



## **TRANSCRIPT**

### **Working with people with autism: the autistic perspective**

#### **Words on screen:**

00:00:17 Working with people with autism:  
the autistic perspective

#### **Narrator:**

00:00:28 It's estimated that up to half a million people in the UK are on the autistic spectrum. All people with Autism share difficulties in communication, but their condition will affect them in very different ways. Some can live relatively normal lives, whilst others may need a lifetime of specialist support.

#### **Conversation Scott Mould and his Mother:**

00:00:52 Scott, can I ask you something?  
00:00:54 Yes.  
00:00:55 Have you got all your DVD's together?  
00:00:57 Yes, I have got my tapes, yes, yes, yeah.  
00:01:00 Yeah?

#### **Narrator:**

00:01:00 Forty-six year old Scott Mold has spent the weekend in North London with his mum and dad.

#### **Conversation Scott Mould and his Mother:**

00:01:03 They are all packed in your sack?  
00:01:05 Yes.  
00:01:05 Are they?  
00:01:07 Yes, yes, yes I will show you upstairs, I packed them.  
00:01:09 Right, can you bring it down then?

00:01:11 Does that just go straight through to the ...

00:01:13 Right, you want it downstairs.

**Narrator:**

00:01:11 Scott has learning disabilities as well as Autism and he is getting ready to return to his supported housing.

**Conversation Scott Mould, his Mother and Father:**

00:01:18 I am not being cross with you or anything alright, but what happened with the water in the night, in the bathroom?

00:01:24 You had an accident didn't you? It was alright.

00:01:26 I was washing my face well to make myself ... because I felt like it and then ...

**Scott's Mother**

00:01:32 He is very loving and very caring. He wants to be like a normal person, he wants to do the normal things. He doesn't know how to react to people in the correct way and has to be reminded. He often wants to be friendly with other people but doesn't really know how to.

**Conversation Scott Mould, his Mother and Father:**

00:01:54 Sorry I did that.

00:01:55 It's alright Scott.

00:01:56 We just wanted to know what happened.

00:01:57 It tends to drip from your hands a lot doesn't it?

00:01:59 Yeah.

00:02:00 Because you put a lot of water on your hands?

00:02:01 Sorry I did that.

00:02:02 It's alright Scott.

00:02:03 We just wanted to know what happened.

00:02:03 These things happen, don't they?

00:02:06 You are not going to make it [unclear] for me are you?

00:02:07 No.

00:02:07 No.

00:02:09 See you later, alright.

00:02:11 Dad's not driving is? Where are you ...

00:02:12 No, I am driving.

00:02:14 I am not extra [unclear] I am not very naughty, I am not naughty, I am not always extra [unclear]. I am not ...

### **Scott's Mother**

00:02:19 Scott has all these rituals that he has to go through, and these seem to comfort him and settle him down.

### **Conversation Scott Mould, his Mother and Father:**

00:02:26 I am ...

00:02:26 Off you go.

00:02:27 I was excited about when I saw Peter and David, when you ...

00:02:30 Because you were Thunderbirds. We will see you later, about half past two to three.

00:02:34 Mind how you go.

00:02:36 Bye.

### **Narrator:**

00:02:39 Some people go through life encountering problems with colleagues without understanding why. Marie Harder is a Professor of sustainable waste management at Brighton University. Marie was only diagnosed with Asperger's Syndrome two years ago.

**Marie:**

00:02:56 I have got Asperger's, it means basically I have verbal communication problems, and I misread, misread people and they misread me a lot. I don't see these rules of conversation, I can't learn them; it is very difficult for me to understand all the unspoken things that people mean in an interaction.

**Marie in a meeting with a man:**

00:03:17 I think obviously the trick is not to commit yourself to ...

**Marie:**

00:03:19 If I interrupt people in a conversation, or I have got an idea and I am trying to get it across, and I am focussing on it, they may see me as intensive and pushy and argumentative, and I'm not, I might be actually ... I would be horrified probably sometimes to think I have upset somebody.

**Marie with colleagues:**

00:03:36 ... Wednesday, isn't it, so ...?

00:03:38 Okay.

00:03:38 Yeah.

**Marie:**

00:03:39 These can happen at any time.

**Marie leaving meeting with a colleague:**

00:03:42 Okay, alright then?

**Narrator:**

00:03:45 Since Marie's diagnosis the University is providing her with support. They have arranged for her to talk with a National Autistic Society mentor whenever she encounters a problem.

**Marie on the telephone:**

00:03:57                   And then I had a meeting coming up, and I couldn't believe over the weekend, I was getting quite anxious about his new office, I just can't imagine ... there's no logic in it at all.

00:04:10                   No, but, no I know where you are coming from though.

00:04:14                   Really, you have seen it before?

00:04:17                   Yeah, but from a different end of the spectrum; yours is an attenuated version.

**Narrator:**

00:04:24                   Weekdays Scott lives in his flat with twenty-four hour care provided by trained staff such as Sarah.

**Conversation Scott and Sarah:**

00:04:23                   When people have got things on their mind. Tell me what ... they are very busy, sometimes they are stressful aren't they?

00:04:39                   Yeah, sometimes money worries.

**Narrator:**

00:04:43                   But mum and dad are always in and out.

**Conversation Scott and his Mother and Father:**

00:04:46                   Scott!

00:04:47                   Hello.

00:04:48                   Alright? Alright?

00:04:50                   Guess what?

00:04:52                   What have I got to guess?

00:04:54                   Guess.

00:04:54                   Shall we go into your lounge?

## **Scott's Mother**

00:04:57 He's got what we call a 'verbal minefield' that's everyday words that people normally would say to other people that wouldn't have any effect on them, but with Scott you have to tread very carefully.

## **Conversation Scott and his Mother and Father:**

00:05:11 Autism is winding me up mum.

00:05:13 What is it? Has it just started?

00:05:15 Yes, my friend [unclear]

00:05:18 What happened Scott?

00:05:21 We are friends aren't we daddy?

00:05:22 How does it happen Scott? Can you ...

00:05:24 It just comes on.

00:05:25 In your eye?

00:05:26 No, it just comes on in my mind.

00:05:28 Oh so something happens in your ...

## **Scott's Father:**

00:05:30 Someone has said or done something that has set him off. And other times when he seems to get these sort of voices in his mind or something that sort of usually reminds him of some traumatic experience in the past when he has been rejected by someone.

## **Conversation Scott and his Mother and Father:**

00:05:46 I can cry can't I?

00:05:48 Of course you can.

00:05:49 Does your Autism make you feel sad?

00:05:51 Yeah. I cry because it's alright to feel sad if you've got feelings isn't it dad? But they are not [unclear] boys are meant not to cry are they dad?

00:05:58

No.

00:05:59

No, not nowadays. It's all rubbish isn't it?

00:06:01

You are off the [unclear] yeah.

**Narrator:**

00:06:02

When Scott gets upset he tends to self-harm.

**Scott's Mother and Father:**

00:06:06

He will shout.

00:06:07

And sometimes swear.

00:06:08

He will sometimes hit himself.

00:06:09

Sometimes hit himself, yeah.

00:06:11

He has been known to give himself a black eye. He is going through hell, because what's going on in his head is like explosions, and he just wants someone to sort of as I see it to comfort you, and that's what I try to do.

**Conversation Scott and his Mother and Father:**

00:06:28

... you could tell by looking at me.

00:06:29

I can tell by your eyes sparkle.

**Narrator:**

00:06:33

Marie wanted her colleagues to understand the difficulty she continually encountered in the workplace.

**Marie:**

00:06:41

I put these examples with visual illustrations into a book to be able to give somebody who didn't know anything about Asperger's an overview of what it was.

And these guys are having a conversation, and these are rules he has to make up and work out for himself; listen first, wait for a pause, keep to the topic.

**Narrator:**

00:06:59 This is just one of the strategies Marie has worked out to manage conversations with colleagues. Today the team are planning a conference on sustainable development.

**Marie in a meeting with colleagues:**

00:07:10 Something that's holding back everything else is a conference announcement.

00:07:13 Yeah.

00:07:14 And inviting those conference speakers.

**Marie:**

00:07:17 I don't think in words, and I don't work in words, so just having a person that I have to respond to, I have get out a toolkit and open up this toolkit and get out the bit which says "I am going to listen to you, acknowledge that you are speaking words, I now have to translate them and respond to you".

**Marie in a meeting with colleagues:**

00:07:32 We might be talking about different things, so let me just jump in and say, I think the conference preparations are a bottle neck. We ...

**Marie:**

00:07:40 While I am speaking I have to also constantly worry about how the other person is taking it. So for example have I been saying too much? Do I need to put the breaks on? Do I need to move sideways? Do I need to pause. Are they in the middle of trying to tell me something? And then if they are I have to stop, put all that aside, and then try to understand their context.

**Marie in a meeting with colleagues:**

00:08:01 So we just have to make sure that the venues are available at all in those windows of time.

**Marie:**

00:08:06 Are they actually talking about the same subject as me or have we already missed each other. So there's a lot going on.

I get to the point where I don't want to be around people, it's a matter of finding a place where you can recuperate. You might play a musical instrument and that allows you to concentrate; almost anything where you are left alone to concentrate without having to interact is effectively a rest.

**Conversation Scott and his Mother and Father:**

00:08:37 What you could do is you could say, would you like a cup of tea dad? Couldn't you? And make him a cup of tea.

00:08:44 There must be a kettle over there somewhere Scott.

00:08:46 Right [unclear]

**Narrator:**

00:08:46 Now Scott is settled but he's had some bad experiences with professionals in the past, including at a residential care home in Wales. One evening his dad tried to speak to him on the phone.

**Scott's Mother and Father:**

00:09:00 And the member of staff who answered it said "Oh I am glad you have phoned Mr. Mold because Scott is standing in the corner of the room bashing his head against the wall and pulling his hair out, can you tell us what we should do about it?" And this is two hundred and fifty miles away and I said "Stop him of course" and he said "Oh how do we do that?"

00:09:19 I had explained actually to a member of staff before that if he had an outburst what to do.

00:09:31 We are the experts, we know our son, we have lived with him for forty odd years and we have seen him develop.

00:09:40 By watching Scott's body language, if you are not observant and you haven't got the empathy of how he is feeling then it will make more difficulties for Scott, and cause him distress, and it will also in the end cause the professionals problems.

**Conversation Scott and his Mother and Father:**

00:09:59 [Performing a verbal ritual]

**Scott's Mother and Father:**

00:10:04 Treat that person as you would like to be treated yourself.

**Conversation Scott and his Mother and Father:**

00:10:08 We have to get going now Scott.

00:10:09 Alright.

00:10:09 ... please I will see you off first.

**Scott's Mother and Father:**

00:10:11 And I think that sometimes is lacking a lot of the time, and people think that people with Autism are just being difficult, or they can change, and they can't.

**Marie:**

00:10:30 I don't see it as a disability, that's for sure. It's a way of being hardwired differently, and most of my problems are due to the rest of society not being able to understand what that means and the implications. So it's a disability to the extent which society makes it a disability for me.

## **Title: Key Learning Points**

00:10:51

There are almost half a million people in the UK who are on the autistic spectrum; all of these people share difficulties in communication, but their condition will affect them in very different ways

Asperger's Syndrome is on the autistic spectrum; people with Asperger's Syndrome often need to learn the rules of conversation

Family carers are often the experts in understanding, explaining and providing care and support to their loved one

Sometimes society makes a disability more of a disability for an individual by not taking the time to understand the individual

**END**