

Evaluating psychological treatments for children with autism-spectrum disorders

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SUMMARY

The internet abounds with promises of ‘miracle cures’ for autism and within the published research literature there are numerous claims and counter-claims for the effectiveness of specific therapies. Systematic evaluations, however, indicate that few treatment programmes have a sound evidence base, and even those interventions that do produce positive findings are not successful for all children. To date, the best researched programmes are those involving intensive, early, home-based intervention, and those with a focus on communication and parent–child interaction. This article assesses the evidence base for some of the better evaluated therapies. There is, as yet, no evidence that any one programme is superior to all others. Indeed, large individual differences in response to intervention suggest that the focus of research now needs to shift to the study of which components of therapy work best for which children and under which conditions.

DECLARATION OF INTEREST

None.

evidence base for many treatments remains limited. This article reviews some of the interventions in common use today and examines the evidence for their effectiveness.

Interventions for children with autism-spectrum disorders

A valuable source of information on interventions can be found at www.researchautism.net. The aim of this website, which is associated with the UK National Autistic Society, is to review the published evidence on interventions in popular use. Over 80 interventions are currently listed, and the quality of evidence (both favourable and unfavourable) is rated by independent experts. The website covers developmental, educational, psychological, pharmacological and ‘alternative’ or ‘complimentary’ therapies (e.g. pet therapies, special diets and vitamin supplements, and some potentially hazardous interventions including chelation, testosterone regulation and hyperbaric oxygen). A rapid scan of this website indicates how few interventions do, in fact, have any evidence of effectiveness.

There are, however, a number of psychologically based interventions for which the evidence base is improving. These include interventions designed to enhance cognitive and behavioural functioning, and those with a focus on the specific deficits associated with autism, particularly in the areas of communication and social skills (Box 1).

Behaviour-based programmes

The effectiveness of behaviour-based interventions for autism was first reported in the 1960s, although the focus then was predominantly on the elimination of ‘undesirable’ behaviours, notably tantrums, aggression or self-injury, with frequent use of aversive procedures, including electric shock.

Throughout the 1970s, treatment was largely conducted on an in-patient hospital basis, often with very little involvement of the child’s family. The procedures used to improve skills such as social interaction or communication were

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Once considered to be a very rare condition, diagnosed mainly in children with severe intellectual impairments and no or very limited language, it is now known that autism can occur in individuals of all cognitive and linguistic levels and that its effects are life long. Consequently, the term ‘autism-spectrum disorder’ is now increasingly used in place of ‘autism’ to reflect the great variation in presentation. Awareness of this wider spectrum has also resulted in radical revision of prevalence estimates from approximately 4 per 10 000 in the 1970s to around 1% in recent epidemiological studies (Baird 2006). Moreover, up to half of all affected individuals are known to have an IQ in the normal range ($IQ \geq 70$). Recognition of the wider prevalence of autism-spectrum disorder has resulted, too, in growing acknowledgement of the need for effective interventions, and there has been a particular focus on developing programmes for newly diagnosed, pre-school children. However, the

BOX 1 Psychological interventions for autism-spectrum disorders

Behaviour based

- Discrete trial training
- Pivotal response training
- Early intensive behavioural intervention (EIBI)

Communication based

- Signing/picture systems (e.g. Makaton language)
- Picture Exchange Communication System (PECS; Bondy 1998)
- Teaching and Education for Autistic and Communication impaired Children (TEACCH; Schopler 1997)
- More than Words (Pepper 2004)
- EarlyBird programme (National Autistic Society 2009)
- Child's Talk
- Responsive Education and Prelinguistic Milieu Teaching (RPMT)

frequently highly prescriptive and inflexible, and took little account of individual factors such as the child's developmental level or the family situation. Over time, however, behavioural approaches have become more individually based, with parents now playing an integral role.

Applied behavioural analysis is a particular way of analysing the possible cause(s) of, and developing specific, behaviour-based strategies for, the treatment of behavioural deficits or excesses.

Discrete trial training and pivotal response training

Behaviour programmes typically involve a range of different strategies, with an emphasis on the reinforcement of desired behaviour. Two particularly well-researched approaches are discrete trial training and pivotal response training, both of which are designed to ensure that newly acquired skills generalise to the child's day-to-day environment.

Discrete trial training focuses specifically on developing skills in a hierarchical manner (using chaining, shaping and fading techniques), systematic identification of reinforcers, continuous monitoring of progress and generalisation to progressively less structured and more natural environments.

Pivotal response training also aims to foster generalisation and, as the name suggests, focuses on pivotal aspects of behaviour such as motivation and responsivity to multiple stimuli. It includes components such as child choice, turn-taking and

other maintenance strategies, and makes use of naturalistic settings and teaching procedures to enhance language, play and social behaviour.

Early intensive behavioural intervention

The pre-school, home-based behavioural programmes (early intensive behavioural intervention or EIBI) developed by Lovaas (1987) for 2- to 6-year-old children with autism exemplify the most intensive (40h per week for 2 years or more) use of behavioural techniques. Of the 19 children initially involved in the study, 9 (40%) showed increases in IQ of up to 30 points and made such significant progress that they were described as 'indistinguishable from normal peers'. A number of well-conducted case-control studies and one randomised controlled trial (RCT), all following the Lovaas model, have now been published (see systematic reviews: Rogers 2008; Ospina 2008; Howlin 2009; Reichow 2009). Several report major changes, especially in IQ, in the intervention group compared with the control group. However, progress in other areas of development was often more limited.

Although one meta-analysis (Spreckley 2008) suggests that there is no demonstrable advantage of EIBI over standard care, other systematic reviews conclude that the outcome is certainly positive for some children. Nevertheless, in all EIBI studies there are children who fail to improve, and others who regress during the course of intervention. This has led to attempts to identify the characteristics of the children who do and do not respond to early intensive intervention. Although initial IQ and language ability (especially receptive language) show some relationship with outcome, the impact of other variables (e.g. age at onset of treatment and severity of autism) is much less consistent.

Critics of these highly structured EIBI programmes – which in the UK can cost around £35 000–40 000 per child (Knapp 2009) – point to the enormous amount of time, money and energy required by the families involved, the restricted curriculum, and the limited range of outcome measures used. Thus, measures of treatment success tend to rely on standardised test scores, rather than assessments of behaviour, communication or social competence in real-life settings. The fact that the children are taught in a one-to-one setting at home, rather than learning with and from their peers, is a further issue of concern.

Furthermore, it should be noted that although the terms EIBI and applied behavioural analysis are sometimes used interchangeably, the two are not synonymous. Applied behavioural analysis refers to a much broader approach to behavioural

assessment and analysis, and is fundamental to many intervention and educational programmes. The effectiveness of teaching parents how to apply behavioural techniques in the home setting, without necessarily involving many hours and years of intervention by mental health professionals, has been evaluated in two RCTs (Jocelyn 1998; Tonge 2006), which report significant improvements in parents' mental health, knowledge of autism and perception of control, together with language gains in the children involved.

Communication-based programmes

Child-focused interventions

Despite the general effectiveness of behavioural approaches for children with autism-spectrum disorders, it has become increasingly evident that programmes with a specific emphasis on teaching speech have little impact, particularly for children with more severe receptive and expressive impairments (Howlin 2006). Recent intervention approaches therefore have focused on enhancing broader communicative abilities, rather than emphasising spoken language.

For example, techniques derived from applied behavioural analysis have been used to increase functional communication skills. Analysis of the underlying function of many so-called 'challenging' behaviours of children with autism-spectrum disorders indicates that these are frequently a reflection of their very limited communication skills. Failure to understand what is going on around them and the inability to express their needs and feelings verbally leave many children with no effective means of communicating other than by actions, which may be of an aggressive or disruptive nature. Systematic analysis of the communicative function of such behaviours and teaching the child to communicate the same needs but in a different and more acceptable communicative form (e.g. signs, gestures, electronic aids) has been shown in many single-case/case-series studies to reduce disruptive behaviours, while at the same time establishing more effective communication skills (Durand 2001; Prizant 2005).

Signing and picture systems

Although various signing or picture systems (e.g. Makaton language; Walker 1976) have been developed over the years to improve the communication skills of non-verbal children with autism, the evidence base for these is generally weak. The one exception, which has been systematically evaluated in RCTs, is the Picture Exchange Communication System (PECS; Bondy 1998). This

system is a picture-based approach to enhance communication. The programme follows a set sequence of stages, beginning with prompting the child to make requests and culminating in the child learning to comment spontaneously through non-verbal means. Single-case/case-series studies have reported increases in spontaneous communication (verbal and non-verbal), improvements in social interaction and joint attention, and reductions in behavioural problems (Howlin 2006).

Randomised controlled trials suggest rather more limited effects. One study found that in classes where teachers had training and ongoing consultation in PECS, pupils with autism showed significant increases in their rates of initiations and use of PECS in the classroom (Howlin 2007). However, there were no improvements in spoken language or scores on formal language tests, and no changes in autism symptomatology. Moreover, treatment effects were not maintained when intervention ceased. Yoder & Stone (2006a,b) also reported some positive effects of PECS on spontaneous communication, although not all children responded equally well (see discussion of individual responses to intervention below).

Teaching and Education of Autistic and related Communication-handicapped Children (TEACCH)

This widely used programme combines developmental, educational and behavioural strategies to enhance communication and minimise behavioural problems (Schopler 1997). There is a specific focus on environmental structure and predictability, with minimal dependence on verbal instruction and maximum use of visual cues.

Although significant gains have been reported in child behaviour, adaptive skills, cognitive ability and parent satisfaction, with some generalisation to non-treatment settings, comparative studies are few, sample sizes generally small, and the results tend to be somewhat inconsistent. For example, Tsang *et al* (2007) compared progress in 18 pre-school children receiving TEACCH with that of 16 controls in eclectic nursery education. After 6 months, the TEACCH group showed greater improvement in perception and motor skills, but no significant changes in IQ or communication; the control group showed greater improvement in daily living skills.

Interventions focusing on parent-child interaction

Several recent programmes designed to foster development in young children with autism have focused not on the child, but on facilitating parent-child communication. Parents trained in

the 'More than Words' programme (Pepper 2004), for example, showed improved communication and coping skills, and a reduction in stress. In children, increased vocabulary and communication skills, and a reduction in behavioural problems were reported (McConachie 2005).

The EarlyBird programme (National Autistic Society 2009), based on a similar format to More Than Words, is designed specifically to support parents in the period between diagnosis and transition to nursery or school. Again, the focus is on helping parents to improve children's social communication skills, as well as providing guidance on how to develop effective management strategies. There are no published studies on the impact of the EarlyBird programme on children's development, but parents involved in the programme report less stress and more positive perceptions of their child post-intervention.

A number of RCTs also demonstrate the success of programmes designed to enhance early parent-child interaction. Aldred *et al* (2004) evaluated the effectiveness of the 'Child's Talk' programme with the parents of 14 children with autism. This focuses on shared attention and parental sensitivity to the child's communicative attempts. Compared with the treatment-as-usual group, parents in the intervention group showed improvements in synchrony; their children showed decreases in autism severity and increases in social initiations, reciprocal social interaction and vocabulary. There were fewer changes in comprehension, adaptive behaviour and ritualistic or stereotyped behaviours.

Another intervention, based on principles similar to those of More than Words, is the Responsive Education and Prelinguistic Milieu Teaching (RPMT) technique (Yoder 2006a,b). This focuses on three main strategies for increasing language: helping parents to learn to follow the child's lead (because children learn best with things that interest them); increasing motivation to communicate (e.g. by placing desired objects just beyond reach); and using social games to provide natural reinforcement. Responsive Education and Prelinguistic Milieu Teaching has been shown to have positive effects on joint attention, turn-taking and child initiations.

Programmes focusing on social/emotional competence and understanding

Several interventions have been developed to improve some of the more fundamental deficits associated with autism, notably those related to imagination, and social and emotional understanding (Box 2). Most rely on case-control

BOX 2 Interventions focusing on socio-emotional competence and understanding

- Joint attention
- Symbolic play
- Theory of mind
- Social skills groups
- Social stories

or case-series designs, although a few RCTs are beginning to appear.

Joint attention and symbolic play

Deficits in these areas are among the earliest signs of developmental abnormality shown by young children with autism. Using a randomised controlled design, Kasari and colleagues (2006, 2008) evaluated the effectiveness of short-term interventions to enhance joint attention or symbolic play in children who were already receiving EIBI. Both groups showed greater improvement in expressive language than the group receiving behavioural intervention alone. Other changes were specific to the intervention received – thus children in the joint attention group made most improvement in joint attention and initiation; those in the symbolic play group made more gains in symbolic and interactive play.

Theory of mind

There are many different programmes designed to address the impairments in 'theory of mind' that are characteristic of autism-spectrum disorders. These range from group teaching programmes, books, cartoons, photographs and toy figures, to interactive DVDs and virtual reality techniques. Although the published findings are generally positive, improvements tend to be related to the specific skills taught. For example, Hadwin *et al* (1996) found that children increased their understanding and performance within taught domains (tasks related to understanding beliefs or emotions or imaginative play), but improvements did not generalise to untaught domains (i.e. those that had not been the focus of attention). Assessments of outcome also tend to rely on child or parent report, or analogue measures, and there is little evidence that the effects generalise to settings outside the teaching situation or that they significantly improve social functioning in real life. Moreover, the techniques used vary widely from study to study, and as sample size in most studies is small, it is not possible to determine which

particular type of intervention is likely to be most effective with which children.

No studies have examined the long-term effect of intervention (the longest follow-up studies are around 2 months). Even when children do show improvements in the areas that are the focus of training, there is the question of whether success is achieved by routes very different from those involved in typical development. In other words, have the children truly improved their ability to 'mind read', or have they simply developed alternative strategies to solve the tasks presented to them?

Social skills

Strategies designed to help children with autism-spectrum disorders improve social competence and social understanding include social skills groups, peer training, social scripts, structured joint play activities, and manualised programmes. Although very few specialist clinics or schools for pupils with autism do not run social skills groups of some kind, recent reviews (Rao 2007; Williams-White 2007; Ruble 2008) highlight the methodological problems of assessing such programmes. These include the lack of a universal definition of social skills, the very wide range of procedures and participants involved, divergent theoretical backgrounds, and the variety of settings. The general conclusion is that, despite their widespread use in both clinical and educational settings, empirical support for social skills training programmes is minimal, and it is evident that a far more systematic approach to research in this area is required.

Social stories

Social stories (Gray 1995) is another approach used to increase social skills and social understanding. Social stories can involve various formats, but frequently utilise simple, cartoon-type drawings to help even very young children with autism understand why they experience specific social problems, why other people react as they do, and how behaviour might be modified in future. Although there are several positive accounts of effectiveness, group sizes tend to be very small, experimental controls are generally absent and, as with social skills training more generally, the evidence base remains limited (Ali 2006).

General educational programmes

Only a minority of children with autism-spectrum disorders will have access to any of the highly specific, research-based programmes described earlier and, for most, appropriate educational provision from an early age is considered to be the most important form of intervention.

There are positive reports of the effects of many different kinds of specialist educational programmes, most of which are based on an eclectic mix of strategies derived from developmental, educational and behavioural research and theory (Harris 2005; Howlin 2008). For some children, high-quality, autism-focused, generic school placements may be just as effective as intensive home-based behavioural interventions (Magiati 2007; Spreckley 2008), and as yet there is no evidence that any one particular programme is superior to others. What seems to be important is that educational provision is highly structured, makes optimum use of visual teaching strategies, and is provided by staff with specialist knowledge of and expertise in dealing with the problems associated with autism. Close liaison between home and school is also crucial to ensure generalisation of skills taught.

Interventions for mental health problems

Most of the best evaluated interventions for autism-spectrum disorders have been conducted with children aged 6 years or younger. However, mental health difficulties, particularly anxiety and depression, affect many children as they move into adolescence, and young people with autism have a greatly increased risk of comorbid disorders of this kind.

Cognitive-behavioural therapy

In child and adolescent mental health service clinical practice, the use of cognitive-behavioural therapy (CBT) for children with autism varies widely, with respect to the type, intensity and duration of interventions used, the characteristics of the young people involved, and the presentation of comorbid problems. Although there is a growing evidence base for the use of cognitive-behavioural strategies for other groups of adolescents, evidence of effectiveness in people with autism is generally weak. There are only a few positive RCTs reported, mainly for anxiety disorders, anger management and social difficulties (Sofronoff 2005, 2007; Chalfant 2007; Reaven 2009; Wood 2009). There are presently no systematic data available to indicate for which individuals with autism CBT is likely to be most effective, or which CBT-based procedures are potentially most successful. There is also the question of how far techniques with a focus on cognitions can be adapted for use with individuals for whom abstraction, imagination, and social/emotional understanding are fundamentally impaired. The issue of whether cognitive-behavioural approaches can offer more than behavioural approaches requires far more research.

How to determine what works for whom?

As is clear from the above, there is no evidence that any one type of intervention is consistently more effective than another for children with autism-spectrum disorders. The findings also indicate that the effects of intervention are often relatively circumscribed. Thus, for example, programmes to improve non-verbal communication do just that – they do not tend to have a significant impact on verbal skills or broader cognitive functioning. It is important to note, too, that until relatively recently, almost all interventions have presented their findings in terms of group or average improvements and this frequently obscures individual differences in response to treatment.

The focus of research has therefore shifted from attempts to demonstrate that one programme is better than another – a somewhat nonsensical aim given the heterogeneity of autism-spectrum disorders – to attempts to identify factors that may predict which subgroups of children are most likely to respond to different interventions. For example, within behavioural programmes, there is some indication that pivotal response training may be more successful for children who are making more social initiations pre-intervention (Koegel 1999). The same authors also demonstrated that, having identified impaired social initiation as a barrier to progress, making this the next focus of pivotal training subsequently resulted in gains in that area as well.

Ingersoll and colleagues (2001), investigating the effects of an inclusive educational group programme for toddlers with autism-spectrum disorders, found that those with low social avoidance at baseline made more gains than those with high social avoidance initially.

Kasari *et al* (2008) explored the differential effects of training to enhance either joint attention or symbolic play. Overall, joint attention training had a greater impact on expressive language than symbolic play training, and the effect was most significant for children with the lowest levels of language pre-treatment.

In a study comparing PECS with RPMT, Yoder & Stone (2006a,b) found that although RPMT significantly enhanced turn-taking, joint attention and initiation, initiations only increased in children with some joint attention skills initially. The RPMT technique also seemed to have greater impact when used by mothers who were more responsive to their children. Children exposed to PECS, on the other hand, showed an increase in requesting behaviour, although this effect was found only in children with initially low levels of

initiation/joint interaction and higher levels of object exploration.

In another RCT of PECS, children with lower developmental levels and greater severity of autistic symptoms showed most improvement in their use of PECS; children with initially higher levels of expressive language showed more improvement in spontaneous communication (pictures and speech) (Howlin 2007).

Assessing treatment outcomes

Finally, there is the issue of how best to assess treatment outcome in autism-spectrum disorders. Many studies, particularly those involving EIBI, have used IQ as the principal outcome measure. However, even a statistically significant increase in IQ scores does not necessarily lead to an improvement in other, more practical day-to-day skills. Future outcome studies need to place greater emphasis on ecologically valid measures that more accurately reflect a child's ability to function successfully within the social environment.

A further problem in evaluating the effectiveness of any programme stems from overreliance on group measures of change. As highlighted in recent reviews of EIBI, it is clear that these programmes do not work for all children and that within-group variation may be just as great as that between groups (Howlin 2009).

When reporting the outcome of treatment trials, care should be taken to ensure that an emphasis on statistically significant group differences does not give a misleading impression of the potential benefits for any individual child.

Future directions

Autism-spectrum disorders are a complex and heterogeneous group of conditions that have a pervasive effect on functioning from infancy through to adult life. The search for effective treatments has been ongoing for many decades, although many interventions still lack any firm evidence base. Recent reviews highlight the rather poor quality of much of the intervention research, and the failure of any one treatment to demonstrate superiority over all others. There are concerns, too, that interventions proven to work in highly controlled experimental settings (efficacy trials) may prove less effective in real-life settings. Rogers & Vismara (2008) note that those interventions with a strong evidence base have been developed and evaluated primarily with children and families from White, often middle-class backgrounds; their effectiveness for ethnically diverse groups remains untested.

Nevertheless, it is clear that there are a variety of approaches that – although not resulting in ‘cures’ for autism – can result in improvements in many areas, including communication, social functioning and behavioural difficulties. It is also evident that the effects of treatment are highly variable, and outcome depends on individual child characteristics. Intensive behavioural interventions are among the most widely evaluated, but there are still few RCTs in this area, and, in fact, there are now more randomised trials of interventions with a focus on communication and early parent–child interaction than for EIBI.

It is also apparent from reviews that other factors, such as degree of parental involvement, integration of multicomponent approaches and, to some extent, duration of therapy (there is no evidence of the enduring effects of short-term interventions), are all crucial in determining treatment effectiveness (Levy 2006).

Finally, as noted above, autism-spectrum disorders persist throughout life. The types of intervention needed in early childhood (which focus mainly on behaviour and communication) may be very different from those required in adolescence or adulthood (when social, emotional and mental health problems may be of more concern). Thus, there is a need for provision that can both monitor and meet individual’s changing needs over the years, and that does not come to an abrupt end when they reach 19 (the age at which a person is considered an adult). Although the need for good liaison between families and health, educational and social services is generally recognised during childhood, there is far less support to facilitate the transition from child to adulthood. Indeed, the provision of specialised adult services for individuals with autism-spectrum disorders remains woefully inadequate and constitutes a major challenge for the future.

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MCQ answers

1	2	3	4	5
a f	a f	a f	a t	a t
b f	b f	b t	b f	b f
c f	c f	c f	c f	c f
d t	d t	d f	d f	d f
e f	e f	e f	e f	e f

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MQs

1 Recent epidemiological studies of autism-spectrum disorders suggest that prevalence rates are around:

- a 1 per 10 000
- b 4 per 10 000
- c 50 per 10 000
- d 100 per 10 000
- e 500 per 10 000.

2 Most interventions that are promoted for children with autism:

- a have sound evidence to show they are effective
- b are known to be dangerous
- c involve special diets

- d are not based on sound evidence of effectiveness
- e are very expensive.

3 Early intensive behavioural intervention is an autism intervention with a specific focus on children:

- a over the age of 6 years
- b aged under 6 years
- c of higher intellectual ability only
- d with significant intellectual impairments only
- e with no language.

4 Behaviour-based interventions for autism:

- a are among the better evaluated interventions for the condition

- b focus on punishing undesirable behaviours
- c always involve at least 40 h therapy per week
- d are only effective for pre-school children
- e are only effective for children with intellectual impairments.

5 Interventions with a focus on improving early mother–child interaction:

- a are among the better evaluated interventions for autism
- b focus on teaching spoken language
- c are effective for all children with autism
- d focus on improving 'theory of mind'
- e have no evidence of effectiveness.