

## **International Day of Persons with Disabilities - #everyonebelongs**

### **Podcast: The Co-researcher's Perspective**

#### **Interviewer**

'Living Life to the Fullest' is a project run by the iHuman Institute at The University of Sheffield. The project aims to improve our understanding of the lives of young people with life-limiting or life-threatening impairments, and the research team included young disabled people as co-researchers. Sally Whitney was one of the co-researchers on the project and today she's going to share with us her experience of co-production from the co-researcher's point of view. Sally, could you start by telling me something about yourself and your background?

#### **Sally**

My name is Sally Whitney and I have a number of complex chronic health conditions. I'm now in my early 30s but I became unwell when I was 17, just before I was about to do my A-levels and I have been increasingly unwell since then. I've struggled with accepting my illnesses and accepting the fact that I have become a disabled young woman and embracing that identity. In the past, I've been very very unwell and spent a lot of time in hospitals, a lot of time in intensive care but now I find myself on the other side, where I'm much more embracing of my identity as a disabled young woman. I have an incredible assistance dog who has made life so much better for me. I'm a full-time wheelchair user and I visit hospital a awful lot. Lots of the time I spend going to London to see specialists, but I have 24-hour care – so I always have a PA with me – and before I got involved with this project, up until the last few years, really I've just been surviving day-to-day. My life was about getting through the day, staying alive, not ending up in intensive care and I kind of got to a point where I thought, 'Well, how am I contributing? Am I of any value? Am I a burden to society and to the community?' And that's really how it felt. And then as I gradually started to improve and I put that down to seeing the right specialists, being on the right medication, pacing myself but also having this incredible assistance dog and having the care that I have, I started to wonder, 'How can I, in this very limited capacity that I have – limited energy-wise, limited with my physicality – how could I do anything that was of value or of worth?' I was very much stuck in a place where I wanted to contribute but I didn't know how.

After I had been partnered with my canine partner Ethan, after about a year we did a partnership ceremony, which is kind of like a graduation thing, it was to say that we were successful, we'd been working together for a year... It was lovely and I had to do a speech and all of the people who'd been involved in his life came – his trainers, his puppy parents – and after I did this speech, Canine Partners came to me and said, 'You speak very well and Ethan's really photogenic. We'd love you to do media work.' So that was my first little foray into actually doing anything that was outside of the house, anything that wasn't just based around making sure that my body functioned. That was the start of things.

I'm a Christian and I had really struggled with getting into church and working with being a wheelchair user and having multiple health needs. So, I started trying to push for a bit more inclusivity, thinking about how we embrace disabled people and welcome disabled people into our church but really I was at the start of that too. So, yeah, before I came into this co-researcher role, I was very much a newbie to doing anything outside of my home and anything that I thought was valuable or that in any way I was giving back. I was desperate to, but I just didn't know how.

#### **Interviewer**

How did you find out about the 'Living Life to the Fullest' project and what made you want to get involved as a co-researcher?

**Sally**

It was as simple as seeing a little advert on a Facebook post by one of the other co-researchers. She had been involved in, well, she's involved in quite a lot of research and stuff around healthcare, and I think that she'd been in communication with Kirsty Liddiard, our project lead and she had suggested to Kirsty that actually the way to recruit co-researchers was to probably do it through a digital platform. I think they were having trouble, not necessarily engaging with people who wanted to do it but managing to secure people as co-researchers. So, she put out this advert and it was just saying, 'Are you living with a life-limiting or life-threatening disability? Are you interested in sharing your experiences and becoming a co-researcher?' And I just spotted it and I thought, 'Hmm, yeah, that kind of sounds like me and it would be great to get involved in something which was relevant to me,' and that idea of research and actually doing something very much appealed. So, I replied and I said, 'I'd like to give it a go,' not really fully understanding what being a co-researcher meant(!) or what that would involve but I just wanted to know a little bit more about it.

**Interviewer**

You mentioned that you hadn't done anything like this before – did you have any concerns about joining the project?

**Sally**

I had concerns but also there were things which overrode those concerns. So, I guess with this project, the thing that really appealed was that it was an opportunity to look into the lives of people who were like me or other people who've had experiences like me. I felt like this project wasn't doing it in a tokenistic manner. I genuinely felt that it was a project that really was a genuine inclusion though for some of the co-researchers – and this for myself included – it was actually the first time that we'd ever been asked questions about our lives, not just about our impairments. Speaking for myself, but I'm sure other young people with disabilities, a lot of our lives have been around managing our disabilities by medical teams and medical professionals and all the questions that we're asked are around those things. So, this was actually one of the first times we'd been asked about what our lives were like and it was the first time that there was an opportunity to consider disability in a more positive light. The fact that the project was called 'Living Life to the Fullest' really appealed to me because that's kind of a mantra that I have that my life is different to the life that I initially planned for. I wasn't born disabled and I did have plans for myself and what my adulthood would look like but a project that was talking about living life to the full in the face of disability was really appealing and there was definitely this element of countering this story of tragedy that often goes along with being a young person and having a disability, so that really struck me. But, yes, it would be a lie to say that I didn't have some concerns and some anxieties about taking part, not because of the project itself but because of my lack of self-esteem and that. So, I'd had no experience in research prior to that. I had been out of the academic field for such a long time. Back when I was at school, I was a real academic and I got all the top grades. I started at medical school briefly but it had been a long time since I'd been in that area and I just really wasn't sure if I actually had anything to contribute at all and so saying, 'Oh, I'd like to join this project,' but feeling like I probably didn't have very much to offer was quite nerve-wracking. Also, my health is so precarious. It was quite a risk to say, 'I'd like to be involved in this,' but then to be able to articulate that my health fluctuates and being able to make a firm commitment was quite difficult. But actually, once I joined the team, I realised that all those anxieties were not based in any foundation

because the team was so welcoming, and it turned out that a lot of people had the same concerns or had the same issues and that was really refreshing.

**Interviewer**

So, what was it like to work alongside the academics on the team?

**Sally**

It was very exciting but also slightly intimidating at first until I got to know them. Dr Kirsty Liddiard is the lead researcher for the project and she was immediately incredibly welcoming. I really didn't feel that there was any feeling of pretension on her part or superiority and actually I didn't feel a huge amount of inadequacy on mine. I really thought that I would! She helped me to, well, she empowered me to believe that I had a valuable role to play. She kind of hammered home how my lived experience of disability was a valid and valuable contribution and so it was really interesting to feel like I was working *with* academics and people who'd be studying in the field of disability studies for years and years - Professor Katherine Runswick-Cole and several academics who were working on the project and have huge amounts of experience - and then there was me and some other co-researchers who had very little experience at all but I immediately felt welcome and I immediately felt that this was something that I could get my teeth really sunk into and that perhaps I did have a role to play.

**Interviewer**

Could you give us an example of the ways that you contributed to the project?

**Sally**

When I initially was starting with the group, one of the first tasks was to read over an interview schedule which we were going to use as our interview questions for initially interviewing all of the young people that we had identified that we wanted to kind of gain some of our research from but then that went on from me just reading over that and making changes to then me writing my own interview schedules for interviewing more people and I got to write my own paper and that was based on the fact that I had been invited to present with the rest of the team at a disability studies conference in Lancaster last year. I never thought I would have those opportunities. I genuinely had imposter syndrome when I was up there. Everyone up in Lancaster had 'Doctor' or 'Professor' in front of their name and there I was with no academic qualifications apart from A-levels and having tried to be at medical school and having ended up in hospital, so really feeling totally inadequate and underqualified. And yet when we went in and we presented the 'Living Life to the Fullest' project, everyone in that room wanted to hear what my experiences were of being a young person and living with disability but more than that they wanted to know what my experiences were of co-production and being a co-researcher. It was really the first time that people had looked at me in a capacity as someone who could add something as opposed to just being a medical conundrum. That was amazing. I honestly didn't think that I would have had the opportunities that I've been given, and I think something that's important to mention about co-production, particularly co-production within the field of disability, is that if you're working with people who have disabilities then there has to be a really flexible method of working. Kirsty and the team have been really amazing at that. Something that I was particularly nervous about was articulating my needs. I didn't feel confident to say, 'Guys, I can only do this meeting for this period of time,' or, 'I'm not going to be able to work on this this many hours a day,' but everyone made it clear - Dan, Katherine and Kirsty - from the beginning made it clear that this was on a very flexible kind of schedule and that they understood what it was to be a disabled person but working as a researcher. So, we utilised lots of digital methods. We used

Google Docs a huge amount and it's been amazing to be sat at my computer and we're writing journal articles and chapters of books, all of us from different places and I can see what everyone else is writing and we're all adding in our comments and that's been amazing. We've had Skype meetings. All of the interviews that I've done with young disabled people for the research have either been over Facebook Messenger, for the disabled young people who don't have the capacity to either talk via video link or don't have the energy to do that, or via Skype. So, it's all been done digitally. I've done all of it from bed. But then when I have met up to go to either conferences or we had a research analysis retreat, it was all done with the understanding that the co-researchers were all disabled young people so there was funding for the putting up of our Pas in hotel room as well as finding accessible places for us to stay, the fact that we would be driving up in our wheelchair accessible vehicles to these places. So, I just felt much braver and stronger and able to articulate my needs. Previously, I wouldn't have been able to say, 'Guys, it's been about fifteen minutes that we've been on the phone now and actually I need to change position' or 'I need to have a rest' or 'it's been too much for me,' or even to email in and say, 'I'm at hospital all week. I can't work.' But because everyone else in the team has been really forthcoming with their own, not issues but just with their own needs – and some of them were related to disability, some of them were related to other things – I felt really empowered to just be open and honest and it's led to a really friendly and welcoming, accessible working environment. It's made me realise that actually if I continue to seek out working environments like that, I *can* do some work, which genuinely wasn't something I thought that I could do. Two years ago, I could not wrap my head around how I could be in any working environment and suddenly I've realised that I can, and I just needed to find the right people.

### **Interviewer**

Do you think it's important for research in disability to be co-produced? What do you think are the benefits of doing research in this way?

### **Sally**

In the world of research around disability, I think it's so important to have research that uses co-production. If you're looking at any research that's looking into the lives of a certain group of people – in this case disabled young people – I think it's probably impossible to get an intimate and balanced view without incorporating lived experience. For example, the creation of an interview schedule for interviewing disabled young people without having co-researchers who've got that lived experience would have been really difficult. Creating that interview schedule with co-researchers helping to create those questions provided an opportunity that we were able to form questions where we could receive answers that truly reflected the lives of disabled young people and what was important to them. I feel that that could only really come about in an organic way with the input of co-researchers. I also think that doing co-production having had lived experience really also helps with the interpretation of our research and it's helped to guide the direction of the research. I think it would have been far less balanced and varied if we didn't have this team of co-researchers. So, I think in answer to your question, I'd say that I don't see how co-production *couldn't* be helpful in research, particularly looking at the lives of other people and around disability, I think it's vital. I, for one, and I know this is the case for many people – disabled people, young people often feel really ignored in society and so, for me, this has really been a method of empowerment. I genuinely feel that this has helped me find my place in society and it's done so by me giving my feedback about what my life is like. It really has opened my eyes to what I'm capable of and I've actually now got to the point where I'm considering the possibility of work and I'm doing a little bit of research work that's paid, and I never thought that'd be a possibility. So, I do think it's particularly important for research around disability for those reasons but also because it's really

hard if you're thinking about disability, it's hard to understand both the struggles but also the joys of living with disability without having people in the research team who've had those experiences. As I said before, I think there's often a lot of stigma around the lives of disabled people, particularly those who are young, and that it's a terrible life, it's a tragic life and it's ultimately full of sadness, and actually having co-researchers in the team who were able to talk about their own experiences and pour those into the questions we asked others, really provided a fresh perspective. So, for me, my answer would be yes I think it's vital to have co-production when doing research around disability.

### **Interviewer**

It's clear that you've really enjoyed being involved in the 'Living Life to the Fullest' project. What would you say that you gained from it and would you recommend other people to consider becoming co-researchers?

### **Sally**

I think one of the most valuable things has been a sense of self belief. I genuinely did not think me, myself, as a disabled young woman who had been an enormous pressure on the NHS, who had 24/7 care, who really relied on other people... I had felt like a burden. And suddenly my eyes had been opened to the fact that maybe I have something to give back. Firstly, I just had this reawakening of my mind! I used to have a fairly vigorous academic mind and all of those things went to sleep as I struggled for the 15 years or so with just coping with being unwell. And suddenly, this new field has opened up to me and I'm excited by it. I'm excited by the theorising that we're doing as a team. We're co-producing documents and journal papers and we're producing this book and it's just amazing to be working with academics but also co-researchers on real things and things which are going to be read by other academics and other people in the field. Also, I've gained this really appreciation of the fact that I've been through difficulties in my life and a huge amount of struggle, but actually some of those things are valuable because I can use those experiences and I can relay them into putting them into my research, the research that we're doing. Actually, some of those things have given me qualities that make me now a better researcher. And I've learnt that I actually have a voice, and more than that, people want to hear what I have to say, which I find incredible. The fact that my experiences are things that people want to hear about and they want to hear them in my own voice is amazing. But, even more than that, being in a team of a mixture of academics and co-researchers, doing this co-production work, has stemmed the beginnings of lots of friendships. I really feel hooked into this team. I feel invested and I feel like a valued member and I don't want to stop doing it. The friendships that have blossomed have been wonderful, both professional friendships and closer friendships, and those wouldn't have come about if I hadn't answered that advert. I guess also, having worked on the topic of disability and researching disability and hearing from other young disabled people has helped me get more of an insight into my own disabled identity. I now consider things in a different way that I wouldn't have before. The young people that we've interviewed, the papers that we've written and the conclusions that we've come to have actually reflected back on to me and onto my thinking and how I feel about myself as a disabled young person. It's just been incredibly empowering to be working on papers with academic professionals who've been in the field for so long. We've published papers in journals. I've written a paper which has also been published. I'm now co-leading an impact project on the topic of how assistance dogs help transform the lives of young disabled people. It's a topic that I feel incredibly passionate about, having had the experience of having a wonderful assistance dog in my canine partner Ethan. I'm so excited to be leading on that and to be doing more research into it. We're now writing a book which is amazing. I can't believe that I'm in the situation where I'm helping write a

book. I'm incredibly excited about writing the chapter on the relationship between faith and disability because I know it's a topic that hasn't been hugely researched before. It genuinely feels like a gift that I'm able to be doing this research into things that I find so important and so interesting. There was so much I didn't know about disability studies. In fact, I didn't really know what disability studies were before I came into this project, and now I know so much more. When I first started and we were starting to do these papers and we were doing it with Dan and Katherine and Kirsty and they were starting to write these papers, I started reading things which were real, theoretical disability studies and I suddenly realised how that reflected my life so much but this was actually an area of study and I started learning things that I didn't know about. To begin with I had to kind of say, 'Hang on, guys, what's "crip time"? I don't know what you're talking about!' and 'Oh, hang on, I don't know what post-humanism is!' but now I understand those things and through working together I'm really adding things to our papers and it genuinely is co-production. It's not just tokenistic. It's not that they're writing the papers and then kind of signing off that I was vaguely there – I've written some parts of those papers too. And they genuinely seem to want my input! And it still surprises me today that they want to hear what I have to say. You know, I'm sitting at my computer and I'm typing away and I'm adding things to the papers that we're writing, and we're writing them together. It's just incredible that I have been welcomed into the team and that I'm co-producing. I'm co-producing research in the field of disability and it's fantastic.

#### **Interviewer**

Thank you so much, Sally.

You can find out more about the Living Life to the Fullest project at [livinglifetothefullest.org](http://livinglifetothefullest.org) and as Sally mentioned, she and the rest of the project team are now working on a book that will be published by Emerald in 2020.