



# MEETING THE NEEDS OF CHILDREN WITH AUTISTIC SPECTRUM DISORDERS IN THE EARLY YEARS

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Distilled from workshop presentations for the New South Wales Autism Society, 3-4 April 2004, Sydney

*The spectrum of autistic disorders is now known to be far more prevalent than previously thought and diagnosis is being made at earlier ages. There is also a consensus that early intervention and support can have a significant impact on the quality of life for individuals and their families. This presents the problem of how to organise effective education and support in the early years. This paper analyses some of these issues and makes the case for considering a principled eclectic approach, including the best aspects of some specialist approaches, to meet these very individual needs.*

## **Autistic spectrum disorders (ASD)**

The spectrum of autistic disorders includes not just classical autism (Kanner, 1943) and Asperger Syndrome (Asperger, 1944, trans. 1991), but also a range of less well-defined conditions that all share a pattern of developmental differences referred to as the 'triad of impairments' (Wing, 1996). These are difficulties in social and emotional understanding, all aspects of communication regardless of language level, and a lack of flexibility in thinking and behaviour. There is nothing that protects these children from other disorders and many will have additional problems, such as language difficulties and/or general intellectual impairment. ASD are biological disorders but as yet there are no clear biological markers, so they have to be recognised from the pattern of development within the triad.

Parents and early years professionals need to know that a child has an ASD because this enables them to suspend their normal intuitive understanding of behaviour and try to work out what that behaviour means for this particular child. For example, a child may not be making eye contact with others but this, by itself, has different implications according to the cause. The child may have an ASD but alternatively may have a severe visual problem, or may have profound learning difficulties, or another neurological disorder such as Fragile X, or may have been severely abused. Nor does the presence, rather than the absence, of a particular behaviour of itself signify an ASD, as when the child has severe temper tantrums and appears non-compliant. Those behaviours may result from neglect or mismanagement at home, from a conduct disorder, from developmental delay or ADHD as well as from an ASD.

Behaviour may be the only level we can see; but the ASD does not lie in that behaviour itself, rather in what underlies it. There are no behaviours that are of themselves 'autistic', which is why it makes no sense to talk of 'autistic features' or 'traits' (and still less of 'autistic tendencies'). All behaviours are human responses to states and situations, and that is no different in ASD. Behaviours can be a clue to what the child is thinking, feeling, understanding and so on, but they cannot by themselves tell us what to do or help us understand the child. Knowing the child has an ASD means we can interpret those behaviours in the light of our understanding of the key difficulties in ASD, and thus we are more likely to reach a sensible notion of what is happening at the psychological level—the level at which we need to try to work. However, each child with an ASD will be different from every other—in spite of the common triad of difficulties—so we also need to understand that particular child and how the ASD interacts in that child with other skills, abilities, attitudes, difficulties, personality, and past and present experiences.

ASD are developmental disorders, which means that the disorder arises during development. This often confuses parents, because the main social problems may not appear until the child has to engage in more complex social interactions with peers, or the language problems until the child has to use language in social and communicative ways (instead of isolated words or single, echoed phrases). As with any developmental disorder, when we see a child we do not see a list of symptoms, but the results of how that child has adapted to those difficulties. The blind child is not the same as a

sighted child who wears a blindfold: the former has developed a different way of perceiving and interpreting the world. So, children with ASD also develop compensations for their difficulties. They may learn to listen by looking away at a blank space but, if the adult makes them look at a confusing and overwhelming face when being addressed, they may lose that capacity to attend to what is said and, moreover, may experience sensory overload and even pain. Thus, they need to be taught to understand eye gaze as a signal and to use it as such, but that must be done by working from where the child is, rather than imposing behaviour that is for our benefit rather than theirs.

The difficulties in recognising and responding to social and emotional signals that are the core of ASD also mean that infants with ASD are unable to benefit from the social and emotional 'scaffolding' that enables typically-developing infants not only to learn about themselves and others, but also about the world (Hobson, 2002; Trevarthen et al., 1996). Thus the initial difficulties that are inherent in ASD are compounded by secondary 'handicaps', as they miss out on all the opportunities to learn and develop through the social and emotional pathways that are the hallmark of intuitive human learning. Their failure to social reference (to check the reaction of a trusted adult), for example, means they have no support in knowing how to react to novel items or events. According to personality, then, they may become fearful of everything new and withdraw into themselves or, alternatively, completely reckless with no sense of danger. They are by themselves in working out how the world works and in developing their own meanings. That is why they may develop their own idiosyncratic (even bizarre) way of relating to events with a lot of superstitious behaviour. If you do not know why people do things and you rely on coincidences of behaviours and events, it is not surprising that you might think that you have to be wearing a beach hat to get an ice-cream because you were wearing it when you first got one, and why you therefore insist on wearing that hat the next time you want an ice-cream, even if now it is raining.

There are strengths as well as difficulties in the 'autistic' style of thinking, however. The reliance on 'working things out' for themselves and not being distracted by social stimuli makes children with ASD very logical, focused and determined, and this can be a strength, if it is harnessed in a positive direction. Children with ASD may have violent reactions to events because they easily panic over what they do not understand or because they lack

the social and communicative skills to control others and get their needs met in more acceptable ways. However, they are not mean, spiteful or deliberately aggressive, and have an innocence that can be very attractive.

Peers as well as adults need to have some understanding of ASD, so they can recognise how vulnerable and scared these children often are and that what may seem like aggressive or defiant behaviour comes from a lack of understanding or skill. The plea for valuing and respecting all children as the basis for education and care (Porter, 2003) applies even more to children with ASD. Yet, because ASD are transactional disorders, in that they affect, and are affected by, the behaviour of those around them, this is more difficult to achieve. We say that children with ASD have problems socially interacting with us, but that also means that we have problems socially interacting with them. We say that they have problems communicating with us, but then we have equal problems communicating with them. The source of these problems is the same in us as it is in them. We do not have empathy with one another, because we are different and they have missed out on the socialisation that would have brought them into our cultural understanding. Without that natural empathy we, like them, have to try to work out why they do what they do and what their behaviour means. This is a difficult task, which is why parents and staff find children with ASD challenging, but in making the effort, and recognising the difficulty, we come to understand the nature of the problems they face. We have one another and a social structure we understand and are comfortable in; they are on their own and depend on us to understand and support them and then, through education, to help them understand.

### **Diagnosis and special needs**

As indicated above, ASD are biological disorders, but are diagnosed by clinical judgement of development and current behaviour. Autism, in the sense of the tight category defined by Kanner (1943), was thought to be a rare disorder, affecting four in 10,000 worldwide. We have now recognised that there is a broader range of disorders that share the fundamental difficulties, and better understanding and awareness of these conditions has led to substantial revision of the prevalence rates. The current 'best' estimate is one in 160 (Fombonne, 2002), which makes ASD the most common of the developmental disorders.

In many situations, diagnosis is the key to resources, but a recent multidisciplinary report in the UK (National

Initiative for Assessment and Screening in Autism [NIASA], 2002) recommended that early intervention and family support should be from the point of identified need, pending diagnosis. It was recognised that the 'least damaging assumption' in ASD was to assume it might be and to act accordingly, while pursuing later diagnosis. As long as it is recognised that it may not be an ASD, the child will not be harmed by the explicit and structured teaching that is appropriate for children with ASD, whereas they will be harmed by delay in providing what is needed on the misguided assumption that we should not label and categorise children at this young age. If we do not have labels and categories that help us make sense of the child's behaviour, and enable us to provide appropriate teaching and support, the alternative will not be *no* labels, but hurtful and stigmatising labels such as 'aggressive', 'defiant', 'stupid', 'naughty', 'in need of discipline' and so on.

Although the diagnosis of an ASD is an important part of identifying special needs, it is not the sole determinant. Special needs are based on strengths and interests as well as weaknesses. Most children with ASD will have a distinctive learning and thinking style, based on their preference for visual and logically ordered information, learning through cognitive rather than social routes and finding rote and habitual forms of learning far more comfortable than problem-solving approaches. That does not mean that they should be left with these rigid learning styles, but just that the child will have more success if learning is initially approached through these preferred modes and then the child helped to develop learning strategies that enable adaptation to other forms of learning, as needed. What education needs to do is twofold: firstly, help the child compensate for any difficulties they experience (a compensatory approach), including missed opportunities to learn; secondly, help the child develop in ways that address the fundamental features of the ASD (a remedial approach).

### **Intervention and education**

Education is not the same as a clinical treatment: it is also the way in which cultural information is developed and shared in a society. Thus, in developed societies such as the UK and Australia, education is an entitlement for all children, including those with ASD. However, we need to move that philosophy beyond rhetoric so the issue becomes one of how we can adapt what is provided (or the way it is provided) and support the child with ASD in gaining access to the broad and relevant curriculum that is the right of all children within

our society (Jordan, in press). The majority of children with ASD will be in mainstream provision, but it is unlikely that this will be possible for all, at least at the beginning. What is needed is a range of provision and a resourced policy of helping children move towards more inclusive settings as they, and the settings, are prepared (Jones, 2002). Sadly, the child is often placed in a mainstream setting in the early years without this preparation, simply on ideological or pragmatic grounds (young children can be 'managed' because they are little and their behaviour is not yet that extreme) and only get the specialist help they need once that placement has 'failed' in some way (Jordan & Powell, 1995).

However, education also has a therapeutic role in addressing the ASD itself, and it is this aspect which most specialist approaches address. In a time of the Internet and mass media, parents are no longer dependent on professional advice in deciding what they should be doing with their child. Many parents know more about what is happening in North America (from where most specialist approaches are marketed on the Internet) than what is available locally. It is good that parents are empowered with information, but unfortunately there is no 'quality control' of this information, and parents are vulnerable to claims that are often misleading and sometimes fraudulent. Increasingly aggressive marketing, backed up with legal action, has discouraged many professionals from challenging these claims, especially where they see justice in the parents' position that what they are offered at the preschool stage is 'too little, too late'. What is needed is the development of effective early years education for these children, and support for their families, to offer real choices. Where this has been done, most parents support local provision (Webster et al., 2002; Dyer, 2002).

To date, there has been no scientific comparative study and no evidence of any single approach being better than any other. There are approaches where there is at least some evidence of success (Jordan et al., 1998) but the context in which they are produced and marketed needs to be remembered. In the USA, most approaches are developed within university research departments, and their continued existence and development depends on their success in being marketed locally, nationally and internationally. That fits into a competitive society where approaches need to demonstrate that they are the 'best', even to the extent of denigrating others. In the UK (and in Australia, as far as I am aware) there is an alternative tradition of

developing eclectic approaches and a consensus on what constitutes 'best practice' through professional sharing. Neither of these systems is without problems, and provision in the UK has certainly benefited from the stimulus that has come from being challenged by these marketed interventions. However, there has also been a distortion in the provision with some children (whose parents are well able to advocate on their behalf) receiving the bulk of the funding available through payment for these expensive private interventions, while the majority of children then have less funds available for their provision.

It is also unrealistic, and without any rationale or evidence, to suppose that any one of these interventions can meet all the educational needs of any young child with an ASD. It is not just, as some assume, that one should fit the intervention to the child, but rather that one should fit the intervention to the goal. Most interventions have something to offer in developing a good and effective educational approach for children with ASD, and practitioners should be aware of the strengths and limitations of these interventions and be able to adapt them to fit the particular individual educational plan of each child. This implies well-trained practitioners who have not just learnt how to follow one program and who can go beyond the 'recipe' approach to intervention. This is not an easy or cheap way forward for service providers who are often looking for quick solutions to solve the problem of the apparently growing numbers of children with ASD for whom there has been little planning. It is, however, a principled way forward that will be in the long-term interests of all concerned (except, perhaps those who wish to market single 'one-stop' solutions).

### **Good practice principles**

In the UK, the education, health and social services have reached a degree of consensus about what constitutes 'best practice' in the education of children with ASD (DfES, 2002; NIASA, 2002). These reports endorse the analysis of Dawson and Osterling (1997) who examined common features of 'successful' programs for young children with ASD, and found parental involvement and training to be a key component. They also endorse a multidisciplinary diagnosis and assessment as the basis for determining the child's needs and planning to meet them (Jordan, 2001). This must be individually based and focused on functional independence through increased understanding of themselves and others (Jordan, 2002).

Parents need to be empowered to manage their child in an educational way and supported in balancing this with the needs of the family as a whole. 'Good' parenting is not sufficient to deal with the needs of a child who is neither able to pick up on normal social and emotional signals (Klin et al., 2002) nor give the right signals to trigger the nurturant care of others. Parents can feel de-skilled, and need support in persisting with attempts to engage with their child. Staff in the early years may also experience these feelings, and need to understand and deal with their own reactions, before they can be in a position to support parents. Working together in equal partnership can be the most honest and fruitful way forward in trying to understand the child and build an effective program. There are now a number of programs based on these principles (Aldred, 2002; Chandler et al., 2002; Le Couteur & Sowter, 1997; Shields, 2001).

Early years education has to be based on understanding the child, through a thorough assessment of the child, an analysis of the teaching situation, and an understanding of ASD. Play can be a natural vehicle for teaching the young child to learn through the social/emotional and cognitive routes and to become more flexible in thinking and behaviour (Jordan, 2003; Sherratt & Peter, 2002). The child also needs specific training to recognise and respond to social signals and then staff and parents need to be trained to use those signals in daily interactions. It has to be remembered that, no matter how academically bright the child, it is the 'common-sense' aspects of life with which she or he will have the most difficulty, and where the most support and explicit teaching will be needed. A key problem is having no concept of time and not understanding that events end, or recognising when they are finished. Time is marked by events—so rituals and/or visual sequences of events will help children to organise their time, stay at tasks until they are finished, and make the transition to the next activity.

Communication is another priority for development. When the child does not speak, it is clear that there is a problem, but it can be harder to recognise and respond to the communicative needs of children who may be prodigious talkers with an advanced vocabulary and grammatical structure. ASD are the only conditions in which speech may develop without communication so that the child is not able to fulfil any but the most basic of communicative functions (request, protest and self-stimulation). Such children may talk a lot—but they tend to use speech as a barrier to communication rather than to communicate, since it is easier to talk at others rather than trying to follow conversational rules.

Thus, all children with ASD need a communication program which deals with three aspects: making sure the children are aware of their own needs and share concepts with others; having a means of communication commensurate with their linguistic and semantic level; making sure the environment supports communication through its responsiveness to the communicative attempts of the child and through supplying the appropriate degree of communicative pressure (Jordan, 1996).

### **Learning from specific interventions**

Jordan (2002) gives a breakdown of the key characteristics of a range of approaches for children with ASD in the early years. Here, the intention is not to evaluate these approaches or even to review the evidence on evaluation, but to suggest what might be taken from each when building a principled early years program for a child with an ASD.

### **Building a principled eclectic program**

There should be a basis for selecting the elements of the program for a child, and principles for the final eclectic mix that results. The strength of single approaches is that practitioners can be thoroughly trained in that approach, so that they understand its rationale and structure and do not just concentrate on the 'paraphernalia' (such as the visual schedules in TEACCH [Treatment and Education of Autistic and related Communication handicapped CHildren]) or try to follow the method as an invariant recipe. For the inexperienced practitioner, therefore, it may be best to start with a single approach (TEACCH probably being the most generally useful and adaptable) and add in elements to compensate for any missing or weak aspects, while maintaining the overall approach. It is an important discipline to shadow a child with an ASD following any eclectic program, to see it through their eyes and make sure that the elements that have been introduced do not conflict or confuse.

The strength of the eclectic approach is not just that it can combine the 'best' features of other interventions but that it can be responsive to the individual and to the situation. All interventions have several aspects or parts, some of which may be very different from one another. Thus, a typical ABA program run by modern proponents (e.g. Maurice, 1993) does not just involve the discrete trial one-to-one sessions for which it is making the claims, but intersperses these with play periods.

The elements chosen will depend on the goals for any child at any time and may vary over time as the child's priority needs change. Nor will these specific approaches be the only resource for planning the child's program. There will also be ways of accessing the opportunities for the social, academic and life skill education that should be available for any child. Priority needs for most children with ASD will be enabling social interaction; increasing understanding of themselves and others; developing communication; and learning how to pay attention, follow instructions and share interests. Parents and staff may feel that managing behaviour is a priority, but effective management strategies can only come from understanding the behaviour and teaching the child alternative acceptable responses. Children with ASD cannot just inhibit behaviours, so there is no point in simply trying to stop behaviour. It is necessary to establish the reason for the behaviour (panic, a response to a particular trigger, the function it serves for the child) and then to develop alternatives or establish a new routine for the behaviour (e.g. work, then play) if it is simply that the child is doing the wrong thing at the wrong time. Changing behaviour is never easy, so it is preferable to set up structures that help the child to avoid challenging behaviour and learn what is required.

### **Conclusion**

There are no easy or single solutions to the needs of young children with ASD. Practitioners need to take account of the triad of impairments but also to get to know the individual and see how that child is dealing with his or her difficulties, making sense of the world and developing skills and interests. The aim should be initially to provide prosthetic teaching environments that do not alter the condition but enable the child to compensate for the difficulties it causes. That may include finding non-social ways of teaching the child for academic and skill learning, or teaching one-to-one until the child can be prepared to learn in a group. It is important to give the child access to as diverse learning opportunities as possible to prevent the secondary problems that come from being kept out of the very situations they need in order to learn. Priority should be given to specific and explicit teaching of early social and communicative behaviour and understanding.

Over the 60 years since its first identification, there has been tremendous growth in our knowledge and understanding of ASD. There has also been considerable

**Table 1.** Contribution of common named interventions to an early years curriculum in ASD

INTERVENTION	STRENGTHS	CAUTION
<p><i>TEACCH</i> (Mesibov &amp; Howley, 2003)</p>	<ul style="list-style-type: none"> <li>• Structured teaching through visual means</li> <li>• Based on individual assessment of strengths and weaknesses</li> <li>• Trains good work habits and independence</li> <li>• Aids understanding of time</li> <li>• Reduces stress through a prosthetic environment</li> <li>• Develops receptive communication</li> </ul>	<ul style="list-style-type: none"> <li>• Over-dependence on external structure—need to build up internal understanding</li> <li>• Isolated learning—supplement with social play</li> <li>• Depends on adult structuring—teach problem-solving and reflection</li> </ul>
<p><i>ABA/IBI</i> (<i>Applied Behaviour Analysis/Intensive Behavioural Intervention</i>) (Lovaas, 1987)</p>	<ul style="list-style-type: none"> <li>• Teaches conformity to instructions</li> <li>• Teaches basic habits</li> <li>• Can be used to teach 'entry' behaviours to enable integration</li> <li>• Records behaviour to check progress</li> </ul>	<ul style="list-style-type: none"> <li>• Encourages passive learning and dependence on cues—generalisation program</li> <li>• Depends on external rewards—train functional behaviours for natural situations</li> <li>• Danger of abusive treatment—monitor</li> </ul>
<p>Interactive approaches:</p> <ul style="list-style-type: none"> <li>• <i>HANEN</i> (Sussman, 1999)</li> <li>• <i>Foundations for Communication</i> (Chandler et al., 2002)</li> <li>• <i>Son Rise/Option</i> (Kaufman, 1994)</li> <li>• <i>The Interactive Curriculum</i> (Nind &amp; Hewett, 1994)</li> </ul>	<ul style="list-style-type: none"> <li>• Exaggerated forms of natural parenting style</li> <li>• Using music (or singing) to add meaning and structure</li> <li>• Developing relationships with key adults</li> <li>• Learning to enjoy being with others</li> <li>• Developing a sense of themselves and others</li> </ul>	<ul style="list-style-type: none"> <li>• Relationship only to trained adult—need to integrate outside sessions</li> <li>• Unrealistic expectation of child in control—mark periods when child or adult is in control</li> <li>• Need for more unobtrusive methods as child gets older</li> </ul>
<p><i>PECS (Picture Exchange Communication System)</i> (Bondy &amp; Frost, 1994)</p>	<ul style="list-style-type: none"> <li>• Develops spontaneous expressive communication</li> <li>• 'Menu' of what can be 'chosen'—teaches limits to availability and helps extend interests</li> </ul>	<ul style="list-style-type: none"> <li>• Artificial situations teaches 'odd' behaviour—introduce at home</li> <li>• Needs child at stage of representation in semantic understanding</li> </ul>
<p>Cognitive interventions:</p> <ul style="list-style-type: none"> <li>• <i>IT</i> (Jordan &amp; Powell, 1991)</li> <li>• <i>Bright Start/High Scope</i> (Jordan &amp; Powell, 1990)</li> </ul>	<ul style="list-style-type: none"> <li>• Develops understanding through intact modes</li> <li>• IT provides a comfortable environment</li> <li>• Builds cognitive understanding and sense of autonomy</li> </ul>	<ul style="list-style-type: none"> <li>• IT hard to generalise—need to integrate with life and rest of curriculum</li> <li>• No 'recipes'—needs training</li> </ul>

development of effective teaching techniques and our understanding of how to provide 'autism-friendly' environments. We are learning to move away from addressing 'deficits' alone to recognising children with ASD as children first. We are moving towards a situation where we can celebrate diversity and set a mutually positive agenda for the future. Early years education matters for all children, but there are none for whom it can make so much difference as children with ASD.

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