

# **PUPILS WITH AUTISM**

## **UNIT 18**

### **ENGAGING EFFECTIVELY WITH PARENTS/CARERS AND FAMILIES**

#### **LEARNING OUTCOMES**

Trainees will

- Understand the potential impact of a diagnosis of autism on families
- Appreciate the importance of good relationships and communication with parents of children on the autism spectrum
- Gain knowledge on the different ways in which the school staff and parents can liaise and communicate, and
- Understand some of the issues around after-school provision for children with autism.

#### **ONLINE RESOURCES**

The content and tasks throughout these PDFs are supported by online resources that are designed to facilitate and supplement your training experience.

Links to these are signposted where appropriate. The resources use graphics and interactive elements to:

- Highlight salient points
- Provide at-a-glance content summaries
- Introduce further points of interest
- Offer visual context
- Break down and clearly present the different stages and elements of processes, tasks, practices, and theories

The online resources offer great benefits, both for concurrent use alongside the PDFs, or as post-reading revision and planning aids.

Please note that the resources cannot be used in isolation without referencing the PDFs. Their purpose is to complement and support your training process, rather than lead it.

You should complete any learning or teaching tasks and additional reading detailed in this PDF to make full use of the Advanced training materials for autism; dyslexia; speech, language and communication; emotional, social and behavioural difficulties; moderate learning difficulties.

To find out more about the resources, how they work, and how they can enhance your training, visit the homepage at: [www.education.gov.uk/lamb](http://www.education.gov.uk/lamb)

The first resource for this unit can be found here:

[www.education.gov.uk/lamb/autism/parents-families/intro](http://www.education.gov.uk/lamb/autism/parents-families/intro)

## **BRIEFING 1: THE PROCESS OF ADAPTATION FOR FAMILIES**

Getting a diagnosis of autism can give families and children with autism access to specialised support and services. However, it should not be necessary for a child to wait for a definite diagnosis before his or her needs are identified and addressed (see the National Autism Plan for Children on diagnostic assessment (NIASA, 2003)<sup>1</sup>. Staff and parents will know the areas in which their child needs support, and strategies can be put in place to help the child without a diagnosis. That said, having a diagnosis enables parents and staff to access information and support services specific to autism, and finally knowing why the child has difficulties is usually a huge relief to parents and carers.

For many parents receiving a diagnosis can be a reassurance or something of a relief:

*It was heartbreak and relief.*

However, a diagnosis of autism can also come as a great shock, and it can take months and years for parents to come to terms with the information. After diagnosis, families often have to cope with a condition they know nothing about and with little idea of what to do and where to go next. Many parents also describe a sense of loss for an imagined future for their child. Although a diagnosis may feel like the end of the world for some parents, it is important for them to appreciate that their child is still the same person that they always have been and that knowing about the condition they have can help them to maximise their child's potential and help them to live life to the fullest.

Clearly, it is not possible to know exactly how a parent feels about the diagnosis or the school, as we all react differently to situations depending on our past experiences, confidence, ability and physical and emotional well-being. The feelings of parents of children with autism will differ depending on the nature of their own experience of school, their relationships with other professionals, the other demands they have on their time and the resources to address these, and the degree to which

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<sup>1</sup> National Initiative for Autism: Screening and Assessment (2003). National Autism Plan for Children (NAPC), (the NAISA Guidelines). London: the National Autistic Society.

they and others find their child's behaviour distressing or challenging. The range of emotions they are likely to experience may include failure, anger, sadness, loss, guilt, frustration, isolation, inadequacy embarrassment and hopelessness, in addition to positive feelings of love, happiness, pride, and satisfaction when their child has shown success or they have felt a sense of achievement in something they have done for the child.

**See online resource:**

[www.education.gov.uk/lamb/autism/parents-families/emotions](http://www.education.gov.uk/lamb/autism/parents-families/emotions)

Most parents of children with autism will have spent many hours thinking about which school and which approaches are likely to be of most benefit to their child and are likely to go on thinking about this throughout their child's education. They will need much reassurance that the school placement is working well and be anxious if feedback from staff suggests otherwise. Their current feelings with the situation and their past experiences need to be borne in mind by staff. How staff respond to them and vice versa will determine how the interaction proceeds. In autism, we know it is important to be empathic and to 'get into the child's shoes', and it is also important to 'get into the parents' shoes'.

**See online resource:**

[www.education.gov.uk/lamb/autism/parents-families/difficulties](http://www.education.gov.uk/lamb/autism/parents-families/difficulties)

Even when parents and carers have come to terms with their child's diagnosis, families can still experience a whole range of difficulties, including:

- social isolation - parents can find it difficult to take their child on holiday, to socialise with other families, or even to go to the local shops as the child may find these situations hard to understand and manage due to their difficulties in understanding unfamiliar situations, problems in social understanding and sensory issues. They can feel overwhelmed with anxiety which leads to behaviour which is challenging for the child and for parents and the general public
- strain on relationships either between parents or with the extended family
- mental and physical health problems - parents are more than twice as likely to be in poor health themselves in comparison to parents who do not have a disabled child and it can be assumed some of this ill-health is stress-related
- A study also found that 93% of families of disabled children report some form of financial difficulty. Many families face barriers to working and struggle with the extra costs of raising disabled children, which is calculated to be three times higher than for other children. 34 per cent of households with a disabled child have no one in paid work.

## Impact for the siblings

Having a person with autism (including Asperger syndrome) in the family has an impact on everyone, not just parents. There are positive aspects to being a sibling of a person with autism, for example lots of brothers and sisters say that learning to see the world through the eyes of their sibling has taught them to become more tolerant of people's differences. However, some siblings of children with autism may require additional support at school, for example, if they experience teasing from other children. At home, they may experience a lack of privacy, disruption of their home life and a feeling of resentment that the focus of the family is always on the person with autism. Older siblings may worry about whether they are going to have to look after their brother or sister after their parents have died. All of these factors can have an impact on the health of siblings and research indicates that having a disabled sibling doubles the chance of a child displaying BESD. Although being the sibling of a child with autism can be a stressful experience at times, research has suggested that it does not necessarily have a negative effect in the long run. There is growing awareness of the need to address the issues faced by siblings and workshops and literature have been developed in response to this (Brock<sup>2</sup>; Knott<sup>3</sup>).

Some families of children with autism will also draw on members of the extended family for practical or emotional support. Grandparents, in particular, may often help out with childcare. One in five children under 16 is looked after by their grandparents in the daytime and more than a third of grandparents spend three days a week caring for their grandchildren. However, members of the extended family may not have an understanding of autism and in some cases this can result in their relationship with the immediate family of a child with autism becoming strained.

### TASK 1:

Watch the video clip "SNAAP".

#### See this clip:

[www.education.gov.uk/lamb/autism/parents-families/snaap](http://www.education.gov.uk/lamb/autism/parents-families/snaap)

This after school club was set up by parents, for parents. What are the main needs that the parents say the club fulfils? What role does the school play in this context?

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<sup>2</sup> Brock, C (2007) *My family is different: a workbook for a brother or sister of a child with autism*: London: NAS

<sup>3</sup> Knott, F (2009) *Sibgroups: supporting siblings of children on the autism spectrum, perspective and experiences of able autistic people*. Good Autism Practice Journal, 10, 2, 18-26

Now watch the video clip “parents”.

**See this clip:**

[www.education.gov.uk/lamb/autism/parents-families/communication](http://www.education.gov.uk/lamb/autism/parents-families/communication)

In this clip the school sets the agenda for the work with parents. How is this different to SNAAP? What are the advantages and disadvantages to each approach in terms of :

- The school?
- The Parents?

## **BRIEFING 2 – HOME-SCHOOL LINKS**

### **Developing the awareness and understanding of staff members**

When children with autism come into a school, it is crucial that all staff members are aware of what each child may find difficult and how they can be supported. Much of this information can be supplied by parents and it is crucial that parents are asked by staff for key information (e.g. likes; dislikes; strengths; fears; interests and main areas of need in school). The following is a quote from a young person with autism:

*I want teachers to remember what they told my mum: that they would tell other teachers about me not liking too much noise, and to help me write down homework because I am slow at writing.*

The Special Education Needs Coordinator (SENCO) has responsibility for ensuring that all members of school staff know which children have autism and for providing them with advice and support on making provision for them. The following quote is from the parent of a child with autism:

*We are relatively satisfied with the support our son now receives at mainstream school because it has a fantastic SENCO who absolutely understands autism. The school has a strong ethos of inclusion, supported by the head. The SENCO has taught us things we didn't know!*

Some schools have developed ‘communication passports’ setting out information about a child’s strengths, areas of difficulty and strategies to use to support them. These help to ensure that children receive consistent support from all school staff. (See unit on Identifying the Needs of Pupils on the Autism Spectrum for more information) Parents and children and young people themselves should be involved in developing this information. Many children find it helpful to have one identified and trusted person that they can go to when there is a problem during the school day. This person can then help to resolve problems and develop the awareness and

understanding of other staff members, as well as ensuring that families are made aware of any problems that have arisen during the day.

A useful set of questions for staff to consider in relation to parents is as follows (where X could be a classroom activity/ a problem behaviour/ home-school contact/ or homework):

- How do the parents see X?
- What can we do/have we done to enable the parents to understand X?
- Have the parents the opportunity (and the means) to give their views on X?

### **Working together: establishing home-school links**

Parents are often the experts on their children, and their knowledge of their children's interests, dislikes, triggers for anxiety or challenging behaviour, and strategies which are effective in supporting them can be very valuable for school staff. Some pupils may not show the difficulties and frustrations they are experiencing during the school day, but will 'bottle them up' until they get home. So parents will be able to alert teachers to problems which may not be apparent in the school environment.

Many pupils need support to apply what they learn in school to other areas of their life, and they may find it difficult to manage the transition between home and school and the differences in 'ground rules'. Therefore consistency of approach to supporting a child with autism is vital and this can only be achieved through good home-school communication, as well as communication with other professionals working with the family.

As you learned in the unit on the research base for interventions with information on TEACCH, structured conversations with parents can help develop ongoing communication between parents and a key teacher. Structured conversations can help teachers to gather information from family members about a pupil with autism, including:

- Their aspirations for their child – what they would like them to achieve, both in terms of academic progress, but also in developing social and emotional understanding, friendships, life skills etc
- Particular areas of difficulty for their child, including any co-occurring conditions
- Factors that cause the pupil stress or anxiety, (e.g. sensory sensitivities, fears or particular objects or routines that they need to stick to)

- Ways to help the pupil to manage stress or anxiety, (e.g. an activity or object that is of particular interest or that can help them to calm down), as with this child with autism:

*When I get stressed all I need is my water bottle, but even a professional won't know this... without them knowing anything about me they can't know that.*

As with any child, the skills and needs of a child with autism will evolve over time, so it is important to have regular conversations with families to assess how things are going and to make sure that the child is getting the support they need to progress.

### **Making home-school communication accessible**

As discussed above, when a child is experiencing difficulties at school, this may not be apparent until they get home when they feel able to express their frustrations in a more familiar environment. Therefore it's really important that parents are able to communicate any concerns they have with school and vice versa. With the development in technology, the tools available to teachers and parents are increasing.

#### **See online resource:**

[www.education.gov.uk/lamb/autism/parents-families/communication-links](http://www.education.gov.uk/lamb/autism/parents-families/communication-links)

Traditionally, written entries have been made in home-school books which go to and from school, but some schools now use email with some parents or have homework on a central school website which parents can access and some staff in outreach teams have used text messaging. It is important to note that parents differ in how they wish to communicate and so schools need to have a range of options from arranged visits, informal discussions, letters, diaries, email, text, phone to showing parents video footage of the child at school to illustrate progress and/or concerns. The literacy, home language and communication skills of parents also have to be taken into account and adjustments made.

Parents of children with autism can find it depressing if communication focuses on what the child finds difficult or what they are unable to do or if they are only contacted to discuss the problems their child is having or if there has been an incident. Good home-school communication will also highlight the positives. That might be in relation to doing a good piece of work, but for a child with autism doing well at school will be measured in many other ways than just academic progress. So a positive report might highlight how the child was able to sit on the mat at story-time for 10 minutes or answered a question in class.

Children with autism find it much more difficult to cope with change. This might be a big change, like moving schools, or it could be a 'smaller' change within the school like a change of teacher or teaching assistant or a change to the timetable. It is important, therefore, to make sure that families are aware of any changes at school which may affect their child and to work with the school to help prepare the child for this. Equally, if a child seems more anxious or their behaviour at school changes, the school will need to find out from families if there are any changes at home which may be contributing to this and mean that the child needs additional support.

Attending meetings at school, such as reviews, can be stressful for parents. Some parents of children with autism may also find social situations difficult and may not have good memories of school themselves, and so meeting professionals in school can be particularly difficult for them. Schools can do a lot to make meetings more accessible for parents, including:

- Keeping the number of attendees to a minimum – while it's important to have all the relevant professionals present, it can feel intimidating for a lone parent to attend a meeting with lots of professionals
- Informing parents that, if they want to, they can bring someone with them for support and to help them remember everything that is discussed
- Providing parents with as much information as possible prior to the meeting to let them know what will be discussed and give them time to prepare
- Choosing a suitable venue – this will be a particular issue if the parent also has autism, and
- Avoiding jargon or language which parents may not be familiar with.

### **How can a school involve and inform the parents?**

It is important that parents are offered a similar range of options by the teachers they meet as the child moves through the school and that this is within the framework of the whole school policy on how parents are involved and informed. Not all parents value the same things in terms of home-school partnership. Some parents want to be actively involved with work at the school and other parents want to be informed of their child's progress but are not able to or do not wish to work directly with staff or the child in school. Particularly useful areas where school staff can work together with parents, and have an impact, are in sharing their ideas on developing communication, creating a friendship group for the child, strategies to help them deal with stress and anxiety and in deciding on priorities and future placement. Both staff and the parents can offer and share ideas on all of these.



## **Home-school book**

Many schools use a home-school book for the child in which both the parents and the school staff can give information of interest and value to the other. This might include written reports, extracts of the pupil's work and photographs and a summary of what the pupil did during the school day or in the evening or the weekend. It is important that the book contains material from staff and parents that is of sufficient detail to be useful and which is positive in tone - even where difficulties are reported. Staff can suggest positive actions such as continuing, "*So we have decided to do X next time*" or can ask the parents' views on what they feel might help. A strategy used in one mainstream secondary school is to send a postcard in the mail to parents describing their child's success at school.

## **Showing parents how the child spends his/her day**

Many parents of children with autism would love to know more about how s/he spends his/her day. The pupil is often unable or unwilling to tell their parents much about this himself/herself. How does their child manage with the various sessions and activities during the day? It is possible in some cases for the parents to observe their child directly within school, but where this might affect the pupil and others other methods need to be used. Some schools take a video of the pupil in different situations and use this at review meetings with parents.

## **Homework**

Work set by staff at school for the pupil to complete at home can cause difficulties for the pupil and his/her parents. Some pupils with autism see the two places as very separate, and cannot understand why they have to do school work at home. They may fail to write down or understand the task or strive for hours to produce a perfect product. Often the pupil with autism is able to read complex sentences without understanding or extracting the meaning. This can lead staff to over-estimate their ability and perhaps set tasks which are too demanding. In addition, some pupils with autism can have the factual knowledge required but fail to elicit this unless they receive particular prompts, or they may be reluctant to record this on paper. Some may have dyspraxia or specific learning difficulties in addition to their autism, which makes written work very difficult. Again, their ability to talk with ease about a topic might cause staff to think the pupil has been lazy when they come to mark limited or poorly presented written work. This can cause stress for the parents and lead to difficulties for the pupil when they produce their homework. Discussions about what is sensible in terms of homework, including alternative means of presentation such as word processing or dictation, or completing work at school, are vital to avoid extra pressures on the pupil and others. Many staff in schools now give out the homework

at the start of a lesson so that the pupils have more time to make a note of it – or it can be posted on the school website for parents and pupils to access at home, if they have the Internet.

### **Differences in the child's behaviour at home and school**

Many parents of typical children will argue that their child is different in school from how he or she presents at school and obviously different expectations, demands, and context mean that we all vary depending on the situation. However, in autism, the difference between how a pupil appears in his or her outward behaviour and demeanour in school and how he or she acts at home can be extremely different and it is vital that staff are aware of this and take serious note of parents who say that their child is very challenging and emotionally distressed at home. For some of these pupils, several aspects of their school day have caused them distress but they have never told anyone about this. Some pupils with autism literally look fine at school as their emotional state is often not expressed through their facial expression when in fact they are extremely anxious and stressed. When they arrive home, it's as if the volcano erupts and they then engage in challenging behaviour towards their brothers, sisters or their parents. The pupil manages to contain all the anxieties and difficulties s/he experiences at school and then releases these on his/her return home.

When life at school and home is going well for the pupil, and parents and staff are receiving positive reports from each other, it is likely that parent-staff relationships will be easy to develop and maintain. But, both staff and parents need to prepare for times when the pupil's behaviour or performance might be viewed as a problem either at home or at school. Staff- parent relationships might then be more difficult. It is possible, for example, for each to blame the other for something they are doing or not doing with the pupil. It is important in these instances to gather very good information on the nature of the problem and on the factors which may be contributing to this at home and school. It can be easy to take the quick route and guess what the cause might be, without doing adequate checking out and getting clear, factual information from all involved. Engaging in speculation is not a useful strategy and is likely to lead to the apportioning of blame and ineffective solutions. This is particularly true when the pupil's behaviour appears to be very different at home from his behaviour at school. A pupil may pose no major behaviour problems to staff and be very undemanding and well behaved in school.

For some pupils, the reverse scenario is true, particularly when the pupil first starts attending school. The pupil may be relatively easy to manage at home, perhaps because the environment is fairly constant and familiar, and there are few demands to be sociable or to engage in tasks which are not interesting to them. In school, the pupil finds him or herself in a noisy, confusing, social environment where people attempt to communicate with them in ways which they often do not understand. In

addition, they may be encouraged to engage in tasks which may hold little interest or meaning for them. Their reaction is to try to sabotage the activity or to escape or to do nothing, all of which challenge the teaching staff. When parents and staff hear very different accounts about the same pupil, they may find it hard to believe or they can be quick to blame the other for something they are doing or not doing to the pupil. It is important to acknowledge that very different behaviour at home and school is a phenomenon found in some pupils with autism (as it can be with other children too).

## **Planning for change**

### **TASK 2**

Think about the range of options you offer to parents/carers of pupils on the autism spectrum to obtain their views and share your work with their child. What do you think you are already doing well? Identify at least 3 actions that you will take to improve the communication with some of the families you work with.

### **BRIEFING 3 – THE EXTENDED DAY**

After-school clubs and short break services are important opportunities for pupils with autism to develop their social understanding and to enable their families to have a break and spend time with their other children. Yet parents of children with autism frequently report being denied access to after-school clubs.

*I've been told that there is no support for my daughter to attend breakfast club, after school clubs. (Parent)*

The most commonly reported barrier to access is that staff running such activities lack confidence in supporting a child with autism.

School staff, who know the pupil well, could help to address this by providing training to the staff running the activity, and helping them to understand what support the pupil needs to take part in the activity, and perhaps attending some sessions with them.

Pupils who will require an individual supporter to take part in after-school activities may be eligible for direct payments, which could be used to fund this support.

Some schools have also set up lunchtime or after-school clubs specifically for pupils with SEN or for pupils with autism. Some will benefit from these, but others may

prefer activities which help them to integrate with their peers in other activities which are offered in a mainstream school. Families of pupils who travel to and from school in taxis or minibuses sometimes report that their children are unable to remain in school for after-school activities because of an inflexible transport schedule.

*.... in special school, the taxi collects him so he cannot stay for after school activities. (Parent)*

This should not prove an insurmountable obstacle, for example, one local special school has simply come to an arrangement where they transport a group of pupils to youth clubs, straight after school, once a week.

### **TASK 3**

Think about the after-school activities offered in your own school. Are pupils with autism accessing these already? If not, what might be the reasons for this? How can you make existing activities more accessible? Or are there other activities that you could run which would be more appealing to children and young people with autism