

Speaking of Research

Series 2 - Nikki Smith

SUMMARY KEYWORDS

Autistic inclusion, research participation, PhD research, mainstream schools, autistic experiences, participatory methods, research question, data collection, government policy, school policy, autistic young people, neurodivergence task, Department for Education, teaching strategies, confidence and belonging.

SPEAKERS

Nikki Smith, Catherine McDonald

Catherine McDonald 00:04

Hello and Welcome to Speaking of Research a podcast from the South Coast Doctoral Training Partnership. I'm Catherine McDonald, and in the second series of our podcast, we're focusing on research that addresses global challenges. We'll be in conversation with doctoral researchers about their research, which global challenges they hope to inform, and how they hope their work will make a difference. In this episode, I'm joined by Nikki Smith from the University of Brighton, whose work is challenging the exclusion of autistic people from research. Nikki, can you start by telling us a bit more about that?

Nikki Smith 00:43

Yeah, so my PhD is about the variation of experience of autistic young people of all genders in mainstream secondary schools in England. I was a teacher for 15 years, so this is a topic that's very close to my heart. I've taught a lot of autistic young people, and their experiences are all so different that it's very difficult to categorise them as one group of people. So, the challenging I'm focusing on and talking to you today is something that's been a problem, I think, for a very long time, and that is most research about autism and disabled people on the whole, or actually, minority communities, has been done on them rather than with them. There are many studies that aim to help the autistic community, but people who are actually autistic often haven't really had a say in what gets researched or how it's done.

Catherine McDonald 01:30

And how are you planning to tackle this research?

Nikki Smith 01:32

As an autistic person myself, I didn't want to do my PhD research on autistic people, I wanted to do it with them. And there's a phrase in the disabled community about nothing about us, without us. And I've had that in my mind all the time. So, I wanted to hear from autistic voices about the conception and development of my research question and my data collection methods. Hart's Ladder of Participation, which is quite a popular analogy, I think, and it's used quite a lot in research, has a degree of participation. So, at the bottom rung is manipulation, the next two rungs are decoration and tokenism, and they are non-participatory methods of research. And then there are degrees of participation going up the ladder to eight, where eight is child initiated, shared decisions with adults. So clearly, for a PhD, that's not really appropriate. So I like to think of my PhD research sitting between rungs five and six, where the people who are going to be the focus of my research are consulted and informed, and it's an adult initiated research project, but with the input from a group of young autistic people.

Catherine McDonald 02:50

That phrase that you quoted, there 'nothing about us without us', is such a powerful phrase, if people listening take one thing away from this podcast, wouldn't it be great if it was that. Tell us what you found out so far.

Nikki Smith 03:06

I recruited a group of five young autistic people we met at the University of Brighton. I provided snacks to encourage their participation, and I gave them my research question, and they picked it apart between them. I tried not to have too much input, and they decided that it was really, really broad. So, what I had to do was, kind of explain that the overarching research question then gets divided up into sub-questions to help answer the initial question. And they really liked that idea, and they came up with all these sub-questions about the aspects of school that they found challenging or didn't find challenging. The next thing we did was look at how I was going to get information from my participants. So, I had these ideas, I had a diamond nine activity where you rank aspects of school in a diamond nine shape. And they didn't like that at all. They were saying that they would spend so much brain power trying to fit their ideas into the template that they wouldn't actually think about the aspects themselves. So, we scrapped that all together, and they said, why don't you just have columns? And then they said, why don't you use a star profile? And I didn't even know what a star profile was. And anyway, it turns out that it's like a target, like a dartboard, and in the middle, you've got zero, and on the outside you've got 10, for example. And the star has points that come out from the centre. And then you could mark the points with the aspects that they thought were important to research, and then rate your aspect of school on the star diagram. It was incredible, it was such a good idea, and I've developed that since.

Catherine McDonald 04:47

And without their input, you wouldn't have got there.

Nikki Smith 04:49

I wouldn't have no and the other thing that I put to them is something called blobs, which are emotionless blobs with no gender or ethnicity or anything like that, because I thought they were really good way of maybe expressing emotion, and they didn't like those either. They were like, we don't understand these, and then what's that blob doing? And then they were saying things like, that blob looks like he's being crept up on by someone on fire. So they really didn't like those at all. And I thought they were really good idea. So we kind of came to an agreement that some people, because one of the group really did visualise things, and she loved the blobs. So we agreed that actually, they should come without context as an option for describing how they felt at school for young people that did see things in a visual way.

Catherine McDonald 05:37

Such great examples of why the people the research is about need to be involved right from the start.

Catherine McDonald 05:44

Such great examples that you're listing. If you could project forward Nikki to the end of your PhD, what would you like its legacy to be? What would you like it to have informed or changed?

Nikki Smith 05:53

Absolutely.

Nikki Smith 05:57

I would like it to inform schools about the different ways that autistic young people experience school. There are too many school policies that just say autistic people don't like this or autistic girls need social skills, autistic boys have bad behaviour. It's very general, and I was lucky enough to actually as part of the South Coast DTP placement scheme, I was working with a research group from the University of Birmingham who were informing the decisions of the task and finish group for the Department for Education. Department for Education set up a neurodivergence task and finish group to try and make recommendations to the government to help include young autistic people. So I would really like some of the research that I do to be able to inform government policy on a national level, as well as school policy on a local level.

Catherine McDonald 06:53

And you're going to take your five research participants with you throughout the whole journey, are you?

Catherine McDonald 06:59

Well, it's a little bit difficult because a couple of them have in their GCSE year. So, I don't want to, you know, overwhelm them with stuff that they really don't need to, but they're really keen. I need to think about it very carefully, because I've got another meeting with them. I taught a couple of them, so it was quite funny they said to me at the end, you've got homework for us to do now Nikki and I went yes. So, I'm going to take what I've developed since our first meeting to them and see what they think, and then have a conversation with them and see how much input they want going forwards. I'd quite like a couple of them to stay around so that when I've analysed some of my results, I can possibly ask them if they recognise some of the stories that are being told and check the authenticity of my analysis and the stories that I've heard, but that's something that I need to speak to them about really.

Catherine McDonald 07:42

You mentioned earlier on, obviously your huge experience as a teacher, and that you taught many autistic children. Was there one experience that is sort of forefront in your mind throughout all of this? You know, one particular experience where you were in a classroom with an autistic child in the cohort that you were teaching, and you knew that in some way the system was failing them. Is there one experience that stands out?

Nikki Smith 08:06

The one experience that stands out, actually, is the opposite of that. So, I had the privilege to teach a group of six autistic young people who had been predicted U's or very low GCSE grades in science. And there was, there was discussions about pulling them out. I said, you can't do that to them. I mean, a couple of them wanted science GCSE for the college course they wanted to do. So, I had six autistic young people, and I taught them using primary models. So, we put all the tables together. If we did something, we did it all together. We wrote on the tables with whiteboards, and one of them was nonverbal, and so he replied completely on his whiteboard or by writing on the table. And at the end, when the GCSE results came in, every single child in that room passed with a distinction their entry level science, which was what I was teaching them. But on top of that, they all got entered for GCSE double Science Foundation, three of the six got four four, which is a pass in science. And every single child in that room got a number. So they went from being predicted U's or ones they all got, no one got less than two or three. And that, for me, really showed me that actually, with the right resources and the right time and the right class size and the right teacher, that I think autistic young people's outcomes could be massively improved. But obviously that's a system level request. You know? That's something that many many schools couldn't do. So that was the experience that made me say, actually, autistic young people can succeed, and it's not all about GCSE results. It's about confidence. It's about belonging and feelings of self-worth, which a lot of autistic young people don't have, and that small group definitely had that. And I

was so proud of them, because they did all the work. I was just so proud of them. So that's the experience that stays with me.

Catherine McDonald 10:26

And that's an incredible story to end on. Nikki, thank you so much for joining us today.

Nikki Smith 10:31

Oh you're welcome.

Catherine McDonald 10:32

And telling us all about your research, and we wish you all the very best with it. And thanks to you for listening to this episode of Speaking of Research from the South Coast Doctoral Training Partnership. To find out more, please visit southcoastdtp.ac.uk. Don't forget to subscribe wherever you get your podcast to access earlier and forthcoming episodes. This was a Research Podcast production.