In our words: Sixty years of the National Autistic Society and the story of autism in the UK

Oral History Interview with Simon Cullum. April 2024

00:00:00 Patrick Cornwell

I'm Patrick Cornwell interviewing Simon Cullum for the National Autistic Society's *In our Words* project. Simon, please can you confirm your name, spell it for us.

00:00:13 Simon Cullum

Yeah, sure, my name's Simon Cullum. That's C U L L U M.

00:00:19 Patrick Cornwell

Fantastic. Thanks very much. OK, so, how did you come to be involved with the National Autistic Society, and what was your first... encounter with autism?

00:00:34 Simon Cullum

Probably start with the first encounter, as that leads on to the involvement with the National Autistic Society. And my first encounter, my son was at an, sort of, private American school. He started just after the age of 2. And, fairly early on, sort of, three or four months into his start at the school, the teachers noticed he was, sort of, different to the other children. He'd, sort of, hide under a table and cry and not get involved. He was, sort of, completely nonverbal. Say, but they didn't mention autism. Not entirely sure they knew what it was, but they suggested we go and see an educational psychologist. So, yeah, we booked it, and up to London we went. Didn't really know what the purpose was, thought, 'OK, school suggested it, let's go along'. So there was an assessment, which was roughly an hour and a half, two hours long, sort of, observing my son, Codey, and getting

him to do various tasks and interact. And basically, we just came away with an aut-, a diagnosis of autism. And I was thinking, 'OK, what is autism? Never heard of it before'. So go home, and we do what most parents do at the start, I guess, go on to Google, and try and find out what we can. And, back then, that was probably about 14 years ago now, it was all doom and gloom. Lots of stories about what the child won't be able to do in life. And it was all quite terrifying. So that was our first experience of autism. It was like this, yeah, terrifying diagnosis, and just felt all alone, and, OK, what do we do now? So I went back to the school and gave them the report. And although they don't have... any real SEND help there, and nothing really beyond dyslexia, well it didn't back then anyway, 14 years ago, we got Codey a one-to-one support teacher. I think he had three of them in the end, who stayed with him until he left the school. And that helped enormously. When he was, sort of, having meltdowns could take him away from a class, calm him down, do some things individually together. And as the years progressed, it became more academic, as in going... over lessons again outside of the classroom. And when anxiety and pressures became too much, would go into a quiet room and have some sort of one-to-one support there. But going back to, sort of, how we got involved with the National Autistic Society, it was fairly soon after that, it would have been a few... what was it? It's more of a, probably getting on towards a year after my son's diagnosis, my father suggested we might want to do something charitable-wise because we got Codey all the support we possibly could early on. There's all this, kind of, occupational behaviour therapy, all, sort of, privately, outside of the school. Sort of, any help that we, sort of, found out about as an option, we went and got it for him. And we're thinking, most... parents aren't able to do that for their children. Some can, but it's all extremely expensive and there was nothing for free that we were getting.

00:04:13 Patrick Cornwell

Simon, could I just stop you just there for a second and let's come back to that point in just a moment. I just wanted to go back a bit and fill in some gaps there. So Codey was born 2010, was it? Something like that?

00:04:32 Simon Cullum

2007.

00:04:33 Patrick Cornwell

2007. OK. So that gives us an idea. Yeah. And, so when you first heard from the private school about their concerns, how did that feel?

00:04:52 Simon Cullum

... It... was a confirmation we were, sort of, probably expecting, but didn't really want, because we knew there were some developmental delays at the time. And it was all a bit scary, like, is he going to have to leave the school? Do they not want him there? What does this mean for his future and, sort of, the immediate present time? Sort of, what do we do? They ended up being very accommodating, at the time.

00:05:24 Patrick Cornwell

The school was being very accommodating?

00:05:26 Simon Cullum

They were, yes.

00:05:28 Patrick Cornwell

Had you had any... involvement or sought help via the NHS [National Health Service] or local schools or anything like that?

00:05:38 Simon Cullum

We didn't. Because read stories about how it takes years to get a diagnosis and any kind of help and, 'cause Codey was at a private school, he didn't need an EHCP [Education Health and Care Plan]. At the time he left, there were something like 40 children there who are on the autistic spectrum, but not a single one had an EHCP, because they're all at private school.

00:06:04 Patrick Cornwell

What does it stand for?

00:06:06 Simon Cullum

Oh, educational health care plan... I think it's changed now, but that's what it was back then... Yeah. Lost track now.... Yep. So, no, we didn't, we just went privately because it was a lot quicker, and the quality of help was superior to what we thought anything we'd get for free. If he'd been at a state school, it would have been a different situation. And as, sort of, months progressed, we realised how much this was helping Codey, all the different types of support. So I sort of opened a toolbox and there are so many different ones there to use... for a particular job at any particular time. There's all kinds of different help we were getting in from different people. And so, after a while, we saw the difference it was making and my father thought, wouldn't it be great if we could do something to help families that are less fortunate, by going through the same thing, but can't really get the help that they need for their children. And that's when we approached the National Autistic Society, which, I don't remember exactly when, it must have been... sometime between 2011... 2010, 2011, around about then. And yeah, Mark Lever was the chief exec at the time. And it was strange in the early days because we were, sort of, approaching the National Autistic Society and, sort of, offering to help with some sort of financial support for *a* project, which didn't really have too many ideas at the time. And we weren't taken very seriously for a while. We had to, sort of, keep badgering and, sort of, convincing the National Autistic Society that we are serious about, sort of, helping, not just a small donation, but... helping properly to try and do something to help other families and their children.

00:08:03 Patrick Cornwell

So this was all being, all... building upon your experience with Codey at that point?

00:08:10 Simon Cullum

It was, yes. And it seems that...

00:08:11 Patrick Cornwell

Yeah. So you were... you were sort of trying to sell to the National Autistic Society as it were, don't mean literally sell, but you were trying to show them what you've been able to do and say, can we... can we find a way of delivering that for more families?

00:08:27 Simon Cullum

Help them. Yes. And then, yep, after while it sort of just took off. Had some great meetings. The ideas for a Cullum Centre, that came from the National Autistic Society. It was their idea originally. About, it was, the criteria was outstanding schools at the time. Sort of, build a centre at the school for children with a diagnosis of autism, but not like a separate building where they're isolated, as such, we wanted them to be, sort of, integrated into the school, part of the everyday life there, but to have this support centre with everything they need there, which they wouldn't otherwise get.

00:09:14 Patrick Cornwell

At the heart of that is a... partnership with the local authority presumably, is it?

00:09:21 Simon Cullum

Yes. Local authorities, some are more, sort of, open and accommodating than others. The partnerships there between the National Autistic Society and local authority, there's some great people working at the National Autistic Society who've developed some strong relationships over the years. Some have been *easier* to achieve than others. Some local authorities just don't want to know and some are, sort of, really keen and raring to go.

00:09:48 Patrick Cornwell

So, and how many local authorities, or how many... Cullum Centres have been set up so far?

00:09:58 Simon Cullum

The original... funding was for four Cullum Centres based solely in Surrey, as that's where I live. And... there are, there are three that opened a long time ago now, sort of, roughly ten

years or so. Surbiton was the very first one to open, then there was Hinchley Wood and Rodborough. And Howard of Effingham was the original fourth centre to open, but to this day we still haven't started construction because there have been so many obstacles and delays with various planning permissions. Which is, that's been a right nightmare. And it might finally come in 2026, 2027, perhaps. That's one of the regional four which isn't there yet. And, so that's Surrey's County Council, various local authorities within Surrey. We also have Cullum Centres in... East Sussex and Kent... And there are discussions with a school in Kingston, as well. There are... two in Kent at the moment, which is Canterbury Academy. Or secondary's been open quite a while, the primary is opening soon. There are two down in Sussex, both at Hove Park, they've got two different centres, just, sort of, two Cullum Centres there. I think that's it.

00:11:33 Patrick Cornwell

So you've been working on this through the trust, but in partnership with the National Autistic Society.

00:11:40 Simon Cullum

Yes

00:11:40 Patrick Cornwell

Are there any, sort of, moments now that stand out when you look back over the, over this experience? Any, sort of, defining moments or any memorable experiences that you can think of... during the process of developing the ideas and then developing the actual, the reality of it with local authorities?

00:12:05 Simon Cullum

Memorable experiences... There have been some great people at the National Autistic Society to work with over the years who have been really enthusiastic and done all they can to help make this happen. And a few people at various local authorities as well. They seem to, sort of, come and go, they don't really stick around for that long. Whether it's career progression or people moving about. Some defining moments... receiving, sort of, emails and letters from parents of children at Cullum Centres. Kind of, sounds a bit corny,

but, sort of, thank you letters, sort of, highlighting what a difference it's made to their child, and their family as a whole. That's been really nice to receive. And going along to the openings as well... And, sort of, you know, meeting parents and staff and having the ribbon cut and the centre, sort of, officially open, those are always great moments.

00:13:02 Patrick Cornwell

I imagine, you know, you're referring to getting correspondence from families who, you know, who've been pleased with what's happened for their child. That must like... that must have been very fulfilling for you to have gone that journey from what you've learned through your experience with Codey, to then delivering that, and helping to deliver that for other families.

00:13:30 Simon Cullum

Absolutely yes, because the alternative has been very bleak for these children and their families. A lot of them have been, sort of, just in mainstream school with no support. Just struggling along, miserable, not learning much, with no happy future in sight at all. Others have been sent a long, long way away out of county to a specialist school, which has often been the wrong placement for them, as they're not been, sort of... autistic enough to be at those specialist centres, but they can't cope at a mainstream school. They're kind of in no man's land, some of them. So to be, sort of, accepted onto a place at a Cullum Centre, has been real, sort of, well, life changer for a lot of these families. And just... It's small numbers. There's roughly 20 students-ish at each Cullum Centre. You know, I wish we could help many, many more, but there's only so much we can do as, sort of, one family. But knowing the difference, it's made to those families, that's motivation to keep going. It's really satisfying and rewarding.

00:14:40 Patrick Cornwell

It demonstrates that the approach works, that's the key thing, isn't it?

00:14:45 Simon Cullum

It really does work, yes. There's been... five years research... study now, coming up to the sixth year... is... evaluating the difference that... the centres have made. That reports on the

National Autistic Society website, open for anyone to see. That's, yeah, it was really eye opening. There's loads of, sort of, scary stats there about how children are, sort of, bullied in mainstream schools, how miserable they are, there's all of that. And then there's, sort of, the contrast for those at Cullum Centres and how, sort of, happy they are. On the whole, not everyone. Never get 100%. But just, yeah, to compare the differences. Yeah, that's great to see, it's all evidence in reports. And the model really works. Because generally when a child joins a Cullum Centre, give or take, it's roughly 80% of their time is in the Cullum Centre and 20% in, sort of, mainstream lessons, and the goal is for that to flip around after a while. Which for most of them it does. They're in, they manage to cope in 80% of mainstream lessons, which is a huge achievement. And then they're not in the centre that much compared to when they first joined, which is exactly how we want it to be.

00:16:17 Patrick Cornwell

... So I guess you're hoping to continue to develop the programme of Cullum Centres with the trust, is that right?

00:16:26 Simon Cullum

Yes, that's right. At the moment, there's scope for a few more Cullum Centres with the current funding that's been made available. There are some discussions at the moment. There's one in Kingston, there's early days of another one in East Sussex, possibly another in Kent. Sort of, the Cullum Family Trust, as a trust, we... stick to the southeast region. We're, sort of, not national. So, generally, it's, sort of, both Sussexes, Kent and Surrey. Because, you know, the family trust, does various other work outside of what we do with the National Autistic Society. Sort of, my sisters are involved with Sussex Community Foundation and Born Free. So there is other charitable work going on as well. It's all based around this, sort of, southeast corner.

00:17:18 Patrick Cornwell

Right. So, just standing back and thinking then about the National Autistic Society, what, from your experience, how do you feel that public perception and awareness of autism has changed in recent years?

00:17:36 Simon Cullum

Of recent years, sort of, looking back at roughly the last 12 years or so, from when I, sort of, first came into the world of autism, awareness has increased considerably. Certainly amongst schools and teachers and the general public. But awareness is all very well, sort of, understanding and acceptance are what really matters, and that's still got quite a long way to go. The understanding has, that has improved. Like the, where there's a Cullum Centre the rest of the school, they have, sort of, assemblies and talks on what autism is and what the centre is all about, how they can help their fellow students. Workplaces seem to be having a bit more of an understanding than they used to. But acceptance is still quite a way off, generally, I feel. Bit of stigmatism around autism and people not... really wanting to have to deal with someone with autism because they don't know how and think why should they have to make special allowances. So we're still not there yet on the acceptance and the help generally speaking there is... or some situations there, there's great acceptance.

00:18:56 Patrick Cornwell

So what role do you think the National Autistic Society has played in, sort of, bringing about the progress that you've referred to there, in terms of awareness and perceptions of autism?

00:19:12 Simon Cullum

There's a great team at the National Autistic Society who lobby the government on various issues, whether it's legislation, funding... they've been going at that for quite a few years. Of course, it's tricky with governments, you have a very short-term plan. The election is only ever a few years off and looking at, sort of, long-term cost effectiveness is never really on their agenda, they're only really bothered about the short-term, so it is quite a battle there. But, yeah, they're, they continue to try and lobby government and try and get change in legislation. And they have been successful, in part.

00:19:56 Patrick Cornwell

... I just wanted to come back to Codey and just pick up on... where he just, the progress he's made since those early days that you referred to. So how have things gone in more recent years?

00:20:15 Simon Cullum

... Well, the early days, anxiety was huge. He was at a school of roughly 1400 pupils, but alone a lot of the time. Feeling alone, sort of, left alone, bullied on occasion. So that was school. But, there were some happy moments, but generally it was a real struggle. And one great thing that the school did allow, being a private school they had the option to, which was for Codey to stay back a year. He was four or five years old when he, sort of, repeated a year, so fairly young. His birthday is in June anyway, so he was one of the youngest. And that did help. That enabled him to stay at the school for longer than he would have done otherwise, having repeated that year. And the progress that he's made, well he's... independent in some ways, not every way now. Anxiety has gone right down. He's a lot more confident than he used to be... Like talking to strangers in, sort of, the earlier days was, well it didn't happen, he'd just run and hide behind his mum. So confidence really has built. And, sort of, self-esteem has gone up and his anxiety down. The... removing various... pressures and... allowing him to get to know himself helped a lot with that over the years. And now he's in a good place. Sort of... in terms of the academic year that he's in, he took two GCSEs last year, maths and stats, and passed them both, which for his, age-wise that was the right time, but academic-wise it was, sort of, a year in advance. So he has progressed very well. He's doing the rest of his GCSEs this May and June. And so, we kept him at the school he was at for, he was there for eight years in the end. And, after that, the school agreed it wasn't really working because he needed one-to-one support, and get to a certain age and... that, that's difficult to manage, when they have to move around to different classrooms around the school, instead of staying in the same classroom all the time. The stigma that's attached to it, being, sort of, seen as very different to the other students who don't have this one-to-one support teacher with them all the time, it's generally, sort of, it came to a point where it wasn't working anymore, and he was going a little bit backwards and struggling. So that was the time to leave. And the, at the time, we saw it as, sort of, a last resort after exploring many options, which was home schooling. Which turned out to be the best option for him personally. Because without an EHCP he wouldn't have got any sort of specialist place... at any sort of specialist school. And, yeah, we made the best of home schooling that we could. And we found some great teachers. For a few years he had a teacher coming into the home every day, then after that it was Zoom lessons. I went down to working two days a week, so the rest of the time I can be there to help him with his learning, which has helped enormously. So it's, yeah, it's, if there was an option, sort of, go back in time, a Cullum Centre would have helped enormously for Codey. It's just with the timings in our situation that didn't, wasn't an option. Because he was, sort of, again, in no man's land. He was 'too autistic', to use that term, to cope at a mainstream school, but not far enough down the spectrum to go to a specialist school. Whereas the in-between is like these Cullum Centres, it's, that

would have worked out really well. So if we could turn back time and do things differently, then would have done. But given the options and, at any particular time, that was, that's the best option for him. And he, he's done very well. He's a happy, confident chap who's learning.

00:24:34 Patrick Cornwell

And how about socially? How, how's he getting on in his social interactions with people, friendships and so on?

00:24:43 Simon Cullum

Really struggled when he was a lot younger, even when he was at school. Quite often at break times he'd, sort of, sit by himself and not really interact. Partly because he didn't know how to, and partly because he was seen as different, so he was, kind of, left alone. So going to, from a school to home schooling, all of a sudden completely cut off and isolated. So we got Codey into various clubs over the years. We got him to kickboxing, hockey, fencing. But we found with all of those clubs, go along and do the sport, and once it's over, everyone just goes their separate way anyway. So there wasn't really that much of a community outside of those clubs. The club ends and that's it, everyone goes home. So a lifeline has been his cousins, who are his best friends. We see them as much as we possibly can. And he's been to parties, and he's made friends... with their friends, and online gaming has been huge. I know it's, sort of, slated a lot, how long some teenagers spend online gaming, but that's been a real life saver, that's helped his communication skills enormously. Through knowing when to join a conversation, how to, without being rude, when to listen, and generally just feel more confident, to feel not so alone. So that's played a huge part as well. But yeah, the clubs were a great release, to get out of the house, to mix with other children of a similar age, so they did help in that regard.

00:26:19 Patrick Cornwell

That's inspiring. Where do you think you're going with Codey in the future?

00:26:27 Simon Cullum

For, goodness knows, many years now... he's, all he's wanted to do when he, sort of, grows up is to be a chef. That's from the very first time he went to a cookery course, it was at Raymond Blanc's cookery school. It was a parent-child baking session. He must have been roughly eight, nine years old then. And ever since then, all he's wanted to do is to be a chef. And, pending GCSE results, he's, sort of, been accepted into a culinary college starting this September, which would be a huge achievement for him. So he went along, went to the interview after the initial application, and yeah, they'd be happy to have him. Just got to make sure he gets the results he needs. Then, yeah, that's his future set.

00:27:24 Patrick Cornwell

That sounds fantastic. So we're going to move towards pulling all of these strands together, Simon, and wrapping up the interview, but was there any other things you'd like to discuss?

00:27:42 Simon Cullum

Any other things... It's, well, it's always been a pleasure working with the National Autistic Society, they're... they're good people. Those that work in charity generally are. They don't really go there to... make a fortune, let's say, they go there to do good. So they are good people. Just a pleasure, pleasure to work with.

00:28:07 Patrick Cornwell

What would you like the National Autistic Society and the trust in cooperation to go on to do and achieve, do you think?

00:28:17 Simon Cullum

We would like to continue helping more children, families, in the world of autism. There's still a long way to go. What we would, ideally, the model that we've created with the National Autistic Society with these Cullum Centres, we would love other wealthy, sort of, families around the country to adopt the same model. And, on an even larger scale... is the government. If they could replicate this and, wouldn't call them Cullum Centres, but whatever they were, government deemed to call them, similar centres all around the

country. Because they do have the funds, they just don't really want to... spend much on autism at the moment, unfortunately, it seems. But we would really love for government to adopt this model. And it's actually cost effective. Because it's some crazy stat like 75-80% of those with autism don't work[1], at least not in full-time employment. So it's all, kind of, benefits they end up getting paid and they cost society, through absolutely no fault of their own. Most of them want to work, they want to achieve something, but because of life circumstances, they are, they find it a struggle. It's actually, but it's been proven in this study that we've done, it's more cost effective to spend money on these centres, invest in it, and reap rewards later on, because it's fewer people in benefits, there's more earning taxes, paying into the economy. But again, the government only sees, sort of, the short-term unfortunately, it's a real struggle to convince them that if they replicated this, even on a small scale to start with to prove the concept, which has already been proved, they save money in the long-run, and would be helping all these children grow into confident, successful adults. Which a lot, unfortunately, it's just a fact, a lot of them won't do, which is very sad.

00:30:26 Patrick Cornwell

What, in what way do you think that the National Autistic Society can help to promote this message in the way that you've described?

00:30:35 Simon Cullum

One example, recently there was an event at Portcullis House in London. Various MPs were invited along to find out more about the work that we've been doing with the National Autistic Society and the Cullum Centres, and to hear various stories, success stories. And to be shown, sort of, the model that this is cost effective. Unfortunately, not that many MPs turned up, even though all of them had an invite. But those that did seemed generally... interested. I'm not sure what's going to come of it, but, sort of, various influential people in government are aware of these centres, that they exist, and, so then, I know the National Autistic Society are following it up at various times, trying to nudge these MPs into, well, going to the next steps, trying to make something happen. So that's the hope, that government will eventually, one day, take proper note and create some centres themselves.

00:31:43 Patrick Cornwell

That's an inspiring model for education and helping people develop. What other areas do you think that the National Autistic Society should be working in, National Autistic Society should be working in to help autistic people?

00:32:02 Simon Cullum

... I'm genuinely not sure there's any area that they should be working in that they're not already. They have a huge training programme... It's, which is to, because most... the stats are in the report, again, I don't remember them offhand, but most teachers have had no training in autism, ever. Or less than a day. They know what it is, but they haven't had any actual training. What we'd love is for... for every touchpoint a child has at school, whether it's catering, janitors, all kinds of teachers, admin staff, anyone they come into contact with at school, if they had specific autism training on what is autism, how to help a child who has autism, various ways of helping them to cope with their day, if they're having a meltdown, what to do, that kind of thing, if every school had that training, that would be a huge step. Because then children who are in mainstream and struggling would be struggling a bit less, if they had more help and support and acceptance from teachers and staff at their school. I know the National Autistic Society are, sort of, working on that, and hoping to achieve that one day. That would be a huge step.

00:33:31 Patrick Cornwell

And does that suggest a model for other parts of society, workplaces and so on?

00:33:40 Simon Cullum

Absolutely, yes. And that's... Because I'm, it was, you know, early 30s, I was diagnosed with autism myself. So I went, sort of, all through school and life up to that point with no knowledge of it, so, of course, no support, no help at all. And often the workplace was a struggle. It could be the noise, sitting back to an entrance or an exit, the lights too bright, people just, sort of, coming over and nudging me, whatever it might be, sort of, not knowing what really to do at lunchtime, want some alone time. And... yeah, so many workplaces are not geared up for those with autism. Often it's through no fault of their own, they've, no one's ever, sort of, approached them and said, 'Hang on a sec, why don't you do this a little bit differently?' It doesn't have to cost a business anything. It can just

be a different way of doing things. So yeah, autism in the workplace, yeah, that needs a lot of help as well. Again, more awareness there and, sort of, understanding, acceptance, and just making small changes, like not having the lights so bright or not having the heating on in the summer if one person wants it on. It's, yeah, there's a lot that can be done there as well.

00:35:03 Patrick Cullum

Can I ask about how it was for you growing up with autism, and at what point did you know that you had au-, you were autistic?

00:35:15 Simon Cullum

Yes. As the years went by, with my son, Codey, sort of, noticed a lot of similarities between him and myself. Mainly to do with, sort of... struggles, like unexpected noises, unexpected changes, something, environment was too hot or too bright, or it's not knowing when to, sort of, join a conversation. I think, hang on a minute, we're so similar. So I went along and had an assessment myself. And yeah, that ended up explaining a lot about the past. That I wasn't just this, sort of, weird nutcase, there were, there were reasons for being different to others at school, and that was autism. Of course, it's too late by then to, sort of, get any help, I'd, sort of, had the journey, become an adult, and got on in life. But yeah, and then seeing, sort of... all the support Codey's got, if I'd had that support growing up, my life would have, sort of, turned out differently. I'd be more, sort of, confident, successful, happy person generally. And that's another reason for, sort of, being involved in the National Autistic Society as well, seeing the difference support makes and, compared to no support at all. You know, it's night and day, really is.

00:36:44 Patrick Cornwell

Can I just, I'm very interested in this, can I just explore a bit more, what was your experience at school like, then?

00:36:55 Simon Cullum

Apart from a few good days, school was, sort of, generally hell up until the time I left. Bullied most days, even by teachers in secondary school, sort of, joining in when

classmates were taking the Mickey, let's say. There was, just treated as, sort of, stupid the whole time. Because back then autism was, awareness wasn't really a thing. Sort of, most people, they hadn't even heard of the word autism, I hadn't myself. So we were just seen as, sort of... kind of, lazy, stupid, uninterested, weird, all those kind of terms, angry, with never any, sort of... acknowledgment as to possibly why different from the others. Just wanted to, sort of, join in, be accepted, but socially it was very, very difficult. And academically, yeah, never any support at all. So yeah, school, I was very glad to leave at 16. Went on to college after that, then university. But school is up to the age of 16, that was, on the whole, hell.

00:38:10 Patrick Cullum

... How did that feel, then... when you got your assessment done, how did that feel, particularly in relation to Codey? Did it... what, what did that feel like?

00:38:29 Simon Cullum

There are a mixture of feelings and emotion. One was relief, because if I didn't have autism after learning all about it and seeing a similarity with Codey, you'd have thought, OK, well, what on Earth is wrong with me? There is relief, as in, it's kind of put to bed all those past years, especially at school, as in, well, I had this condition, and that explained a lot. So it's like relief in that way, as in, I could finally sort of... figure out why I was, sort of... different and treated differently. And there was... I don't know, there's curiosity as well, sort of thinking, well, if I had had support, what could I have maybe achieved in life? What different route could I have taken? Then there was even, sort of, more motivation to really help Codey continue with all the support possible. Which we were very lucky to be able to do privately, which, of course, most families can't. Which is why we're trying to, sort of... make a difference through our partnership with the National Autistic Society. Not sure really what else to say there.

00:39:52 Patrick Cornwell

No, that's really interesting, though, isn't it? Did it deepen your insight into, you know, what the world looked like to Codey, for example, that it, having that understanding for yourself? It must have been quite a moving moment.

00:40:10 Simon Cullum

Yes, definitely. Because I realised that we saw the world in a very similar way. So I guess the relationship with Codey got stronger after that. We were so similar. And, sort of, instinctively knew how to interact with him as I, sort of, knew I was pretty much the same... It was, yeah, it was an interesting journey from that point. Not so much for myself, because at 30-something years old, it's kind of, too late really. Other than putting to bed a lot of history in the past and then just looking forward, forwards. And generally accepting myself more as well... Unexpected noises and bright lights and that kind of thing, it's, that's just who I am, I'm not being weird, it's a condition. Generally, more acceptance of who I am.

00:41:14 Patrick Cornwell

... That's fantastic. I mean, I just found that very moving, very powerful, you know, the empathy between you and Codey now that's there because of your joint assessments, the both of you assessed.

00:41:35 Simon Cullum

Yes.

00:41:41 Patrick Cornwell

... Can I just finally ask you about your hopes for the future, for your, for Codey and your family?

00:41:50 Simon Cullum

Hopes for your future... Well, currently really hope Codey gets into college. He's, I've never had any worries about him putting in the effort and trying. He's like the opposite of a teenage brat, he's a really good guy. Always works hard, dedicated, so got no worries about any, sort of, effort there. I just hope he, sort of, gets on at college with... with the others. It's, say, less protected, certainly a lot less protected than home schooling, and less protected than a school, suddenly being at college. So hope he just gets on with the course and succeeds in it, and then becomes a chef. If he changes his mind one day, then I'll fully support him in whatever else he wants to do. The worst-case scenario, he'll have

some great cooking skills for life. So, he doesn't want to be a chef one day, it's far from a waste of time going on this culinary course for him personally. So my hope is he just does whatever makes him happy. Of course, it's difficult to make a lot of money in cooking. The Ramsays and Kerridges and the likes of the world... yeah, they manage, but, on the whole, it's very difficult. That's, Codey's quite fortunate, he doesn't really have to think about that in his future, he can just do what makes him happy. And that's all I want for him. Just to, just to enjoy life. Because I went through my work life, yeah, not really enjoying it too much, just kind of, just fell into insurance and that was it. So Codey to have the choice of what he really wants to do is very important to me. Whatever he chooses to do in the future, I'll support him. And the future as a family... yeah, not really sure, to be honest, we're just happy as we are at the moment. Things could always be better, the economy, the weather, politicians. But, yeah, it's just, yeah, we'll see what happens. It's all about Codey at the moment. So I see it's, sort of, my life is kind of, well, 46 years old, a lot of it has... been, it's in the past already, it's done. Yeah, probably 20 years-ish left of a work life, maybe 25, maybe, and then retirement, but Codey's got his whole future ahead. So wherever he wants to move to in the future, if he chooses to be a chef or not, we can go and support him. That's basically mine and my wife's future is Codey. That's it.

00:44:23 Patrick Cornwell

And did you want to expand on what's happening in Brighton Hospital at all?

00:44:30 Simon Cullum

There are various, sort of, projects going on there around mental health and around asthma. You know, we helped to create a new wing at the hospital. There is good work going on there, and the Sussex Community Foundation as well, there's the Rockinghorse charity, Born Free Foundation. Well, my sisters are involved in all of that, and I stick to work with the National Autistic Society.

00:44:56 Patrick Cornwell

Simon, thanks ever so much, that's been so inspiring. Thank you for taking the time to record this interview with me.

National Autistic Society

References

[1] Recent employment figures for autistic people can be found here: https://www.autism.org.uk/what-we-do/news/the-buckland-review-of-autism-employment-is-publis