Autism spectrum disorder

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AUTISM SPECTRUM DISORDER

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What is Autism Spectrum Disorder?

Autism spectrum disorder (ASD) is a common difficulty found in young children. It affects over 1 in 100 children in the UK (Baird et al. 2006). All children are different and it is the same with children with ASD. No two children with ASD will behave in the same way. However, children with ASD do share some general features of behaviour. These include:

1. difficulties with language used for communication
2. difficulties with social interaction
3. restricted or intense interests and repetitive behaviours

(WHO 1993)

The spectrum

The range of behaviours shown in children with ASD and the degree to which each child is affected will vary so that the difficulties seen in children with autism are described as being on 'a spectrum'. ASD is more common in boys than girls and is often associated with other developmental difficulties such as learning disabilities and mental health difficulties.

Causes and risk factors

The exact causes of ASD are not yet clear, but there is strong evidence to suggest a genetic cause. ASD runs in families and if one child is affected there is an increased likelihood of another child in the same family having ASD. The precise genes involved in increased risk of ASD have yet to be identified, but is clear that many different genes are

involved. The National Institute for Health and Clinical Excellence (NICE 2011) identifies other factors that increase the risk of having an autistic spectrum disorder. If a child has another chromosomal condition, such as Down's syndrome, or a genetic condition such as Fragile X syndrome, they will be at greater risk of having an autistic spectrum disorder. In the same way a child with birth defects associated with problems with brain development such as cerebral palsy, children with general developmental delays, and those with epilepsy will also be at risk.

How is Autism Spectrum Disorder recognised and diagnosed?

There is no medical test that will identify ASD and so the diagnosis is made on the basis of talking to parents about their child's development and observing how the child interacts, communicates and plays. Before a child can be referred for a diagnostic assessment the risk of a possible ASD needs to be identified.

NICE Guidelines

NICE has developed a specific guideline for recognition, referral and diagnosis of children with ASD based on the best available evidence (NICE 2011). This guideline includes advice about features of development that should alert professionals working with young children and their parents to the possibility of ASD in a particular child about whom concerns have been raised.

The NICE guideline lists a number of signs and symptoms of possible ASD that might be manifest in a child or young person. In the following section the four general features of behaviour listed above will be considered in detail in relation to a young child with ASD.

1 Difficulties with language used for communication

Problems with language and communication may be seen as a delay in spoken language. For example, a child of two years of age may be saying fewer than ten words.

Sometimes a child may use language for communication infrequently, for example using only single words despite being able to speak in sentences. In some cases a child may lose the use of language after it has been acquired.

Loss of language after a child has started to talk, typically occurring in the second year of life, can be considered a 'red flag' for ASD. Parents report a loss of language in over 30 per cent of children who go on to receive an ASD diagnosis (Baird et al. 2008).

2 Difficulties with social interaction

Problems with social interaction may be manifest for example when a child does not respond to their name being called, even though their hearing is known to be normal. There may be a lack of, or a reduced amount of, smiling in social situations particularly in response to another person. There may also be a generally reduced, or lack of, response to other people's facial expressions or feelings. A child may offer cuddles to their parent, but reject cuddles when they are offered by the parent. A child may also show unusually negative responses when asked to do something by another person – sometimes referred to as 'demand avoidant behaviour'.

Interest in others

Problems interacting with others may also include a limited awareness of personal space, or a strong reaction to other people entering their own personal space. A child may show little social interest in others, including their peers. In some children this may go as far as rejecting contact with others. If a child is interested in other children, s/he may approach them inappropriately, and may seem to be aggressive or disruptive. A child who has problems with interaction may not be able to imitate others' actions, such as the initiation of social play with others. They may show a distinct preference for playing alone. Such a child may not enjoy social situations that most children like, for example, birthday parties.

Nonverbal communication behaviours

Even when the child is enjoying an activity, it may not be apparent as s/he may not share their enjoyment through comments, facial expression and other typical behaviours.

Other difficulties with social interaction include poor use of nonverbal communication behaviours, such as eye contact, pointing and general use of gestures. Although the child may place the adult's hand on an object in order to get help, they will not necessarily use gestures and facial expressions to communicate.

Joint attention

The development of joint attention is part of the development of social interaction skills in most young children. However, in young children who have difficulties with social interaction, joint attention may typically be reduced or even lacking. A child may lack the ability to look where the other person is looking, or to follow where the other person is pointing. The child may look at the person's hand instead.

3 Restricted or intense interests and repetitive behaviours

These may be seen as a lack of imagination and variety of pretend play. The child may have unusual or restricted interests and/or rigid and repetitive behaviours. For example, they may insist on watching the same DVD over and over again. There may be repetitive movements such as hand flapping, body rocking while standing or sitting, spinning, or finger flicking. The child's play may be repetitive or stereotyped, for example opening and closing doors. The child may have an excessive insistence on following their own agenda. They may show extreme emotional reactions to change or new situations and insist on things always being the same. Some children have an over- or under-reaction to sensations, for example textures, sounds or smells. Some children may have an extreme reaction to food for example, an excessive reaction to the smell, taste, texture or appearance of food. They may have extreme food fads.

Signs of ASD before the age of two

Recent research has uncovered less dramatic signs of possible ASD before the age of two. Zwaigenbaum and colleagues (2009) found that between 12 and 18 months, infants who go on to develop ASD can be distinguished from typically developing children in a number of areas.

Visual skills A child at risk of ASD may have an unusual way of watching objects as they move and may show a fixation on objects.

Motor skills A child may show reduced activity levels, and delayed fine and gross motor development.

Play skills Children may show delayed development in copying actions, limited toy play, and repetitive actions with toys.

Social communication skills With regard to social communication, differences may include unusual eye gaze, lack of looking at the person when their name is called, a lack of social smiling and copying.

Demonstrating emotion The child may also show extreme emotional responses to ordinary situations and a reduced expression of positive emotion.

Babbling There may be a delay in babbling, especially to-and-fro social babbling.

Cognitive skills The development of thinking and learning abilities may be slower than in a typically developing child when tested by a health professional.

Differentiating factors between children with ASD and children with developmental delays A number of early unusual behaviours also distinguish between infants who go on to develop ASD and those with other developmental delays, including language delay. These behaviours include, unusual exploration of toys, repetitive movements, reduced social communication, and reduced, or lack of, sharing of positive emotion.

Referral

Once concern about a possible ASD is established a child will be referred for a diagnostic assessment. The referral for an assessment will usually come from a professional who works with the child. Health and early years' workers take any concerns expressed by parents about a child's behaviour or development seriously, even if they, or other professionals, do not share them. It is essential if a parent has a concern to discuss it with their GP, health visitor, community nurse or other health professional involved.

The Autism Team

NICE (2011) recommends that in 'best practice' assessment should be carried out by a multidisciplinary group, the autism team. This will include a paediatrician and/or child and adolescent psychiatrist, a speech and language therapist and a clinical and/or educational psychologist. Other professionals whose expertise can be called on include an occupational therapist, a specialist health visitor or nurse, a specialist teacher or social worker. The autism team should have specific skills and understanding in carrying out autism diagnostic assessment and communicating with children and their parents about the diagnosis.

Assessment

The assessment to diagnose an autism spectrum disorder will involve both a detailed discussion with a child's parents or carers and direct assessment of the child. Parents will be asked about their child's development with a focus on the patterns of development and behaviours that are characteristic of children with ASD as set out in the World Health Organisation's International Classification of Diseases (ICD-10; WHO, 1993). This classification refers to difficulties in the areas of development affected in ASD as referred to above: communication and reciprocal social interaction, restricted interests and repetitive behaviours.

The assessment process with the child will involve interaction and observation to consider the child's social and communication skills in order to evaluate those areas of

development in terms of the diagnostic criteria set out in ICD-10. In addition to the ASD diagnostic assessment, the professionals involved in the process will need to consider other possible diagnoses and also other conditions because, as outlined earlier, children with ASD are at a greater risk of other developmental, medical and mental and behavioural conditions.

Diagnosis

A diagnosis, if it is offered, will be based on all of the information gathered from talking to the parents and direct assessment of the child, as described above. The diagnosis and its implications will be carefully explained and parents or carers will be provided with information about support that may be available locally.

However, parents will react differently to such a diagnosis. They may need time to process the information particularly if English is an additional language. They may need time to consider the implications for the child and the family and to have further discussions with other family members. They may with hindsight have further questions and there may be other cultural issues to consider. Best practice, therefore, is to offer parents or carers a follow-up appointment within six weeks of the diagnostic assessment to give time for further discussion.

What works supporting children with ASD?

Many approaches to supporting children with ASD have been proposed. Although there is no ‘cure’ much can be done to help the children and their families. Parents will want to know which approach will work best for their child now, that will also have the most benefits for their child’s development in the long term.

Current research is not able to offer clear cut answers for parents. However, there are ways of supporting children which are effective in developing the child’s skills in the main areas of difficulty seen in ASD and reducing the behaviours which may interfere with their everyday life.

For example, there are some comprehensive programmes which aim to address the range of behaviours which are typically seen in ASD. Other approaches offer a narrower focus on specific aspects of development and behaviour, such as language and communication difficulties.

Evaluating intervention programmes (see also Chapter 9)

Research Autism, the UK charity, lists over 1000 interventions that have been suggested for children with ASD (2014). The range includes:

- medication
- diet and nutritional interventions
- behaviour and development programmes
- education and learning programmes.

While this extensive list appears to offer parents a wide range of options to choose from, unfortunately many of these interventions lack evidence for their effectiveness. Even where there is evidence that a particular treatment works, it is important to look at the results from many studies not just one. This is because while one study may suggest an approach is effective, another may not find positive results. Pooling the evidence from as many studies as possible provides a much better guide to the effectiveness of an intervention. In addition, because all children with ASD are different and are affected by ASD in individual ways, any programme of support will need to be tailored to the individual child's needs and those of his or her family. Parents need opportunities to discuss with the professionals who are working with them the evidence for what works, their child's needs and their own preferences for support.

NICE (2013) has produced a guideline on the management and support of children with ASD which draws on the evidence for what works. In the United States of America, The Agency for Healthcare Research and Quality (AHRQ 2011) has also completed a review of

159 studies of interventions to support children with ASD which might help parents and professionals make decisions about how to support children with ASD most effectively. AHRQ concluded that there were some interventions that showed promise, but the evidence should be treated with caution.

Behavioural approaches

Both NICE and AHRQ reviewed many different approaches including behavioural, educational, medical and therapeutic interventions. In the following section the focus will be on behavioural and educational programmes for which there has been some evidence of effectiveness.

Behaviour programmes can be used when working with children on many areas of development, including attention, play and self-help skills, as well as language and communication. Such programmes can also be used when working with children with challenging behaviour. There are different types of behaviour programmes but they all use an approach called Applied Behaviour Analysis to teach new skills.

Applied Behaviour Analysis (ABA)

The studies reviewed by AHRQ showed positive effects of ABA on children's language, thinking and reasoning and daily living skills.

ABA is based on the principle:

- a behaviour that is rewarded is more likely to be repeated
- a behaviour if not rewarded will diminish.

In ABA approaches, the behaviour to be learnt is often broken down into small steps for teaching and each step is taught one at a time.

- There is a target behaviour.
- The professionals working with the child use motivating rewards for the child.

- These rewards reinforce the target behaviour when it occurs.

In the reviews, the programmes that worked best required a well-trained ABA therapist who worked 1-to-1 with the child for more than 30 hours a week over a period of one to three years. In practice, the level of intensity of 30 hours a week for so many years may not be possible. For the family, the intensive nature of such a programme can make severe demands on everyday life and family routines would need to be adjusted to make room for the work on the programme**.**

The Picture Exchange Communication System

The Picture Exchange Communication System (PECS) is an example of one way in which the ABA approach has been applied to communication (Bondy and Frost 1994). PECS was originally developed to be used with children with Autism Spectrum Disorder in order to help them develop communication skills. It has also been used with a range of children who have communication and cognitive difficulties, as a form of augmentative and alternative communication. It needs to be used by a trained practitioner.

PECS is a highly structured behavioural approach which uses modelling (See chapter 2) and prompting to teach the child functional communication. It teaches the child to communicate, using pictures, by giving the adult a picture card in exchange for the item required.

Training is divided into six phases which must be followed in the order set out by the programme.

Phase 1 Requesting is learnt at phase 1 where the child is taught to exchange a picture for a desired object, initially with prompting from the adult trainer. The picture will represent a highly rewarding object which hopefully will motivate the child. The initial prompts involve the trainer physically moving the child's hand to the picture.

Phase 2 In phase 2 the distance between the child and the trainer is increased and prompts are reduced.

Phase 3 The child is taught to choose the appropriate picture from a selection in a communication book or board. A communication book consists of pictures relevant to the child's needs that are specifically selected to help the child develop some basic communication skills.

Phase 4 In phase 4 the child learns to combine a set phrase such as, 'I want' with a picture to construct a short sentence.

Phase 5 In this phase the child learns to respond to questions such as, 'What do you want?' with pictures and/or speech.

Phase 6 In this final phase the child is taught to comment by responding to questions such as, 'What do you see?' and 'What is it?' with pictures and/or speech.

PECS is widely used in a variety of educational settings in the UK. AHRQ concluded that although PECS is effective at increasing the number of words used by children for up to three months after intervention, improvements do not seem to be maintained over the longer term. Equally NICE did not find strong evidence to recommend the use of PECS, but did consider the evidence promising enough to suggest further research would be useful.

Social communication programmes

NICE recommends that specific social communication programmes should be considered as part of the package of support offered to children with ASD and their families. These programmes use play-based approaches which aim to increase the joint attention of an adult and the child, to focus on the social interaction between the two and their joint engagement. In many such programmes the therapy is delivered by parents who are trained to implement the approach. (See chapter 9 for a discussion on programmes.) One example is

the More than Words programme (Girolametto et al 2007) developed by the Hanen Centre in Canada. This programme is used by speech and language therapists in the UK. Another example is the Pre-school Autism Communication Therapy (PACT; Green et al 2010) which was the subject of a large research study. This programme will be considered in some detail as it shares key features with other play-based social communication programmes.

Pre-school Autism Communication Therapy (PACT)

PACT uses natural interactions between a child and his or her parents to develop social communication skills. Parents attend two-hour training sessions twice a month for six months followed by monthly booster sessions for six months. Sessions are led by a speech and language therapist. Between sessions, families are asked to complete 30 minutes of daily home practice. In the sessions parents learn to adapt the way they interact with their child to maximise opportunities for the development of social communication skills. The training is supported by video work. Parent-child play sessions are videoed and this is followed by a feedback session. In the feedback session parents are encouraged to reflect on their interaction with their child. They are given the opportunity to identify their own skills that they used to support successful communication.

Shared attention

PACT targets the main difficulties children with ASD have with social communication. Children with ASD tend to lack the ability to share attention with an adult when relating to an object or event in the world around them. This means they have difficulties drawing an adult's attention to something they are interested in and also have problems responding when an adult attempts to direct their attention. If a child does not share attention with an adult, s/he cannot see that gestures and words refer to things and events in the world. And so it is clear that shared attention is an essential part of the foundation for developing language and communication. For this reason PACT starts by helping parents

achieve periods of shared attention with their child. Establishing shared attention can be achieved by the parent waiting and carefully watching their child's focus of attention, recognising when there is an opportunity to share attention and quickly responding to it. For example, if a child is playing and looks up, the parent can respond in a way that demonstrates they are sharing attention with the child by commenting, smiling and showing pleasure in what the child is doing.

Communication skills

Communication is about conveying our thoughts, feelings and interests to someone else. This can be done with language or nonverbally, using eye contact, facial expression and/or gesture. Communication can occur as a response to someone else. It can also be used to start an interaction or to keep an interaction going. Children with ASD usually communicate less than typically developing children. When they do communicate their speech or their nonverbal communication may not be clear or it may appear unusual and so may be difficult to recognise. PACT helps parents to recognise when their children are communicating and to support any form of communication.

Communicative intent

The idea of communicative intent is an important aspect of communication. This emerges when a child realises that his actions and vocalisations have an effect on other people. The child will then begin to intentionally communicate with others. Children with ASD initiate communication less and show a more limited range of communicative intentions than typically developing children.

A child with ASD may cry, look at an object or even name it because they want it but the intention of the communication is unclear because s/he does not make a clear attempt to direct the adult's attention to the object they want. PACT trains parents to facilitate intentional communication by using pauses in their interactions to encourage the child to

produce a communication response. This helps the child become aware of the parent as someone who responds to communication through actions and words.

Timed Responses

The timing of the parent's response to their child's attempts to communicate is crucial in developing the child's social communication responsiveness. The aim is to reduce mistimed responses and to increase well-timed responses which are adapted to the child's focus. This can include commenting on the child's topic of interest and showing interest and pleasure in their play.

Parents are encouraged to follow the child's lead in play rather than trying to direct the child. Instead of making demands on the child parents are encouraged to offer well-timed responses such as commenting. Parents are trained to identify the child's behaviours as meaningful communication and to respond to them as though the child intends to communicate.

Use of language

Parents are also trained to think about the language they use with their child and to modify it so that it matches the child's language abilities. They are asked to use language that matches the child's focus of interest and what the child is intending to communicate. This may involve the parent assuming what the child intends but this assumption is based on careful observation of the child's focus of attention and activity.

Conclusion

From these foundations PACT goes on to build on the range of communication functions the child uses to support their development as an active communicator. The programme trains parents to elaborate and expand on the child's own play as well as their communication and language. This includes taking part in conversations at whatever level of language the child achieves.

The PACT study showed the programme was effective in supporting parents to provide well-timed responses to their children. It was also effective in increasing the frequency of social initiations made by the child and the amount of parent-child shared attention. Thus, the training had clear effects on those aspects of behaviour specifically targeted by the approach. However, the degree to which the intervention had benefits beyond parent-child interaction was less certain. No improvement was seen in the child's interaction with an unfamiliar adult or on the child's functioning in school, as reported by the child's teacher. Beneficial effects of the gains made during the training may emerge from further research which focusses on the long-term effects.

The Learning Experiences – an Alternative Program for Pre-schoolers and their Parents

NICE also recommends that there should be further research into the core symptoms of ASD and into the programmes which aim to support children with ASD across all their areas of need, developmental skills and daily living skills.

The Learning Experiences – an Alternative Program for Pre-schoolers and their Parents (LEAP), now being used as a model for pre-school-aged children, is one such programme that shows promise. LEAP is a comprehensive approach to supporting children with ASD. It has many components and works through everyone who knows the child. Parents and other adults in the family are trained in behavioural teaching strategies. Pre-school staff are taught about what ASD is and about the LEAP programme. They are taught effective communication and teaching strategies for children with ASD and how to organise and manage a classroom so the environment supports a child with ASD. They are also taught how to manage behaviour positively and how to support interactions with other children. The other children in the school can be trained to use LEAP. If they are given social skills training they can help to support the communication and social interaction of children with ASD.

How parents can be supported to support children with ASD

Because ASD can affect many aspects of a child's development parents can best support a child with ASD if they have a clear understanding of the condition. NICE (2013) recommends that families are given information about ASD, how it can be managed, and what support is available. Parents should expect there to be a case manager or key worker who has an overview of the child, the family and their needs, so that as these needs change appropriate support can be offered. Parents should be provided with contact details for local and national organisations that can offer support.

National organisations/programmes

The National Autistic Society

In the UK the National Autistic Society is an excellent source of information, advice and support for parents and families as well as for individuals with ASD.

NAS Early Bird Programme

For parents whose child has just received a diagnosis, the NAS run parent training programmes called EarlyBird (www.autism.org.uk/earlybird) which are available in many areas of the UK. EarlyBird is delivered to a small group of families and lasts for three months. It combines group training sessions with individual home visits. Video feedback is used during the home visits to help the parents apply what they have learnt and to continue to work with their child at home.

Early Bird support

The aim of EarlyBird is to support parents to facilitate their child's social communication and appropriate behaviour in everyday settings. By offering support as early as possible the programme also helps parents handle their child in the most effect way when he or she is still young. This can pre-empt the development of inappropriate behaviours. A key part of the programme is to provide parents with information which will enable them to

better understand their child's ASD. This knowledge can help parents see the world through their child's eyes and develop more effective ways of interacting and communicating. The programme gives parents insight into problem behaviours by helping them understand why their child's ASD can lead to such behaviours.

Visual support

It also explains how providing an appropriate structure can reduce the triggers for the behaviours. For instance, visual support can be effective for children who are visual learners. The National Autistic Society (2013) offers advice on ways to present information visually so that parents can support their child with different aspects of everyday living. For example, some children with ASD benefit from structure and routine which can make everyday life more predictable. One way of helping a child understand daily routines is to create a visual timetable which uses pictures or symbols to represent each activity or event in a schedule, enabling the child to more easily understand the structure of their day.

Local groups

The NAS has local groups run by volunteers where parents can meet other families with children with ASD. Drawing on the expertise of others is an important way parents can find the support they need. Sharing experiences with other parents in a similar situation provides invaluable support and advice on managing particular behaviours, knowing where to get help and how to access services.

Conclusion

In this chapter ASD has been discussed as a common developmental difficulty which affects how children communicate, play, interact socially and react to everyday situations. These characteristic patterns of development and behaviour help identify children who are at risk of ASD, and are used by health professionals to decide whether an ASD diagnosis is appropriate. ASD differs between children in the degree and range to which ASD behaviours

are seen. Nevertheless for any child, ASD is likely to have a significant impact on everyday life for the child and their family.

It is important when deciding what support to put in place for a child that parents are aware of the evidence from research studies about what works. They will benefit from having the opportunity to discuss with the professionals supporting them which programme or approach is most appropriate for them and their child.

In this chapter a number of specific behavioural and educational approaches that may be effective for children with ASD have been presented. These approaches often involve parents delivering the programme, with training and support from the professionals. In addition to specific approaches, parents need information and advice about ASD. This will help them to understand their child better so they can respond in a positive way to any challenging behaviour. They will also learn how to modify the environment and everyday routines in order to minimise the chances of such behaviours occurring.

While ASD is a lifelong condition, well supported parents can maximise the opportunities for their child’s development and well-being.

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