claimed that by using Facilitated Communication people with autism were able to demonstrate levels

Table 1 A review of controlled trials of facilitated communication, 1990–1996 a

| Total studies | 45 |
|---|-----|
| Independent communication confirmed b | 8 |
| No evidence of independent communication | 37 |
| Total subjects | 359 |
| Autistic/ Pervasive Developmental Disorders | 265 |
| Learning Disabled (moderate to profound) | 82 |
| Cerebral Palsy | 9 |
| Other (head injury; unknown) | 3 |
| No. of subjects for whom independent communication confirmed ^c | 23 |
| No. of subjects showing no evidence of independent communication | 336 |

^a Data summarised in this table are based on the reviews of Green, 1994; Howlin, 1994 and subsequent articles in the Journal of Autism and Developmental Disorders

of knowledge, understanding, or literary skills, which would be remarkable even for individuals of superior intellectual ability and education. "Many are now communicating ... and producing written language of such complexity as to challenge commonly held beliefs about the language of people diagnosed as autistic or significantly intellectually impaired" (34).

However, there have been increasing, and wide-spread concerns about this form of intervention. Firstly, the results of independent evaluations consistently indicate that when both client and facilitator are provided with the same information, success is relatively good; if they are provided with different information, success rates are extremely low. In a review of the literature up to 1996, 45 control trials of Facilitated Communication were identified, involving over 350 subjects. As Table 1 indicates, independent communication was confirmed in only around 6% of subjects. Even in these cases, responses were often only partially correct, and generally consisted of minimal, one word answers.

In order to overcome many of the criticisms raised by proponents of this treatment, attempts at evaluation have become increasingly more sophisticated. In one of the most recent of these, Bebko et al. (11) employed multiple assessment methods with 20 students on two separate occasions. Findings differed across methods and between occasions, but unlike many previous studies the authors did find some evidence of independent communication in 9 subjects. However, the most striking finding was that amongst students who were clearly capable of responding independently, their responses under facilitated conditions were actually inferior to their unsupported responses! The authors suggest that

such students may become more passive in their responding when using Facilitated Communication and they conclude that in a quarter of their sample there was evidence that communication was hindered rather than enhanced in the presence of a facilitator.

Secondly, there are concerns that an over-emphasis on facilitation techniques can have a negative impact on children's progress more generally. Thus, there are indications that in schools or educational districts where there has been a major transfer of resources into Facilitated Communication, this has been to the detriment of the wider curriculum.

Thirdly, the remarkable typescripts sometimes produced have led to unrealistic expectations of children's abilities, and in some cases have resulted in children being inappropriately transferred to mainstream and academically demanding courses with which they are unable to cope.

Finally, and most disturbingly, there are grave concerns about the many unfounded accusations of sexual abuse against parents or other carers made by children in the course of facilitation sessions (67, 126).

So extensive have been these criticisms that in 1994 the American Psychological Association (3) adopted the resolution that: "Facilitated Communication is a controversial and unproved procedure with no scientifically demonstrated support for its efficacy".

Pet therapies

Claims of apparently dramatic improvements in behaviour after exposure to pet therapy of various kinds, appear in the press from time to time. As one mother, somewhat ruefully wrote, "Nobody wants to give up without a good fight... If you had a child like this you would try everything (even putting your child into a tank with dolphins)" (106).

Redefer and Goodman (121) report on improvements in social interactions and reductions in stereotyped behaviours after children with autism were exposed to a dog (breed unspecified) for 18×20 minute sessions. However, the role of the human therapist in this experiment could not be disentangled, and although the authors suggest that a combination of animal therapy and peer mediated intervention might be "maximally productive", they provide little practical or theoretical evidence to support such a view.

The Doman-Delacato method

"Patterning" or the hands-on, systematic exercising of autistic children by their parents and usually teams of volunteers, as advocated by Glenn Doman and Carl Delacato was once viewed as another possible cure for

^b Communication rated as "Confirmed" if established in >10% of subjects

c For individual subjects "Confirmed" indicates minimal naming responses – usually single words; partially correct responses are also included

autism (36). By stimulating muscle activity in a controlled and intensive manner, it was claimed that this could repair damaged neural networks. Although any intervention involving intensive one-to-one interactions for many hours a day is almost bound to have some positive effects, evidence for permanent change, or any concomitant neurological improvements, has never been forthcoming. Despite the enormous demands (both financial and physical) made on families undertaking this form of therapy, there has been no systematic appraisal of its effectiveness with children who are autistic, and serious criticisms about the use of such methods generally have been raised by a number of authors (35, 166).

The Higashi schools and Daily Life Therapy

Daily Life Therapy, as practised in the Japanese run Higashi schools, has been claimed to produce unprecedented progress in children with autism (80, 81, 82). It is postulated that the high anxiety levels of many children with autism can be reduced by physical exercise, which releases endorphins controlling anxiety and frustration. The focus of the curriculum is on group work, music, art and drama, a vigourous physical education programme and a rigorous control of challenging and inappropriate behaviours.

Unlike the schools in Japan, which stress the importance of integration, the American based schools offer only segregated provision. The Boston school, which also accepts children from Europe, has around 100 students, aged between 3 and 21 years with a wide range of ability and disability. However, concerns have been expressed about the rigidity of the approach, the lack of emphasis on individual development and the rather sparse living conditions (17, 118). There have even been reports of physical abuse (32). Early promotional publicity suggested that Daily Life Therapy could "cure" autism, although the claims are now more modest, and focus on the reduction of behavioural problems. The fees are expensive and because most of the children are boarders, this means they are separated from their families. Parental accounts generally suggest that, in the short term at least, behavioural difficulties decrease, often very markedly, and compliance improves, although there are fewer reports of dramatic improvements in social-communication skills.

There have been no long-term or comparative outcome evaluations of children who have attended the Higashi school nor any assessments of the advantages or possible limitations for individual students. Whereas a number of reports indicate that there may well be components of the programme that could be usefully introduced into more traditional teaching curricula, it has also been suggested that the Higashi philosophy could

profit from incorporating practices derived from broader based educational approaches (17, 40, 118, 157).

Intensive behavioural programmes

There is little doubt that the use of behavioural procedures has resulted in major improvements in the education, management and treatment of children with autism over the last three decades. The benefits are particularly striking when parents are involved in therapy and such techniques are now widely accepted as playing a crucial role in intervention (27, 65, 92, 142, 147). It is clear that behaviourally based strategies can be used to reduce many behavioural difficulties or to improve certain aspects of social, communicative and cognitive impairments. Nevertheless, until recently they have been viewed as a means of ameliorating some of the deficits and difficulties associated with autism, not as a cure for the fundamental disorder. In 1987, however, Ivar Lovaas published a paper (93) reporting far more dramatic outcomes. A group of 19 pre-school children, who had been involved in intensive (40 or more hours a week), home based, behavioural programmes for two years or more, was followed up at the age of seven. Their progress was compared with that of a less intensively treated control group (receiving 10 hours or less intervention a week). Before treatment began the mean IQ of the experimental group was 53 (range 30-82) and that of the control group 46 (range 30-80). At follow-up, the experimental children were found to have gained and maintained 20 IQ points, 9 children were placed in mainstream schools and several were described as being "indistinguishable from their normal peers". In contrast, the IQ of the control children had risen by only 8 points and all but one child remained in a special school.

McEachin, Smith and Lovaas (100) reported on the same children some years later, when the experimental group had mean age of 13 years (range 9-19) and the controls a mean age of 10 (range 6-13). The mean IQ of the intensively treated children was 84.5 and that of the control group 54.9. Vineland Adaptive Behaviour composite scores were superior in the experimental group (71.6:45.7) and Maladaptive Behaviour scores were significantly lower (10.6:17.1). A wide range of other measures also indicated that the experimental group was functioning at a much higher level than the controls. Approximately half the group (9 children) had done particularly well and 8 were described as having "normal functioning" and as being "indistinguishable from average children on tests of intelligence and adaptive behaviour". A later paper by Perry et al. (113) also claims "recovery from autism" in two siblings with autism exposed to the Lovaas programme.

Perhaps not surprisingly, these reports have generated considerable controversy and criticism. Particular concerns have been raised about the lack of random assignment to treatment and control groups, the variability of measures used to assess functioning before and after treatment, the confusing way in which IQ data are presented, the representativeness and comparability of the groups of children involved, the use of different cut-off ages for the selection of echolalic and nonspeaking children and the failure to use independent assessors in the evaluation of the programme (105). By far the greatest controversy, however, has arisen over the use of terms such as "cure", "recovery" or "normal functioning". It is highly likely that any child exposed to such intensive treatment would, at least in the short term show improvements in adaptive behaviour, and possibly, too, in their scores on IQ tests. Certainly, other studies have reported marked improvements in IQ scores following pre-school intervention programmes (59). However, important as such gains are, they do not indicate normal or even near normal functioning. As Mesibov (105) points out, "There are many high functioning people with autism with near-normal IQ's participating in regular public school programs who remain severely handicapped. To think otherwise is to minimize the severity of the social, cognitive, and communicative aspects of autism". Mesibov (105) together with Mundy (108) also note that many of the skills required for normal functioning are not assessed. Thus, there are no measures of social interaction, friendships, conceptual abilities, social communication, obsessional and ritualistic behaviours, or disturbances of mood; all of which are important aspects of autism.

Lovaas himself (94) points to other caveats concerning the outcome of treatment. Firstly, the very intensity of the therapy makes it difficult at times to recruit adequate numbers of therapists and even more difficult for others to replicate this work. Secondly, although around half of the children involved in the intervention programme did make good progress, this leaves around half who did not. "What is left to do is to be of more help to the other half... and this may be a much more time consuming and challenging job than that of helping create the best outcome results". Lovaas notes that the subjects who did best were those who acquired verbal imitation within the first 3 months of treatment; those who did not appeared to be more dependent on visual learning and for them perhaps "basic research in areas other than reinforcement theory may play an important role in the future". For the present, Lovaas' programme clearly confirms the power of behavioural interventions. The true extent of the benefits, however, still requires greater exploration and longer term evaluations, covering many other aspects of functioning are needed if the true costeffectiveness of the time, effort and energy expended by families is to be adequately assessed.

Other approaches to treatment

Gentle Teaching

"Gentle Teaching" (101) is claimed to be successful for all individuals with learning difficulties and challenging behaviours. It is defined as "a nonaversive method of reducing challenging behaviour that aims to teach bonding and interdependence through gentleness, respect and solidarity. Emphasis is placed on the importance of unconditional valuing in the caregiving and therapeutic process" (72). The technique rose to popularity in the wake of growing concerns about the use of aversive procedures but has generated anything but gentle arguments. Proponents describe behavioural approaches as "sinful" (31), as a "culture of death" (21, 22) and as "deliberate torture" (104). In turn, Gentle Teaching has been dismissed as "biased, unscientific and naive (or)... as a mere recombinant of positive reinforcement, manual guidance, prompting and extinction" (10).

At the heart of the approach is the belief (similar to that of the Option Method) that the therapist must learn to value and respond with affection to the client and to recognise "the inherent dignity of each (mentally handicapped) person" (104). The techniques involved include reinforcement, extinction, interruption and redirection of responses, environmental and stimulus control, errorless learning, shaping and fading, teaching quietly, and feedback and assistance. McGee (101) states that although the techniques themselves are not new, "what is new is that mixtures of these techniques enable us to avoid using punishment and, more importantly, teach interactional control which leads to bonding". The strength of Gentle Teaching lies in its aim to improve the quality of life for people with learning difficulties by concentrating on environmental and interpersonal factors, rather than focusing specifically on maladaptive behaviours. However, as Jones and McCaughey (72) point out, there are also weaknesses. Firstly, clear and explicit definitions of what the technique actually entails are difficult to find. This problem is exacerbated by the use of unnecessary jargon and by the fact that the emphasis on different components of treatment has shifted over time (the focus on bonding, for example, seems to have disappeared in recent reports (102)). Secondly, uncritical acceptance of terms such as reward or punishment can lead to problems; for an individual whose self injury is used specifically to escape from social situations, the Gentle Teaching process, with its emphasis on interaction, may in fact be highly punitive and aversive (42). Untested assumptions about the underlying causes of challenging behaviour can also be dangerous. Aggression or self injury, for example, may be indicators of pain or illness; they are not always an attempt to communicate unhappiness or frustration.

More importantly, the effectiveness of this approach is still to be demonstrated. Although it has been

claimed (103) that aggressive, self injurious or withdrawn behaviours could be reduced, on average by 74%, controlled studies have indicated that Gentle Teaching is less effective than other techniques (including visual screening; differential reinforcement; graduated guidance, edible reinforcers and restraint (10, 70, 71, 73, 112)).

Jones and McCaughey (72) in a well balanced review concluded that there are, in fact, relatively few differences between Gentle Teaching and other behavioural treatments. Recognition of the positive aspects of both these approaches and an end to rhetoric, misinformation and personal abuse might lead to far more benefits for people with autism and other learning difficulties.

Sensory integration therapy

Sensory integration is the ability to process, immediately and simultaneously, the many different sensory messages that result from even the simplest action. It has long been established that children with autism have problems in dealing with complex sensory stimuli (110) and that they may be sensitive to particular kinds of stimuli (such as noise or texture). Sensory integration therapy (9) aims to improve sensory awareness and responsivity by using a variety of stimuli, such as swings, balls, trampolines, soft brushes and cloths for rubbing the skin, fragrant extracts, massage, coloured lights or objects with unusual textures. "Deep pressure therapy", (e.g. rolling children up tightly in mats or mattresses) may also be involved.

There are a few small scale reports of the effectiveness of these techniques. Brocklehurst-Woods (23) and Dura et al. (37) found that tactile and vestibular stimulation reduced stereotyped or self injurious behaviours in 3 subjects with learning disabilities. Temple Grandin, an accomplished animal psychologist, who has autism, also claims that deep pressure therapy has been effective in reducing stress and anxiety (51, 52, 53). However, reviews by Shane (146), Arendt et al. (6) and Mason and Iwata (99) point to the totally inadequate experimental design of most studies. Despite fierce criticism there has been an extraordinary growth in the use of these techniques in recent years and Rimland (127, 128) suggests that around a quarter of programmes for autistic children in the U.S. were utilising this approach.

Music therapy

Music therapy does not claim to be able to "cure" autism, but it is said to alleviate problem behaviours and to improve social functioning (1), Alvin was one of the

first to report the use of music therapy with severely handicapped autistic children, and there have been many subsequent studies that support this approach (see 155 for review). However, in most cases, the accounts have been entirely anecdotal and/or based on single case reports with claims that for example "music therapy payed a significant role in developing... emotional, integrative and self organisational experiences" (155). In others the experimental design has been seriously flawed. Muller (107), using rather more rigorous evaluation procedures, found an increase in turn taking behaviour and some decrease in socially avoidant behaviour although not all children improved and in some there was a definite deterioration in behaviour. Children who had higher verbal ability and were less obsessional and ritualistic in their behaviours tended to respond better than others, but the results were not clear cut and findings were complicated by the fact that several children were also involved in holding therapy during the same period of time.

Overall, it seems that musically based interventions as one component of a wider educational curriculum may be helpful for some children, presumably because of the emphasis on listening skills, turn taking and social reciprocity under conditions that avoid the need for complex language or verbal understanding. However, once again, there is no evidence of any long term benefits and Muller's data suggest that for some children musical interventions may have no, or even a negative impact.

Cranial osteopathy

This involves very gentle manipulation being given to various parts of the body, particularly the head. It is claimed that a disturbed pattern of motion in the frontal lobes of the brain can sometimes be identified, or that the whole head is tight and unyielding. Treatment may last for several months, and the effects are said to range from minor reductions in hyperactivity to major improvements in communication. However, there are no adequate evaluative studies of this approach, and claims for success remain subjective and anecdotal.

Physical exercise

Vigourous exercise has been reported to produce positive effects in a number of studies. It is, of course, a crucial component of Daily Life Therapy, as practised in the Higashi schools and Martha Welch suggested that it might play some role in the effectiveness of Holding Therapy. Rimland (124, 125) found that 48% (out of 1286 parents) reported improvements following physical exercise; reductions in stereotyped, disruptive and

hyperactive behaviours, sleep disturbance, aggression, anxiety, self injury, and depression have been noted in other studies. Exercise has been claimed to improve attention span, social skills, alertness, work performance and cognitive functioning in various groups of subjects, including some with autism (41). Elliott et al (41) used a variety of techniques to elevate heart rates in 6 adults with autism and then compared general motor training (elevating heart beats to 90–120 beats per minute) with more vigourous exercise (elevating heart beats to above 130). Only the latter resulted in any significant improvements, leading the authors to suggest that *vigourous* aerobic exercise, may be a useful component of integration programmes.

Psychotherapy

Although in his original writings on autism it is clear that Kanner believed the disorder to be biologically determined, subsequent comments on the lack of warmth shown by parents and their tendency towards a "mechanization of human contacts" (76) led many to view the condition as being predominantly psychogenic in origin (15, 19, 109). This had a profound and widespread influence on therapeutic practice, and throughout the 1950's and 1960's individual psychotherapy (mainly in the form of psychoanalytically oriented nondirective play therapy) was considered the treatment of choice (48, 151). Almost all reports of psychotherapeutic interventions have been single cases studies (96), and there have been virtually no systematic attempts at evaluation. Campbell et al. (27) concluded that "psychoanalysis as a treatment for autism has a limited value" although they also observe that Hobson (61) has discussed some possible strengths of this approach, including the emphasis on object relations and affective contact.

For older, more able individuals with autism, individual psychotherapy or counselling may be useful in helping them to deal with anxiety or depression, and the pain that may come from recognising their difficulties and differences. However, unless therapy is combined with direct practical advice on how to deal with problems, the outcome is unlikely to be effective.

Pharmacological treatments

In a recent review of treatments for children with autism, Rimland and Baker (129) note: "The vast majority of parents who take their autistic children to medical professionals are offered prescription drugs as the treatment of choice". Whilst this statement is probably **not** true for parents in much of Europe, it is clear that in the US a wide variety of medication is used to treat or

Table 2 Most frequently prescribed drugs for children with autism in the USA (from Rimland & Baker, 1996)

| Drug | No. prescriptions | % children rated as "improved" | % rated as "worse" a |
|-------------|----------------------|--------------------------------|----------------------|
| Ritalin | 1971 | 27 | 47 |
| Mellaril | 1668 | 34 | 28 |
| Benedryl | 1582 | 26 | 22 |
| Dilantin | 878 | 24 | 28 |
| Haloperidol | 852 | 37 | 39 |
| Tegretol | 799 | 33 | 24 |

^a Remainder of cases rated as showing no change

ameliorate many of the problems associated with autism. Surveys of American parents indicate the huge range of drugs prescribed and the variation in parental views of their effectiveness. In a study based on data from 6,568 parents, Rimland and Baker (129) found 6 particular drugs to be used most frequently, although their effectiveness seemed very variable. (See Table 2.)

Another survey conducted by Aman et al. (2) and based on replies from 838 carers, found that over 50% of the sample was taking some form of drug or vitamin treatment. Ratings of parental satisfaction with the different forms of treatment indicated that anticonvulsants, antidepressants and stimulants were most popular. Least were vitamins, mood stabilizers, neuroleptic, antihypertensives and sedative/hypnotic.

Drugs may be prescribed for many different reasons although the most common reasons tend to be hyperactivity, aggressive and destructive behaviours, self injury, stereotypies and obsessions, anxiety and depression, and sleeping problems. Medication may also be required for associated problems, such as epilepsy. Some drugs, such as fenfluramine, have also been prescribed as a means of reducing autistic symptomatology more generally.

Despite the use of so many different drugs in the USA, evaluations are frequently inadequate (86). Campbell et al. (27) suggest that only haloperidol, fenfluramine, naltrexone, clomipramine and clonidine have been appropriately investigated.

Haloperidol

Haloperidol, a neuroleptic, has been found to be effective in large scale studies in reducing reduce disruptive, aggressive, non co-operative and hyperactive behaviours. The effects tend to be better in older rather than younger children (at least within the 2–8 year age range) and for children who initially respond well, the long term effects are also good (25, 113). However, sedation can occur and the other main side effect is withdrawal or tardive dyskinesia (7).

Fenfluramine

Fenfluramine is a serotonin-depleting agent and its use in autism was based largely on findings of elevated serotonin levels in some individuals with this condition. Despite the very positive reports of large scale, multicentre studies in the U.S. during the 1980's (132), subsequent investigations began to indicate a wide range of negative side effects (12). These included mood disturbances, irritability, agitation, eating and digestive problems, insomnia or lethargy, weight loss, and learning problems. By 1996, concerns about side effects were so widespread that Campbell et al. (27) conclude "fenfluramine is not viewed as a therapeutic agent for autism".

Naltrexone

Naltrexone is an opiate antagonist that has been used particularly in the treatment of self injurious behaviour and hyperactivity (26, 27, 60, 84). Bouvard et al. (20) also noted improvements in sociability, communication, and attention; although Benjamin et al. (13) reported initial increases in self injury. A recent study in Holland (161) found no therapeutic effects for adults with autism and/or self injurious behaviours, and in some cases behaviour problems increased. In general, Campbell and Cueva (25) concluded that there have been too few double blind and placebo controlled trials of adequate size to confirm the drug's effectiveness.

Clomipramine

Clomipramine is a serotonin re-uptake inhibitor from the class of tricyclic antidepressants. Its apparent effectiveness in treating obsessive compulsive disorders and repetitive motor behaviours led to its trials with autistic patients. However, in a recent double blind study of 24 subjects aged between 6 and 18 years, Sanchez et al. (140) found improvements in only a minority of cases. Adverse effects can be serious (50) and include grand mal seizures, behavioural toxicity, constipation and sever urinary retention. Not surprisingly, Campbell et al. (27) warn, "It is recommended that this class of drugs be used judiciously in individuals with autism".

Clonidine

Used to reduce tics, hyperactivity, impulsivity and inattention in Tourette's syndrome, Clonidine has been used more recently with children with autism. However, studies to date have been very small in size, and few conclusions can be drawn about its efficacy or safety. There is some indication that hyperactivity may be re-

duced, although even here findings are variable and the drug may increase the risk of cardiac problems (27).

Methylphenidate (Ritalin)

Although stimulant medication has been widely used in the U.S. to control problems of over-activity and attention there are few, if any adequately controlled trials of its effectiveness with children with autism. The largest is that of Quintana et al. (119) who used a 6 week long cross-over, placebo design with 10 children. A "modest" improvement in hyperactivity was recorded, and there were no obvious side effects although problems such as irritability, tantrums and stereotyped movements have been noted in other studies (4).

Many other pharmacological approaches to the treatment of autism have been tried over the years, but as Campbell et al. (27) warn, "No conclusions can be made concerning the efficacy and safety of these agents because the findings are based on small sample sizes and open studies without placebo control". For updates on the effects of other drug treatments see recent reviews (25, 30, 86).

Dietary and vitamin treatments

It has been suggested that food intolerance or allergic responses may be responsible for at least some of the behavioural disturbances observed in autism (16, 29, 156, 159). Bidet et al. (16) found that 7 out of 10 autistic subjects exhibited at least one positive test towards an allergen and Rimland (125) also notes that around 40–50% of parents who had removed milk, wheat or sugar from their children's diet felt that this had been beneficial. However, Renzoni et al. (122) failed to find evidence of food hypersensitivity in children with autism, when compared to age and sex matched controls.

As in any group of children, a small minority of individuals may show abnormal reactions to specific substances, but in many cases children are incorrectly identified as being "allergic" (153). If sensitivity is suspected, this will need to be systematically tested, usually by means of an exclusion diet. However, it is important to be aware that for many autistic children food may be a very important source of motivation and to remove favoured items, unnecessarily, from the child's menu could well result in increased distress and disturbance.

There is surprisingly little evidence that the restricted diets of some children with autism do result in nutritional deficiencies. Raiten and Massaro (120) in a study of the diets of 40 autistic and 34 control children found that the autistic group actually had a significantly *greater* intake of most nutrients. Despite this, vitamin treat-

ments especially those involving vitamin B6 (pyridoxine) and magnesium are often recommended (85, 97, 98). Surveys by Rimland (127, 128) and Rimland and Baker (129) found that up to 46% of parents reported improvements in their child following this treatment, but 5% were said to show a deterioration in behaviour. Side effects such as sensory neuropathy, headache, depression, vomiting and photosensitivity have been reported by Pfeiffer et al. (114) reviewing recent evidence for the efficacy of B6 and magnesium note the methodological problems of many investigations (small sample size, lack of clear information on dosage, dubious reliability and validity of outcome measures and insufficient long term follow-up data). They conclude that, as with any other treatment, high doses of vitamins should not be given casually or indiscriminately, and the possibility of unwanted side effects should not be discounted. What is helpful for one child may not be so for another, and individual monitoring and close attention to possible negative responses should always be an integral part of the treatment regime.

Educational programmes

In general, of course, these should not be regarded as "treatments" for autism; the aim is to develop children's skills to the optimum level possible. Exactly what that level is will be determined by the child's own innate abilities, but certain types of teaching approach are likely to be more effective than others.

The TEACCH programme

The importance of structured educational programmes for children with autism has been well documented over the last quarter of a century (43, 45, 54, 56, 142). Schopler et al. (142) found that autistic pupils made more progress in structured settings and Rutter and Bartak demonstrated that children exposed to task oriented, "academic" programmes made better educational progress and showed superior language and work skills than children in less structured environments.

The TEACCH programme, developed by Eric Schopler and his colleagues in North Carolina, and now widely used throughout the USA and many parts of Europe, is an educational approach that is founded on the need for structure. It is not a curriculum as such, but more a framework for teaching that emphasises the need for appropriate environmental organisation and the use of clear visual cues to circumvent communication difficulties. The programme takes account of developmental levels and the importance of individually based teaching, as well as using other behavioural and cogni-

tive approaches as necessary (143). There have been many reports of the effectiveness of this approach (27) although there have been no recent comparative evaluations.

In the hands of skilled teachers there is little doubt that such a framework for teaching has many advantages. However, there is a danger that less experienced teachers may apply the approach in a more rigid way than is appropriate, thereby sacrificing individuality and spontaneity. The need to ensure that, over time, students are eventually able to cope within far less structured, community environments must also be recognised. Otherwise, the gains achieved using such a highly specialised approach may be lost once the student is exposed to a different environment.

Other educational approaches

There are of course many other different approaches to teaching children with autism. Some involve integration, some segregation, and some a mixture of the two. Many focus specifically on teaching strategies that are devised to overcome the fundamental impairments associated with autism. Quill (117), for example, provides much useful information on programmes designed to improve social and communication functioning. Butera and Haywood (24) describe the "Bright Start Programme", which concentrates on the development of cognitive and metacognitive abilities. Harris (59) summarises changes in teaching approaches over the last two decades, noting the move towards more naturalistic approaches and the use of intrinsic rather than extrinsic reinforcers, the reduction of aversive procedures, the increasing emphasis on social relationships with peers, the development of more effective communication strategies (rather than a focus on speech) and the value of functional assessments in the reduction of behavioural problems.

Nevertheless, despite the undoubted improvements in education for autistic children, much still remains to be done. Many children remain nonverbal, and the technological advances that have enabled individuals with severe physical impairments to communicate more effectively, still need to be further adapted to meet the needs of autistic students. Moreover, the individual benefits and limitations of specific teaching programmes require much more detailed evaluation. In addition, although advances in the functional assessment of behaviour and reductions in the use of aversive procedures can only be welcomed, flexibility in both practice and philosophy continues to be required. Not all challenging behaviours, for example, can be fitted neatly into the functional categories encapsulated in measures such as the Motivation Assessment Scale (38); it is also argued that the present nonaversive technology may be insuffi-

Table 3 A summary of early intervention studies for children with autism 1985-1993. (Based on Rogers, 1996)

| Author | N | Mean Age ^a (sd/Range) | Mean IQ (sd/Range) | Comp. Group | Length a X time | A:C Ratio | Base | Type of Programme |
|--|----|----------------------------------|---|--|--|----------------|---------------|--|
| Hoyson et al., 1984 | 6 | 40 | ? >70 | None | 6–16 | 4:10 | School | Developmen- tal+behavioural |
| Fenske et al., 1985 | 9 | 48.9 sd=5.6 (42–58) | Most < basal on PPVT | 9 >5yrs | 45.9 (13–101) ×27 hrs p. week | ? | Home & school | Intensive behavioural programme |
| Anderson et al., 1987 | 14 | 42.79 (18–64) | 57.25 (21–86) | None | 12–24 × 20 hrs p. week | 1:1 | Home | Modified Lovaas programme |
| Harris et al., 1990 | 10 | 56.9 (49–66) | 65.8 (43–83) | Normal peers | 7.9 (6–11); × school day | 3:5 to 3:10 | School | Developmental curriculum |
| Rogers et al., 1991 | 49 | 45.77 sd=10.0 | 70.30 sd=22.91 | Mixed behav. problems | 18×22 hrs p. week | 1:2 | School | Emphasis on lan- guage, social, play and emo- tions |
| Lovaas et al., 1987 & McEachin et al., 1993 | 19 | 34.6 (24–46) | Initial 53 (30–82) FU (i) 83 (ii) 85 | Matched controls; <10 hours per week therapy | 24×40 hrs p. week | 1:1 | Home | Behavioural programmes |

^a Ages and length of programmes are given in months. Age refers to time programme began

cient for some students who require more sophisticated aversive procedures to gain control over highly dangerous or disruptive behaviours (59).

Early intervention programmes

The highly intensive, behaviourally based programmes of Lovaas and his colleagues have not been the only ones to indicate the importance of early intervention. Rogers (133) reviews the outcome of 6 early intervention projects for children with autism that were conducted between 1985 and 1993. Details of these programmes are presented in Tables 3 and 4.

As Rogers makes clear, all the studies suffer from important methodological flaws, including the failure randomly to assign children to non/treatment groups and a lack of blind evaluations. Many are based on very small samples and the numerous different components involved in therapy further complicate the analysis. The length and intensity of therapy is also variable, ranging from 15 to 40 hours a week and from 6 months to over two years. Nevertheless, it would seem that children who begin receiving intervention between the ages of 2 and 4 make better progress than those who receive similar help at a later age. Successful interventions also involve intensive support (of 15 or more hours per week), tend to last at least 6 months and require a high adult: child ratio. However, as Rogers notes, many more ques-

tions remain to be answered before the specific effects of early intervention can be determined or before much more extensive funding can be justified. These include the effects of different types of treatment, the responses of different subgroups of children within the autistic spectrum and isolation of the crucial treatment variables responsible for change. Other variables that need to be more rigorously evaluated are the comparative roles of parents and other professionals, the value of one-to-one versus group teaching, and the optimum timing, intensity and length of intervention programmes. There is an urgent need for the development of standardised protocols to assess functioning before and after treatment in order to make valid and reliable comparisons between programmes. Outcome studies also need to span a much longer time period.

Are there lessons to be learned from the miracle workers?

In examining the more extravagant claims made for some of the therapies described in the first section of this paper, two main factors emerge. Firstly, there is the assumption that all children are equally amenable to therapy. There are no data on who responds well and who does not. There is no attempt to carry out individual assessments of children, nor to relate individual characteristics to outcome. Many treatments, too, are not exclusive to children with autism and may claim

Table 4 Outcomes of early intervention studies

| Author | Outcome summary |
|------------------|--|
| Hoyson 1984 | Significant increases in developmental rates in all areas. |
| Fenske 1985 | 67% of children entering programme before 5 years of age achieved "positive outcome"; 44% in mainstream school. Only 11% of those entering after 5 had "positive outcome"; only 11% in regular school. |
| Anderson 1987 | Significant gains in language, self-care, social and academic development in first year. Gains continued in children who remained in therapy for 2 years. However, no children placed in mainstream school. |
| Harris 1990 | Language age (PPVT) increased by average of 10.7 months over 7.9 months of intervention. |
| Rogers 1991 | Significant changes in cognition, perceptual/motor, social/emotional and language skills. Autistic symptoms declined. Autistic children made as much progress as controls. These improvements maintained or increased over the following 12–18 months in treatment. |
| Lovaas 1987 | No IQ change in control group; experimental group increased IQ by a mean of 20 points. 9 subjects had IQ's within normal range and had transferred to mainstream schools. |
| McEachin 1993 | At a mean age of 11.5 years (i.e. 5 years after intervention ceased) experimental children had maintained IQ gains of over 30 points; control children had increased by only 8–9 points). Compared with controls, experimental children had made significant improvements in social functioning (Vineland) and maladaptive behaviours had decreased. 47% in mainstream school; but none of controls. 8 said to be "normal functioning" |

impressive results for a whole range of other problems from depression to dysfunctional family life.

Secondly, most involve highly intensive, one to one interaction, either with parents or other professionals. The interaction may last for relatively brief periods of time or may be much more prolonged (as in the Doman Delacato programme or the Options Method). It would be very **unlikely** that this degree of stimulation could fail to have positive effects in the short term; the crucial question is whether or not these benefits endure when therapy is moderated or discontinued.

However, it is also important to recognise that even the least scientific of these interventions have certain positive factors in common. Such programmes offer families clear and concrete guidelines on what they themselves can do to help their child. Parents are explicitly encouraged to value their child as a person in his or her own right and to expect that he or she is capable of much more than they may hitherto have dreamed of. Moreover, parents themselves are often given far more time, care, attention and encouragement than is usually offered by hard pressed professionals working in staterun health, social services or educational settings. Neither should the value of giving parents faith in themselves and in their ability to help their child be un-

derestimated, although, at the same time, it is important to avoid raising false hopes, or setting unrealistic goals.

It must also be acknowledged that almost all of these programmes involve therapeutic strategies that may be of value for at least some children. The emphasis on physical contact or exercise involved in Holding therapy, the Doman Delacato techniques or Daily Life Therapy may well prove beneficial for many. A focus on communication skills and the need for augmentative forms of communication is the one positive feature of Facilitated Communication. The use of obsessional behaviours as rewards and as ways of gaining the child's co-operation is an undoubted strength of the Option Method. Music therapy may be an excellent way of encouraging reciprocity in some children, and programmes that emphasise more effective ways of integrating sensory input may be of value for others. Similarly, the avoidance of aversive procedures whenever possible and the emphasis on personal worth as embodied in Gentle Teaching are clearly important factors to bear in mind in any intervention programme.

Questions to ask before undertaking treatment

No matter how seductive the claims or glowing the testimonials from satisfied parents, it is essential to remember that there is no such thing as a universal panacea. Even within physical medicine, drugs that have brought widespread advantages to many, such as aspirin or antibiotics, may have no effects in certain conditions, and for some individuals, or some illnesses they may actually prove dangerous and harmful.

Before being tempted by promises of miracles, before parting with large amounts of money, or in some cases (as in specialist boarding school provision) from their own child, parents must be encouraged to seek the answers to at least the following questions:

- Who does this programme work best for? Is it more effective for children of high or low ability or for those with good language or poor communication skills? Does it work better with younger or older children? Are there any family factors that seem to be related to outcome?
- Which children does it work less well with? Are there any medical or physical risks, or any particular sub-groups of children who should be excluded?
- What assessments are carried out on individual children prior to treatment? What are the criteria for acceptance into treatment, and what are the exclusion criteria?
- What evaluation methods have been used to assess the outcome treatment? What objective and scientific evidence is there that children undergoing this therapy do better over time than those who have no spe-

- cial treatment, or who are involved in treatments of other kinds?
- Given the current age and the intellectual and linguistic functioning of my child, what is known about the likely prognosis (in the absence of any special treatments) as he or she grows older? Bearing this in mind, what is known about the long term effects of this particular treatment; what difference is it likely to make to my child as he or she reaches adolescence or adulthood?
- How much does it cost; how much time will be involved; what will be the pressures or restrictions on other aspects of family life?
- What alternative interventions might be tried? What information is there concerning the relative effectiveness of these?

If these questions cannot be answered satisfactorily, if there are no individual assessments before treatment begins and no formal outcome measures when it is ended, if the results are claimed to be universally successful, for any child or any level of disability, then it is important to be aware that money may be wasted, valuable time lost and much disappointment and heartbreak the result.

The effective components of treatment

The vast majority of professionals involved in the education and treatment of children with autism make no extravagant claims for success. They recognise the enormous differences between children and their very uneven and individualistic patterns of behavioural, cognitive, social and communicative functioning. Thus, any successful intervention programme will need to involve a wide range of different techniques. Furthermore, the choice of these techniques will depend not only on the child's skills and disabilities, but also on family factors that can affect the ways in which intervention strategies can be employed (65).

In general, however, the most successful programmes have the following components in common:

- A reliance on behaviourally oriented strategies, but in conjunction with a careful, and individualised analysis of the factors underlying difficult and disruptive behaviours and the involvement of families in therapy (65, 144, 147).
- The recognition that many so-called undesirable or challenging behaviours are a reflection of the child's inadequate communication skills and that by teaching more effective communication strategies, many previously disruptive activities (such as tantrums, aggression, repetitive speech, stereotypes or self injury) can be significantly reduced (38, 116, 145).

- Understanding the importance of obsessions and rituals, not just as an underlying cause of many behaviour problems, but also as having a vital role in reducing anxiety and as extremely powerful sources of motivation and reward (63, 64, 65).
- The need for structured teaching programmes with a particular emphasis on visually based cues that provide the child with a predictable and readily understandable environment, and one that minimises the confusion and distress that can result from reliance on verbal cues (74, 117, 141).
- A focus on the development of social-communication and play activities, especially with peers (88, 117, 165), and the exploration of the possible benefits of introducing specialist training programmes, for example to improve understanding of "Theory of Mind" (55, 111, 149).
- And, perhaps most importantly of all, recognition of the importance of early diagnosis and the provision of appropriate advice and support for parents. This, can do much to help minimise or avoid later problems for many of the difficulties that are viewed as seriously challenging in adult life, especially those that arise from inappropriate social interactions or the pursuit of ritualistic or obsessional interests, are frequently behaviours that have been present from an early age. All too often, it is not that the behaviours themselves have changed radically, but that society's attitude to these has altered. The response to a 3 year old child with a penchant for rubbing his hands on women's tights, for example, will be very different to the response to similar behaviour in a 30 year old!
- Finally, treatment approaches that are family centred, rather than exclusively child oriented would seem to offer most hope to the majority of parents. Establishing effective management strategies that can be implemented consistently, but in ways that do not demand extensive sacrifice in terms of time, money or other aspects of family life seem most likely to bring about steady improvements for all involved. The long term value of early and highly intensive behavioural programmes still awaits appropriate assessment (135). Until the cost effectiveness of this approach to intervention is fully evaluated, not only in terms of the child's progress, but taking account, too, of the demands on parents and the limitations that may be placed on family functioning as a whole, caution is needed before it is adopted on a much wider scale.

Conclusions

Although, as yet, there is no evidence of any cures for autism, appropriate treatment and education are clearly

essential in helping to minimise or avoid secondary behavioural problems and to ensure that children develop their existing skills to the full. Intervention in early childhood can have a major impact on the quality of life in adulthood, and is likely to prove far more cost effective than crisis management in later life. A focus on the *prevention* of problems will undoubtably be more productive than fruitless searches for cures.

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