

Video Transcript: Co-production in Birmingham – commissioning all-age autism support

Simon Colbourne: Originally I got involved because our eldest son died unexpectedly in 2013 having struggled with mental health issues for most of his life and having apparently had the best support that he could from the NHS.

So initially I was wondering why had this happened a couple of days before his death, I went to a meeting about proposed new service called the Edgbaston Wellbeing Hub. I could see that it offered the sort of support that might actually help, and was going to talk to him about it when he got back from a trip to see friends in Wales. But unfortunately he never returned.

I was a board member of the Wellbeing Hub, while it existed, but I've been on various mental health related boards and groups ever since. In 2018 I was diagnosed with autism and soon realised that there were very few services for just the adults, in Birmingham.

I became a member of the Birmingham Autism and ADHD Partnership Board, and as part of that became part of the Adults Task Group. I was then involved with the design and development of the service right from the start, and because I was involved with other groups, I could then bring in some of the work that had previously been done by the Clinical Commissioning Group. And also there is a NHS Midlands Regional Autism Focus Group that collects a lot of information from a lot of service users or potential service users across the Midlands.

They put together a quite a lengthy document, a basic needs assessment, and we were able to bring that to the design of the service. It then became apparent that one service provider probably couldn't provide everything that this document was asking for. So we then had a bit of a rethink as to the design of the ask and instead of it being everything going back to one service provider to provide everything it became looking for an umbrella organisation that could then manage support for all the other organisations and also act as a point of contact for people wanting to use service.

It was good to go back to the NHS and say, actually, we don't want to do this, we want to do that. They looked at it and said yes, and so we've then got the funding that's excellent too.

I started in a very low place grieving for the loss of my son and feeling very angry that despite all the huge efforts particularly by my wife, to find support for him, he never got the help that he needed.

I also felt very guilty that I'd not done enough or understood more, but once I realised that I was autistic I also realised that he probably been autistic too and had never been diagnosed and never supported in that way.

Being involved with patient participation which is largely what I did with the NHS, had some benefits, but being able to fully engage with co-production has had a lot more, which include being appropriately sponsored by professionals [which] helps to establish

relationships particularly for somebody who is autistic. We're not good at going out at glad-handling and stuff like, that so having somebody say, I think you should go and see this person, do that, that's something really useful, it may seem trivial to the professional but actually its quite a big thing if you are autistic.

Being genuinely valued boosts confidence and self-esteem so you get some point where you do feel that you're an equal and you can say what you think and that works very well.

Being around good communicators helps to develop communication skills so by listening and adapting, particularly again, with autism, there's this thing about [inaudible] and all the rest of it. One of the ways of managing is to listen and look at others to work out how they do something and then imitating that, so that's quite a useful thing to be in a place where you can trust people are you are working with.

Also being involved with people with different values and expectations helps to refine my own values and expectations so I get a much broader view of what's going on and how it all works.

From autism perspective the above all helps reduce over-thinking, improves my social competence which in turn reduces stress and increases the willingness to engage. So from my point of view it's been a long process because I've been doing this for quite a long time now. But particularly in the last two or three years things have got accelerated and I've got a lot more benefit out of it even though I don't get paid for it or anything like that.