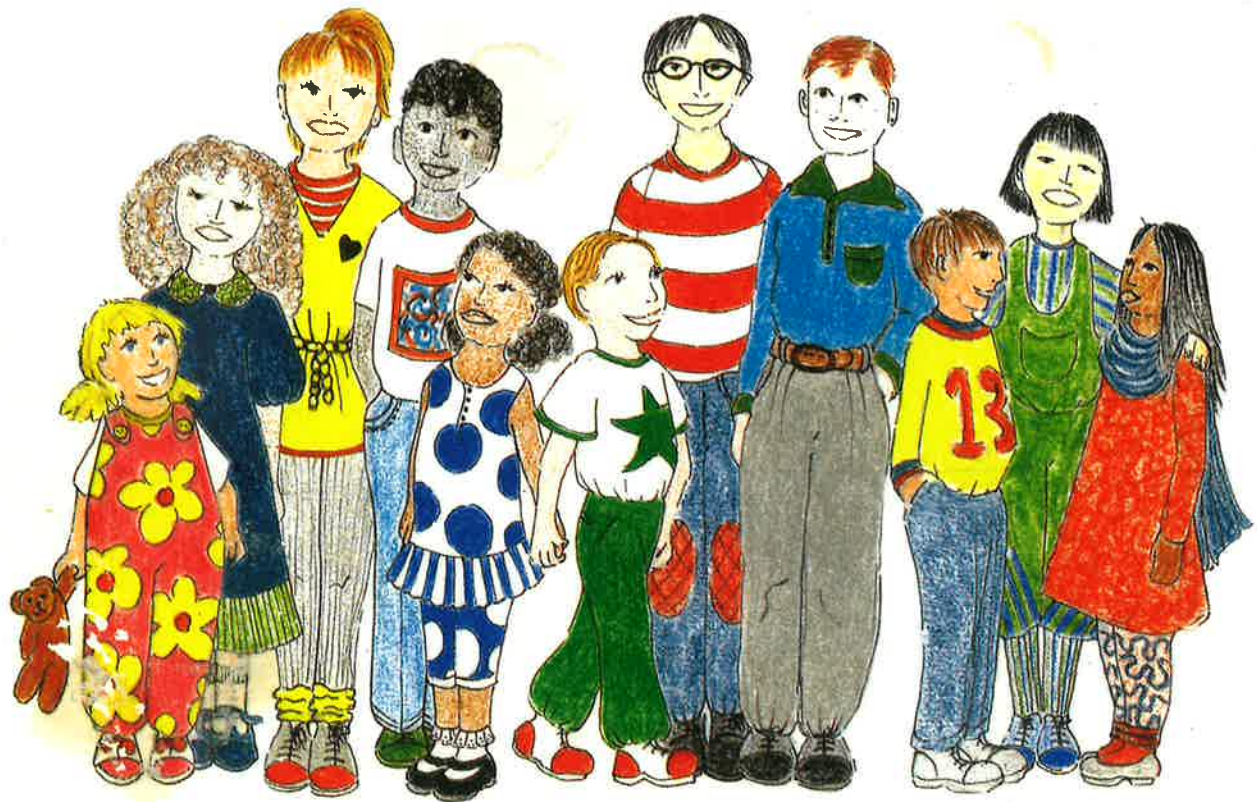


# Children with Autism

## a booklet for brothers and sisters



Julie Davies  
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University of Nottingham





*Note for parents and leaders of sibling groups -*

*Some of the words used in this booklet may at first seem difficult for young children. However, because the problems of autism are complicated and because children at various times will hear technical terms being used, it seemed important to include and try to explain them, rather than leave out these words. This booklet has been written to help children understand autism; providing relevant terms and explanations gives them the chance to make sense of as much as possible.*

*When children read the booklet, support from parents or other adults may be very beneficial. For example, the text can be used by leaders of sibling groups in workshops, by parents as an aid to explanation, or by parents who choose to share reading it with their children. We hope that this booklet will open up conversation and discussion between children and adults, and can also act as a source of reference for consultation from time to time.*

*We are grateful to the Mental Health Foundation who not only encouraged us to undertake the action research project on sibling support which underpinned these booklets, but also funded both the research and the initial publication of this material.*

*Julie Davies  
Elizabeth Newson*

*Other booklets available:*

*For siblings:     Able autistic children (Asperger's syndrome)  
Pathological demand avoidance syndrome (PDA)     (both by  
Julie Davies)*

*For parents:     Able autistic pupils starting mainstream  
primary school  
Able autistic pupils transferring to  
mainstream secondary school     (both by  
Carolyn Brock)*

*Available from the Early Years Centre, 272 Longdale Lane, Ravenshead, Notts.*



## ABOUT THIS BOOKLET -

This booklet is for brothers and sisters from the age of about 7 years upwards, although anyone else is very welcome to read it if they think they would find it helpful.

It will

- explain what autism means;
- describe the sorts of difficulties autistic children have;
- suggest ideas for explaining autism to other people who don't know about it;
- talk about some of the things that you might find difficult as a brother or sister;
- share some of the good things that children have told us about being a brother or sister.

In 1992 in Nottingham and Leicester, fortnightly groups were run for children who have brothers and sisters with autism. These groups were part of a special project to support brothers and sisters, and the children who came to them enjoyed meeting each other as well as talking about what it was like for them. This booklet has been written so that children who have not been to the groups can find out more and read about the ideas that have come up in the meetings. You can read this on your own, or you might read it together with someone else (one of your parents, another brother or sister, or a friend) so that you can talk about it as you go along.



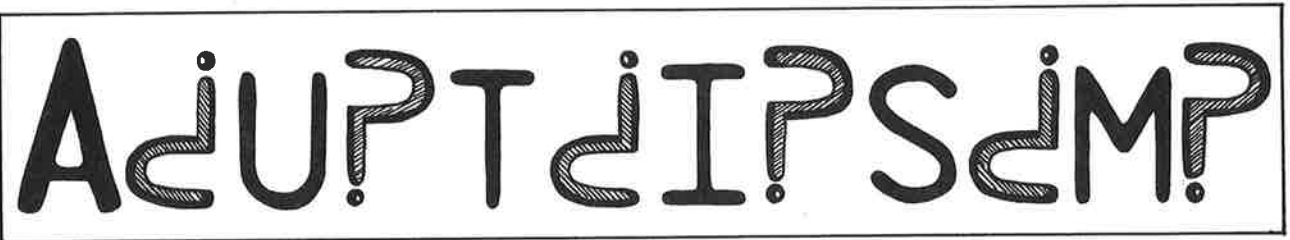


## WHAT IS AUTISM?

### First of all:-

Autism is the name given to the difficulties that your brother or sister has. Obviously you know your own brother or sister much better than we do, but this explanation of autism might help you make better sense of their problems. We will describe what autistic children have in common, remembering that, like other children, every autistic child is different. They have their own looks, their own personalities and their own likes and dislikes.

In this booklet we are going to describe autism and give examples of the sorts of problems all these different children might have. You will perhaps recognise some of them in your own brother or sister straight away.







Children with autism have three main kinds of difficulties.  
The first of these is to do with their **language**.

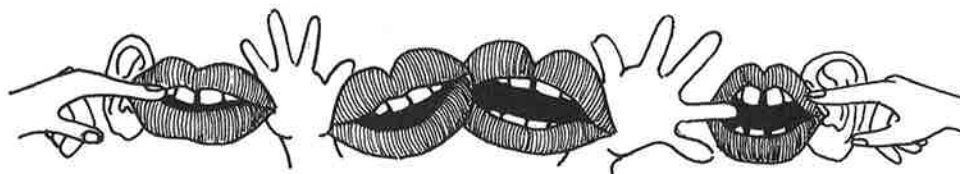
Your brother or sister has difficulties with learning. This means that he or she doesn't understand and pick things up as quickly as you. Any child with learning difficulties will probably have some problems with language, but autistic children have *special* problems with language.

Language is not just about what people say to each other with words. It's also about the meanings people put into their voices when they speak, the expressions they put on their faces, and the movements they make with their bodies to explain things to others.

So language is about using these ways to talk to each other, and about understanding *other people's* words, voices, faces and body language too.

Autistic children have difficulties with **all** these parts of language.

- \* They find it hard to understand what people say, so what others say to them needs to be simple and clear.
- \* They also find it hard to put things into words, to talk to people.  
Some autistic children do not use speech at all, but sign what they want to say.  
Others may not sign, but instead use their own ways of telling people what they want, like taking people's hands to things.
- \* Children with autism find it difficult to understand the meaning you put into your voice (for example, the 'tone' of your voice). It's also hard for them to put meaning into their own voices.
- \* They find it difficult to understand the messages we give to each other without speaking - our body messages, like the expressions we have on our faces, or when we make gestures like waving, pointing or shrugging our shoulders. People with autism find it hard to give their own body messages too.





Autistic children will need a lot of extra help at school because of these problems, so that they can concentrate and learn better.

A second difficulty that autistic children have is a **social** one. This is to do with getting on with other people, making friends, and joining in with other children.

- \* Autistic children find it difficult to take turns. This might be taking turns in a game, or taking turns to say something. It may be very difficult to share doing things together with your brother or sister and hard for you to find ways of playing with him or her.
- \* They may find it hard to know when to look you in the eyes, which is something we know how to do without thinking when we talk to each other. This is called 'eye contact'. When they are not looking at us it can be hard for us to be sure whether they are listening.
- \* Children with autism find it difficult to understand what other people are thinking or feeling. We call this a problem with 'empathy' - not being able to see things from someone else's point of view. So they may sometimes **seem** selfish or uncaring. For example, they may wander off in the middle of a game, they may only seem to pay attention when they feel like it, they may turn the TV off or switch the channel over when you're in the middle of watching it, or something else just as irritating. And they may never seem sorry for these things.
- \* Autistic children often have what are called 'behaviour problems' which means they do things that can be difficult for the rest of the family and for people at school. They may not do what they are told, they may get frustrated and have tantrums, they may make irritating noises, make a mess in the house every day, or they may hit out at other people sometimes. All of these things are not very 'social' - they make it difficult for them to get on with people all the time, but autistic children do not **understand** about hurting people's feelings. They may do these things because they are frustrated, or just to see what happens - whether or not there will be a big reaction from other people; or they may just enjoy the feeling of doing them, like making screeching noises!





The third difficulty that autistic children have is to do with the **rigid** way in which they *think* and *do* things. Rigid means *fixed*, they have little imagination in everyday life and want to keep to the same routine, instead of enjoying a variety of things.

- \* They might like to arrange particular things in a special pattern, or do things in a special order. If anyone interrupts this or breaks the pattern, it can upset them. Other changes may be difficult for them too, like wearing a new jumper, getting into a different car, taking another route to the shops.
- \* They may repeat exactly the same actions with a particular toy or object, or want to play the same video again and again. You might have heard this sort of behaviour called 'obsessional'. Some of these children's body movements may also be repetitive at times; for example they may flap their hands a lot or look at their fingers, jump up and down, tap surfaces again and again, spin objects like coins and stare at them, or twiddle a piece of string most of the time.
- \* It means that autistic children often **don't play in the same way** as you do, and can't play your favourite games with you because they prefer to do these other things. It's very hard for them to take part in the pretend play that many children enjoy, like imagining they are someone else, or acting out scenes with dolls or a lay-out. They may be able to think up some ideas for the *obsessional* things they do because they are so interested in them, but can't use their imagination so easily in the other parts of their life. Sometimes they are fascinated by the patterns they see on TV, like Blockbuster numbers or programme credits or the weather map, without understanding what they mean.



- \* Autistic children are also rigid in their language. We've already looked at problems with language, but you will notice that the three areas of autism overlap sometimes. If they talk, they may repeat what you say like an echo because they don't understand how to answer you. So they stick to saying what you have just said. Echoing means that they are likely to call themselves 'you', instead of saying 'I', for example, if you ask, 'Do you want a biscuit?' they may answer by echoing, '**You** want a biscuit' when they mean 'I want a biscuit'.
- \* There may be particular things that the autistic child is frightened of, like loud noises, dogs, hooovers, doors being open, or crowds of people. This is because they easily feel confused and unprotected.
- \* Sometimes children with autism find life bewildering. Doing or saying things again and again makes them feel safer because then they know what is going to happen next. Changes in plans can be especially confusing for them, so your parents may try to prepare them for things long before they actually happen.









### IS AUTISM AN ILLNESS?

No. It is not an illness like measles or a tummy bug, and it is not catching. It is not anyone's fault - it is not your brother's or sister's fault, it is not your parents' fault, it is not your fault. It is something that probably goes wrong before a child is born, although we often do not realise as soon as he or she is born that a child has autism - it might be two, three, four years, or sometimes more, before someone realises. There is no prevention or cure for autism yet, and we don't know the exact cause either - in fact there may be a number of different possible causes, and a number of possible cures to be found in the future.

### IS IT TO DO WITH THE BRAIN?

It seems that the brain of an autistic person probably works in a different way from other people's brains. We don't yet know whether this is because the brain has been damaged, whether a part of the brain is different, or whether the chemicals in the brain work differently. It could be any one of those or even all of them together.

Some autistic children also have epilepsy, which means they sometimes have fits. Epilepsy is *also* caused by a problem in the brain.

You know that your brother's or sister's successes are different from yours, and they may come more slowly. When you are learning things at school - your Maths, your English, your Science, and all the different subjects that you do - they may be learning to point to things, to put their shoes on without any help, to say and understand more words, to read a little, to do puzzles, or to post a letter. Your parents are proud of all these successes, of yours and theirs - they are equally important.

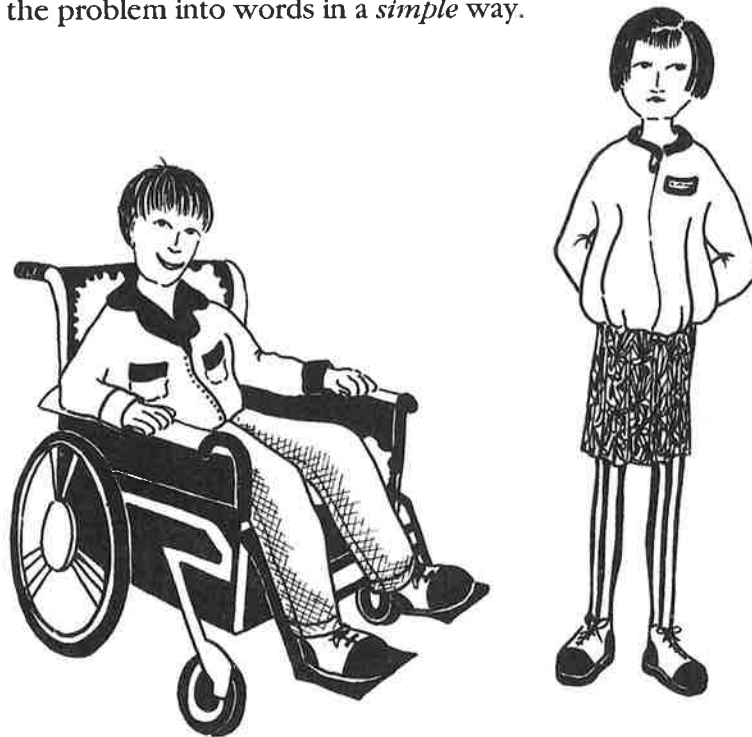


## HOW CAN WE EXPLAIN AUTISM TO OTHER PEOPLE?

It can be very difficult to explain to someone about the problems that your brother or sister has. You might already have found this. Children *and* adults find it hard to help other people understand about autism.

That's probably because -

- a) autism is not very common - in fact it is quite rare. So people may not have heard of it before, although it is becoming more and more well known as time goes on (only about 6 children in 10,000 have autism);
- b) you can't see autism at once, the way you can see other problems - for example, if you saw a child on crutches or in a wheelchair you would recognise a problem straight away. So it is not always obvious that there is a problem at all;
- c) it's difficult to put the problem into words in a *simple* way.





In our group meetings we thought of the sorts of situations where brothers and sisters might want to explain autism to other people. This is what we came up with -

- i) If somebody asks you
- ii) If somebody teases your brother or sister
- iii) If he or she does something that other people find surprising
- iv) If you want to tell someone before they meet your brother or sister - for instance, if a new friend is coming to your house
- v) If it *seems* as if your brother or sister being naughty (but you know different)
- vi) If someone talks to him or her and doesn't get any answer





Here are some ideas for explaining about your brother or sister. You can use some of these if they seem right for you, or you can make up your own after looking at these suggestions. Choose or think of one or more ideas in each of the 5 sections -

1) A *name* for your brother or sister's problem or a *description* of it, for example, "He has autism" or "She has a communication problem"

2) "This means that ..... he has problems understanding and putting things into words"  
or  
..... she doesn't have much speech but she can sign some words"  
or  
..... he has difficulty talking but he can point to things he wants"  
or  
..... she has problems with talking and understanding, and with joining in"  
or  
..... he doesn't understand what other people think and feel"  
or  
..... sometimes she likes to do the same thing over and over or she repeats what she says because it makes life less confusing for her"

If you want to, you can mention that your brother or sister has always had this problem - since he or she was born.





3) What it's like for him or her

for example "He finds things frustrating /confusing sometimes"

"It may seem like she's ignoring you,  
but she switches off sometimes  
because it's hard work for her to try  
and understand"

"Things are sometimes unfair for  
him"

"To him it might feel like we're  
speaking a foreign language  
sometimes"

"She may seem naughty but she  
doesn't understand what people  
expect of her - she doesn't  
understand the rules"



4) So it would help if .....

you let him see that you're friendly"

or

..... you say things in a simple way"

or

..... you use his name first when you talk to him"

or

..... you're patient with him"

or

..... you ignore him if he's playing up"

and so on.

5) Something nice about your brother or sister

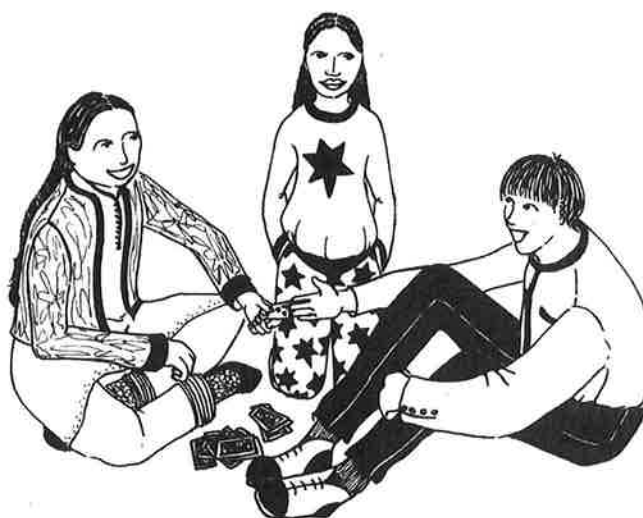
e.g. "He's good at ....."

"She can ....."

"We have fun doing ....."







Other questions that you may be wondering about :-

**1) Will he ever get better?**

**Answer:** There is no cure for autism, but autistic children can be helped to learn at school and at home - they can work on their language, on ways of looking after themselves better and becoming more independent, on their art and craft skills, and on their play. As well as this, the more a child's family and teachers live and work with him or her, the more they will understand how to make life better for the child and for themselves. So it's not just important to think about the *autistic child* improving, it's about everyone learning how to improve the way they live together. This might include finding ways to manage the autistic child's behaviour problems better, finding places to visit that the whole family can enjoy, and taking time for each person in the family to do what *they* want to do every so often.

**2) Why does he want to be on his own a lot?**

**Answer:** Autistic children have difficulties that can be hard for them to put up with sometimes. So they may need their own space to relax. They may also have interests that don't include other people, and be happy doing these for a long time. It doesn't mean they *never* want to be with other people - it just means they may need more space and time to themselves than the rest of the family do.



3) Why won't he play with me? or Why won't he join in with our games?

Brothers and sisters might come up with different answers to this one. Look at these examples and think about how you would answer the questions above.

**"He has obsessions that stop him wanting to find out about other activities"**

**"He finds it difficult to understand the rules"**

**"She doesn't know how to start a game off so I always have to do it"**

**"He doesn't care about winning games so he doesn't see the point of playing"**

**"He finds it hard to join in with a group of children and fit in to what we're doing"**

**"She doesn't have the imagination to think up ideas for playing"**

**"He doesn't understand about sharing."**





#### 4) Why doesn't he get told off like I do?

Answer: In families who have children with autism there may have to be different rules for brothers and sisters at times. Parents may allow their autistic children to do things that they could not allow their other children to do. They know that it is often because of the autistic child's problems that he or she may say and do the 'wrong' thing. They also know that it is frightening and stressful to have autism.

Parents may tell their children off in different *ways* too. They may get cross and shout at their children if they are naughty, but they may find that this way doesn't work with their autistic child. Parents might instead try all sorts of other ways to change the autistic child's difficult behaviour, like ignoring it, distracting his attention to something else, or actually moving **him** somewhere else. This probably feels unfair to you sometimes, but it's part of an unfair situation where one person has a disability and the others don't. We can't all be treated in exactly the same way, because we all have different abilities and needs. You are more responsible and more understanding than your autistic brother or sister, and your parents know that.

#### 5) Why does he laugh when I am upset?

Answer: Autistic children find it hard to understand other people's feelings because it is difficult for them to see things from other people's points of view. So when someone gets upset they may find this confusing and don't know how to behave. It doesn't mean that they *want* to hurt them even more. It may seem like that, and it may be hard not to feel hurt sometimes. Try and remind yourself that it happens because of their problems with **empathy**. If you try and see an autistic person's point of view, you will be using empathy yourself - and you'll realise that not having empathy is a very difficult problem.



6) Why does he ignore me sometimes?

Brothers and sisters have different answers for this one. Here are some examples.  
What would *you* say?

**"He doesn't realise that it's rude to ignore people because he can't see their point of view"**

**"Sometimes he doesn't realise I'm talking to him when I say something to him - he doesn't notice the signs in my face and body that show who I'm talking to"**

**"His obsession stops him thinking about anything else"**

**"Other things catch her attention very easily and she thinks about these instead of listening to me"**

**"He finds communicating hard work sometimes, so he might 'switch off' to shut out any talking"**

**"Sometimes he might not quite understand what we say, so he ignores us"**



If you have any other questions or worries that haven't been discussed here, then talk to your mum or dad, or to another grown-up who you think could help.

### Difficult times

Sometimes you may feel that having a brother or sister with autism makes your own life very difficult. There may be pressure on you to be very well-behaved and responsible, and especially patient when your brother or sister needs attention. You may feel sometimes that you can't do what you want to do, or go where you want to go, because your brother or sister would find it too difficult. You probably find it hard sometimes to play with them or to get through to them, and perhaps miss sharing things with them. You may also feel very protective over them if they are teased by other children, and feel that you should stand up for them, but sometimes it's hard to do that.

#### *Being an older brother or sister -*

If you are **older** than your brother or sister with autism, you may feel (like any other older child) that you are expected to behave well and set a good example. But you may feel that you have to be *especially* responsible and grown up because your brother or sister has autism.

You may also compare with other families and feel that you miss out on things that other older brothers and sisters have, like being able to teach the younger one to do things, tease them in fun, or just enjoy being admired by a younger brother or sister.





### *Being a younger brother or sister -*

If you are **younger** than your brother or sister, it may often feel as if you are actually the older one. You may feel that you have to be especially good and grown-up. You may also do better at school, or in games and sport, even though you are younger, and this might feel a bit strange. You may compare with other families and feel that you miss out on things that other younger brothers and sisters have; for instance, being able to learn things from your older brother or sister, play competitive games with them, or just enjoy being looked after and protected by them sometimes.

If you have any of these feelings to do with being older or younger, it must be difficult for you at times and it is all right for you to feel the way you do. It is also OK if you **don't** have these feelings - it may be that you have other brothers and sisters in the family, or friends to play with, tease, or learn from - other people who you can do things with that you can't do with your brother or sister.

If you do have feelings like the ones described above, you could talk about them to someone else, just as you can ask questions or share any worries you have.







You may find other things difficult that we haven't talked about yet. Here are some of the things that children from the Brothers and Sisters Groups said *they* found hard (the ages in the brackets are the ages of the children speaking) -

"If you leave the door open you can't really do that because he just runs out" (aged 8)

*"Sometimes in the car if he gets in a mood he sort of kicks me" (aged 9)*

"He wants to be alone all the time" (aged 11)

*"She embarrasses me sometimes in front of my friends" (aged 11)*

"We couldn't go to the cinema with him" (aged 7)

*"With my brother you can't exactly have a normal conversation. He'd most likely repeat what you say" (aged 11)*

"Not all people know that he's autistic, but he throws wobbles and things and people think he's being naughty, but he isn't" (aged 10)

*"When he screams it really gets in my ear and it really hurts me...I want to smack him, but I know he's autistic so I can't smack him" (aged 7)*

"His toileting is difficult" (aged 8)

*"It's difficult when he runs about and I'm trying to watch the telly and he keeps running around in front of it" (aged 9)*

"He keeps me awake" (aged 7)

*"I don't like it when she puts things in her mouth" (aged 11)*



"If he's in a crying mood or something it's hard" (aged 8)

*"I wish he could clear up his own mess" (aged 7)*

"If he wants a video then he just brings you to the TV but sometimes you're watching it, so it gets a bit on your nerves" (aged 8)

*"People at school don't understand about it" (aged 10)*

"When he wants something to eat it's hard to understand him...you don't know what he wants" (aged 8)

*"When we play board games...he just walks all over the pieces" (aged 8)*

The children in the groups were also asked what they liked about being a brother or sister. They talked about many different things -

*"He likes songs a lot, us singing to him and playing with him" (aged 5)*

"He likes being tickled" (aged 10)

*"He looks up to me" (aged 11)*

"There's something I love doing with him - I give him piggy backs" (aged 9)

*"I think he's special" (aged 11)*



"I really like being proud of what I've taught him" (aged 10)

*"I read books with him" (aged 11)*

"Sometimes I take him for walks" (aged 9)

*"If I'm upstairs drawing he'll come and colour in pictures with me" (aged 11)*

"Sometimes it's quite good to have a handicapped brother 'cause you don't really tend to have as much fights" (aged 9)

*"Riding a bike with her" (aged 11)*

"I sometimes spoil him" (aged 10)

*"He comes to me and he gives me a cuddle" (aged 10)*

"Swimming with my brother" (aged 9)



**These next two pages are for you to fill in.**

It might be worthwhile writing down your own thoughts, so here's your chance.

You could do this on your own and keep it for yourself, or with someone else to help you.

**The things you find difficult are -**

--

**The things you would like to change, to make things better for you, are -**

--

**The things you would like to change, to make things better for your brother or sister, are -**

--





**The way you would explain your brother's or sister's problems is**  
(see pages 9-12)

--

**The things you enjoy doing with your brother or sister are -**

--

**The other things you like about having this brother or sister are -**

--



## **'My Autistic Brother'**

My Autistic Brother,  
Colin is his name,  
When there's  
Any trouble  
He's usually to blame.  
My seven-year old Brother  
He cannot say a word  
His behaviour is appalling  
And sometimes just Absurd.

When he sits down at teatime  
He always stands right up.  
When he's drunk enough,  
He'll throw drink from his cup!  
He pushes children over,  
He throws things on the floor,  
And when you try to stop him,  
He does it even more.

He tears up bits of paper,  
He often does things wrong  
He likes to run around  
And he is very strong  
He does his wee-wee on the floor  
And while mum wipes it dry,  
He darts away to make more mess,  
Mum follows with a sigh!

I sometimes play with Colin,  
I like to teach him things.  
I try to show him how to skip,  
But he runs around in rings  
He rushes here, he rushes there,  
Dashing all over the place,  
You know when he's done something wrong,  
By the cheeky look on his face.

He really does exhaust us all  
He's always on the go.  
From morn till night you hear mum shout  
'what's he doing now - oh no!'  
I love my brother Colin,  
Although he's such a pest.  
And when he's gone to sleep at night -  
Then we get some rest!

Nicola Holt (aged 9)  
'Communication" Vol (24) 2  
The National Autistic Society.



*For your ideas*





Illustrations by  
J.M.Peet

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