

Breaking through the Barriers of Autism

Autism has been described as a 'modern enigma' – a potentially devastating condition affecting social skills, cognition and learning which appears to be on the increase. SWAP – the South West Autism Project – is directed by **Professor Alec Webster** in association with **Dr Anthony Feiler**, both at the University's Graduate School of Education, whilst the intervention programme is managed by **Valerie Webster**, Senior Specialist Educational Psychologist with Bristol City Council. Here they outline some shifts in thinking about autism and highlight their remarkable results.

Understanding autism

Autism is not an illness that people recover from, nor is it a 'shell' with an ordinary person inside waiting to get out. Autism is best understood as a distinct way of processing information and of being in the world. We do not know exactly what causes autistic spectrum disorder (ASD), although it is now accepted that it is neurological in origin. Hence individuals with ASD are sometimes described as *neuro-atypicals*, in contrast to the majority of *neuro-typicals*. Unfortunately, that

interpret beyond the immediate, or read people's minds and underlying intentions.

Coping with a child with ASD is extremely stressful for families. Until the recent past, many people with severe forms of ASD were assigned to special schools and a lifetime of institutional care.

What research tells us

Although there is no cure for ASD, we do know a great deal about what may help. Individuals benefit from structure, routine,

given 1:1 training for 40 hours a week, 52 weeks a year. It should be said that the positive outcomes reported in these studies carried out in the 1980s have never been replicated and there are question marks about the research methods used and the conclusions drawn. We do not know which child and family characteristics lead to success with different approaches and whether only those children given the most intensive help (most hours per week) make the most progress. No previous work has addressed how best to manage transitions, for example, into nursery or school settings. Our research was designed to address the problem of how Local Education Authorities (LEAs) can design, deliver and evaluate an ASD service, ensuring 'best value' and the most effective provision for children and families.

Investigating the problem

The National Autistic Society has suggested that as many as one in 86 children in English primary schools has a diagnosis of ASD. In Bristol, diagnoses have been increasing recently by some 30 per cent per year, largely due to raised awareness of the problem amongst parents and doctors. SWAP was funded by Bristol City Council over a three-year period and started in

→ A key feature of SWAP is that intervention is tailored to each family and child, based around an initial baseline Psycho-Educational Profile: a developmental test devised specifically for young children with ASD. An Individual Education Plan (IEP) is written to reflect the parents' main concerns and preferences for intervention, together with priorities evident from the assessment. Contact hours are negotiated with the family, up to a maximum of 25 hours per week, which is set by the LEA and reflects the maximum time any pre-school child is allocated educational provision. Programmes are delivered in school terms with guidance provided to parents regarding holiday activities.

Family tutors work towards targets set in IEPs and review progress weekly with parents. Teaching includes behavioural approaches as well as methods from speech therapy, such as intensive interaction, Picture Exchange Communication System and other strategies like visual timetables and social scripts. Individual programmes will emphasise communication, play, social interaction and independence.

Research outcomes include measures of each child's developmental progress; micro-analysis of child-adult interactions using video; and stress impact on families using standardised questionnaires and interviews.

The Programme

SWAP programmes are characterised by small learning steps based on detailed developmental assessments, a high degree of structure and repetition, flexibility and adult tuning to the child's understanding. The overall objective is to enable the autistic child to make sense of what appears to them a bewildering environment and begin to make active, spontaneous engagement with it. What we

have termed 'contingent problem-solving' describes how tutors overcome some of the obstacles associated with autism.

Examples include:

▶ A child with no eye contact and poor social skills is taught turn-taking and how to make requests using a bubble-blowing game.

▶ A child who withdraws into a trance-like state, even on short car journeys, is given an 'I-spy' card to keep him alert.

▶ A child who displays great anxiety at the sight of car keys is shown a sequence of photos (car, granny's house, garden, car, home) and is no longer anxious when he understands what is going to happen.

▶ A child who doesn't understand the 'hands up' rule at school is shown a picture story script each day, illustrating what she has to do and what happens next.

▶ A child with minimal attention span and who cannot be adult-directed is given a 'work station' free from distractions. Toys and activities are introduced gradually when a picture symbol for 'work' is shown.

▶ A child who grabs objects rather than asking for them is trained to hand a picture symbol representing what he wants in exchange for the object (Picture Exchange Communication System).

▶ Children who are unable to accept change are taught by a 'surprise' card to anticipate a change in routine.

▶ Children who are afraid of specific activities or places (such as going to the toilet) are helped by placing pictures associated with their favourite obsessions (Harry Potter, aliens, tractors, etc.).



Key findings

Remarkably, all children made rapid progress and SWAP was effective across a wide range of ability: baseline assessments ranged from a development quotient (DQ) of 24 – a child with severe learning difficulties – to more able children with a DQ of 100. In the best cases, children made DQ gains of more than 60 points in 18 months. Half the sample showed gains in DQ of 20 points or more, and one third showed DQ gains of more than 45 points.

On average, families requested and received 10 hours' intensive provision per week (range 2.5 hours to 25 hours per week). Significantly, differences in progress were not linked to the amount of intervention time. Children who made the greatest progress received a combination of intervention strategies, including support in mainstream nurseries. Perhaps the most newsworthy of the findings is that 16 out of 17 SWAP 'graduates' (94 per cent) to date have gone on to mainstream schools, with varying degrees of support.

It is clear that all families with an ASD diagnosis require access to some form of early intervention, based on a range of flexible approaches tailored to families' needs. There can be no excuse for LEAs not to act on these data. They must work in partnership with parents and other helping agencies to offset the worst consequences of ASD. ■

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The SWAP programme has been a sanity saver...things could not have been done better, absolute praise (SWAP parent)

description does not help us very much, since we do not know which areas of the brain are wired up differently to produce the range of cognitive and social behaviours associated with ASD.

At one end of the spectrum, individuals may have good language and academic skills, with high ability or special interests, such as electronics or music. But the same person may also have incapacitating social problems, anxiety, obsessional eating habits and a rigid adherence to routines. At the other end of the spectrum, ASD is associated with severe learning difficulties, non-existent play, limited creativity or imagination, dramatic tantrums and self-injury, and an inability to make sense of everyday events.

Sometimes referred to as 'flashlight focusing', individuals with ASD seem to perceive the world in narrow beams of understanding, unable to integrate information from a range of sources. They may have a very literal 'take' on what is said to them and are incapable of dealing with jokes or sarcasm because they cannot

predictability and repetition. We know that some form of early intensive intervention leads to a reduction in abnormal behaviour patterns, improved communication and social skills. Children given help early are much more likely to be included in mainstream schools and to live in the community later on. There is a wide range of possible interventions, but there are no panaceas and no guarantees of success for all children.

'S' has made such fantastic progress, you wouldn't know it was the same child...you couldn't pick him out now in a crowd of children...(SWAP parent)

Controversy surrounds many ASD therapies. Behavioural approaches, such as Applied Behavioural Analysis, or ABA, view ASD in terms of learned excesses or deficits. Through intensive systematic drills, new target behaviours are taught, prompted and rewarded by, for example, praise or food. In some versions of ABA, children are

September 2000, with data now available from 26 families. The project is staffed by graduates and learning support assistants who are trained to implement and monitor a range of intensive interventions. Any Bristol pre-school child with an ASD diagnosis can be referred to SWAP. →