

TRANSCRIPT

Challenging behaviour and learning disabilities – independent living

Words on screen:

00:00:17 Challenging behaviour and learning disabilities – independent living

Narrator:

00:00:25 People with severe learning disabilities sometimes use challenging behaviour as a method of communication. This film looks at how their families and support workers can develop the skills both to deal with it, and more importantly find strategies to prevent challenging behaviour occurring.

Professor Jim Mansell, Professor of Learning Disability, Tizard Centre, University of Kent:

00:00:45 Many people, especially with severe learning disabilities, don't have good communication. They have not learned either to express themselves very clearly, or to understand what other people are saying to them. And if they then can't say to us, back off a minute, give me a break, they might cast around for a way which works, a way that they can use which stops us doing what we are doing, and that way might be hitting us, or screaming at us. What we think happens in most cases is that these things develop almost accidentally in childhood, but people respond to them, and so they work. And people use them over and over and over again.

Narrator:

00:01:35 Jan knows all about challenging behaviour, her fourth child Andrew suffered brain damage during his traumatic birth.

Jan, Andrew's Mum:

00:01:43

Andrew was asphyxiated at birth, and the first night of his life he fitted consistently and they found it difficult to control the seizures. So the outlook looked pretty bleak, but I was told that they wouldn't know the extent of any damage, if there were any damage; it was development, his development, that would actually identify what his difficulties might be.

Narrator:

00:02:12

As Andrew grew Jan began what would become a regular pattern of adapting her behaviour, routine and home to accommodate his changing needs.

Jan, Andrew's Mum:

00:02:21

Initially it was just hair pulling and curtain pulling, and as he got older, with the changes in terms of his support, and I guess a lack of consistency in the way he was supported, he started to become destructive and disruptive as well. So he didn't just pull curtains down and pull hair anymore, he actually destroyed rooms, he swept everything, threw things, broke things, and quite big things; it can be something as big as a microwave that he might throw if he was in the kitchen. The new skills he was learning with more difficult behaviours got responses, so it was effective; hair pulling obviously didn't work as well, whereas throwing something had a better impact, and got the response maybe that he needed.

Narrator:

00:03:09

As Andrew reached adulthood Jan decided the best way to safeguard his future was to take control. Using direct payments she recruits, trains and manages his entire team. She has studied Andrew's triggers, and over time has developed a guide which outlines the style of life that suits him best.

Jan, Andrew's Mum:

00:03:30 This is Andrew's essential lifestyle plan. It tells us what makes Andrew happy, it tells us what makes him upset, and it tells us what his important routines are. It is a living document, it helps Andrew by providing good information to the people that support him, information that he is not able to share himself because he is not able to talk, and I guess he does know what makes a good day because he is going to be happy, but if you have not seen him have a good day how are you going to know what makes a good day, there has to be a way of recording all of that rich knowledge and experience, and that's what this plan is.

Conversation between Gary and his brother Andrew:

00:04:12 We are going to Taylor's for tea aren't we?

Narrator:

00:04:13 Andrew's brother Gary helps out whenever he can.

Conversation between Gary and his brother Andrew:

00:04:16 If we ever get up to the chemists and back in time, if!

Jan, Andrew's Mum:

00:04:21 On the whole If Andrew's lifestyle is implemented, and he is well supported, and has a busy active life; not allowing him to be bored, not allowing him to become hungry, not allowing him to be over stimulated – it's just as bad as being bored – on the whole it works.

Narrator:

00:04:39 Andrew now lives in his own home in the village where he grew up.

Conversation between Jan, Gary and his brother Andrew:

00:04:43: Behave yourself for five minutes.

00:04:45 Say no, I just am being silly.

Narrator:

00:04:48 Support worker Phil joined the team a month ago.

Conversation between Phil and Andrew:

00:04:51 Are you going to play with the oven, again? Oh what's in there?

Phil Coughlin, Andrew's Care Team Member:

00:04:57 The thing that's important for Andy is sticking to his routine. Any sort of sidestepping away from it can lead to anxiety, and can upset him. So everything is quite rigid; there are three activities a day, they all started at pretty much the same time and finish at the same time every day.

Narrator:

00:05:17 Every Friday Andrew eats out at a local Chinese restaurant, where he has his own menu to choose from?

Conversation between a waitress, Gary and Andy:

00:05:23 What would you like today Andrew? The sweet and sour.

00:05:26 The sweet and sour.

Narrator:

00:05:27 Thanks to Jan and the other members of Andrew's team his lifestyle is busy, and his challenging behaviour usually manageable.

Conversation between Gary and Andy:

00:05:34 Aargh!

00:05:35 Yeah, it's a bus.

Narrator:

00:05:36 Looking back, Jan can see where she could have been better supported.

Jan, Andrew's Mum:

00:05:40

Children with complex needs are nearly always the ones who are excluded from respite care, so the families that have the most difficulty get the least support. The parents don't get any training, parents just learn by experience. I learned very soon that when Andrew threw one of his most treasured DVDs and it ended up in the washing up bowl, and he still wanted it to work, I quickly learned that he didn't understand consequences. But it is learning on the job, and it would have been so much better if that learning, that understanding, had happened from the time I needed it to happen, from when he was very small.

Professor Jim Mansell, Professor of Learning Disability, Tizard Centre, University of Kent:

00:06:22

Families need, broadly speaking, two things. First of all they need practical support, and there is plenty of evidence that families often don't get the practical support they need. That support needs to be 24/7, it is no good providing support to families that is only available in office hours. Practical, not just advice over the telephone, but the ability to be able to send a couple of people to help out if someone is smashing up the home or whatever.

The second thing that families need is they need access to short breaks; of course people need the opportunity to take a break from what is often a very demanding task. But for these people often their son or daughter is excluded from the short break services that do exist, so people are told, well we do have a short break service, but you can't have it because your son or daughter is so difficult to support that it would raise health and safety issues for us. That is outrageous.

For families there are really three things that you need to do. First of all you need to help the family members to provide the support they provide in a way that reduces the likelihood of the problem arising, and helps people move on from needing to

use their challenging behaviour. The second thing that should be happening is they should be getting that practical help, and the people providing that help need to be working in the same way. It is no good putting unskilled, untrained domiciliary care staff into this sort of situation because they could easily make things worse. And then the third thing the family need are they need constant access to the specialists in the community learning disability team, and in many places there will be a specialist team focussed on challenging behaviour. And those people are important to the family because they are going to be the people who can help review what is going on, advise people about how things are going, and adapt and develop the method of supporting the individual.

Narrator:

00:08:40

As people with learning disabilities grow older, like most people they prefer to live as independently as possible.

Professor Jim Mansell, Professor of Learning Disability, Tizard Centre, University of Kent:

00:08:48

The best outcome for people whose behaviour presents a challenge is that they are able to live the kind of rich and varied life that we would want for anybody without needing to use their challenging behaviour. And that has got implications for staff training, for leadership, because what's required is a service model that is entirely personalised, in which we stop thinking about looking after groups of people, and just focus on each individual, and designing arrangements around that individual that will best support them.

Narrator:

00:09:22

That personalised approach has worked for twenty-four year old Stephen, here enjoying one of his favourite outings.

Stephen was raised by his grandparents, but when his grandmother died he moved into a long stay hospital.

**Pam Wilson, Social Worker, Adult Learning Disability Team,
Middlesbrough Borough Council**

00:09:41 And when the hospital was going to be closing we looked at accommodation for Stephen that would meet his needs. It was identified that he would probably be best within his own environment, so he wasn't challenging to anybody else, so we did find an accommodation and a support team that have been working with Stephen amazingly well, and have done some amazing things with Stephen. And obviously he has progressed really well since he has moved out of the long stay hospital.

Narrator:

00:10:10 Stephen now lives in his own bungalow, with three to one care at all times. It is expensive, particularly at a time of budget cuts, but it has been shown to improve outcomes for Stephen, whereas other approaches haven't.

Kirsty Holder, Team Manager:

00:10:24 Stephen obviously has very profound learning disabilities, coupled with autism. Obviously he can't communicate his frustrations with us, so he generally, to express himself, will show quite aggressive tendencies. But that life we have tried to change that, that isn't who Stephen is, Stephen is a person first and foremost.

Narrator:

00:10:45 The team around Stephen has worked hard to identify the triggers for his behaviour, and to ensure his life is filled, where possible, with the things he likes to do.

Conversation between Kirsty and Stephen:

00:10:55 Would you like to go to the park?

Kirsty Holder, Team Manager:

00:10:58 Stephen doesn't like to interact on a three to one basis, what he likes to do is one to one, so staff are always aware of where the other staff member is, and we take part in one to one activities all day with him if he chooses to. Sometimes he can clearly tell you he doesn't want you there, and he can clearly tell you he wants his own company, and that is fine, we respect that for a period of time, but we don't let him socially isolate himself for any period of time without going and knocking and saying, are you okay.

Conversation between Kirsty and Stephen:

00:11:27 [Stephen Makes noise]

00:11:28 I am going to see the pigs.

Kirsty Holder, Team Manager:

00:11:31 But his life is a rollercoaster, his behaviour can go all over the place; in one day we can have him very happy in the morning, in a split second he can be crying, in a split second he can become self-injurious, or he can be happy, and then he will have a violent outburst. So it is the not knowing where he is going, but what we try to do is see that Stephen's life is a rollercoaster, and we are just there to hold his hand all the time.

Without the support and the dedicated team that Stephen has got around him, I think his life would go back to being an existence where he would socially isolate himself. I could just see it would be a very quick sort of spiral back to where he was before. It would be very much him just being by himself, and that is how he feels safe, he can manage like that, but he shouldn't have to manage like that. He should be able to come and take comfort from others, and that is what he does with his staff team.

Conversation between Kirsty and Stephen:

- 00:12:31 Would you like to go to McDonalds for some dinner?
- 00:12:35 Twenty-five to one.
- 00:12:37 Twenty-five to one? That would be lunch time wouldn't it? So what are you telling us? Dinner time! I am ready, come on.

Professor Jim Mansell, Professor of Learning Disability, Tizard Centre, University of Kent:

- 00:12:45 These are people who because of the severity of their disability, and the nature of their problems, they are going to be in receipt of social care services all of their lives, so we should never turn away from them and stop paying attention to what they need, and whether it is consistently being provided at a good enough quality. That's what I would like to see for people whose behaviour presents a challenge.

Conversation between Kirsty and Stephen:

- 00:13:11 Oh! Yeah, that's the end of that one.

Title: Key Learning Points

00:13:18

Some people with learning disabilities do not have good communication skills- an individual's frustration at not being understood may cause challenging behaviour

Care workers need to really understand the individual, their likes, dislikes and methods of communication and any triggers that may cause challenging behaviour

Personalised support that is consistent may help to reduce challenging behaviour and improve the quality of life of the individual

Environmental factors can be important in reducing challenging behaviour

END