

Co-Producing Research with Young Disabled People **Episode 2, Lucy's Light**

K = Kirsty
L = Lucy
S = Sally

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L The thing about co-production, it's not about having all the answers it's about learning together.

S By using co-production and us all being young disabled people we've kind of leant an authenticity to the research that we've done.

K There's something really important about the way that co-production enables us to value different lived experiences.

L I do see ourselves a bit as pioneers.

K And it's not the data, these are young people's lives and stories that we're working with.

S I feel like we're almost helping represent the forgotten.

K Disability in the context of Living Life To The Fullest is something invaluable.

L And it is about 'nothing about us without us'.

S There have been so many different exciting aspects to it, I'm still excited right now.

L Hello, and welcome to Episode 2 of the Lucy's Light podcast. This podcast is all about sharing inspirational stories, raising awareness of issues and causes, and showing the power and potential we all have inside us. I'm your host Lucy Watts MBE and today I'm joined by two colleagues, Dr Kirsty Liddiard and Sally Whitney to discuss co-producing research with young disabled people throughout ESRC funded research project Living Life To The Fullest. The project seeks to forge new understanding of the lives, hopes and desires of disabled children and young people and their families, as will be explained in this episode. We show our methods of co-producing research for the Co-Researcher Collective of young disabled women, the experiences of the young co-researchers, the technologies that have assisted us in the co-production, how we are forging new ways of conducting research in a collaborative and inclusive way and the impact this has had both on the academics and on the co-researchers. We hope people can benefit from and learn through our experiences of and methods used in the Living Life To The Fullest project. This episode is released to coincide with co-production week, so do join in using the

hashtag #coproweek. So, without further ado, let's introduce you to Kirsty and Sally. Kirsty, would you like to introduce yourself?

K Yeah and thank you Lucy. So I'm a researcher and activist scholar based at the School of Education at the University of Sheffield. My research generally explores disabled people's lives in different contexts but I'm particularly interested in youth and disability.

L And Sally would you like to introduce yourself?

S Hello I am Sally and since joining Living Life To The Fullest project I've been doing some academic research and some writing, which I'm finding very exciting. I'm also a Speaker and work in the media for Canine Partners, a charity which provides assistance dogs to physically disabled people.

L So I thought we'd start off Kirsty by just asking you some questions. So what is the project and how did the project come about?

K OK, so the Living Life To The Fullest project that we're all working on at the moment is a research project that seeks to understand the lives, hopes, desires and contributions of disabled children and young people with what are known as life limiting or life threatening impairments or conditions. We have a group of young people who work alongside us as researchers in the Co-Researcher Collective, so we think the project is a space where children and young people can tell new stories of disability, their own stories that usually aren't told or heard. So the project came about through the researchers we are working with called Dan Goodley and Katherine Runswick-Cole, and they did a big project a few years ago on disabled children in a post-Blair context. And they found a distinct difference between the lives of....or the families of disabled children and young people in general, and disabled children and the families who had life limiting or life threatening conditions. So Living Life To The Fullest began wanting to explore this kind of distinct difference, and that's where the project originated a few years ago.

L That's great, thank you. And can you explain to people why co-production was really important to this project and to disability research as a whole?

Time 4:18

K Yeah I think a great question, and I'm both a disabled person and a researcher and academic so it's always been really important to me to include disabled people in my work wherever I can. And largely, disabled people are usually only seen as, at best, the kind of participants of research. But Living Life To The Fullest positions disabled people as leaders of research, which is something I'm really proud of and I think that's very rare, particularly for young disabled people. There's a history of kind of problematic power imbalances in research, and co-production for me really strives to equalise these power imbalances through the different ways in which we work and how we carry out research with other young people and their families. And I think, thinking about Living Life To The Fullest specifically, it's made the project so much more different than it would have been if it was carried out by a group of academics solely in a university. So I think the way that

we've worked is very different, how we've approached our data collection has been very different, how we've done our analysis has been, you know quite different from how it's usually carried out, and I think that's made the project much more relevant to disabled children and young people and their families. So for me, there's something really important about working in different ways and making research and its findings relevant, accessible and meaningful to the marginalised communities that you're working with.

L How did you go about embedding co-production in the project? So how did this co-production model factor into how you built the project?

K Yeah another brilliant question. I'm saying through you essentially. We had ideas at the beginning of the project that we wanted to share, or distribute responsibility of the project to community research partners and disabled young people, and we knew we wanted to work with disabled young people as researchers in their own right, but we didn't quite know how to go about it. So I think it was shortly after meeting and getting connected with you, and you sort of telling us about online spaces and virtual methods as really important ways to connect with young people and engage with young people, that I think in short we just listened to you and that significantly shaped the research moving forward. And again through your networks and your contacts we were able to build this brilliant community of young disabled women researchers. And again I think for me that shows the benefits of co-production, because if it weren't for us meeting and connecting with you, and you becoming a leader on the project as well, none of what we've done since would have been able to materialise in the same way.

L Oh that's really helpful and I'm glad I've been that much of a pivotal role in the project. It's an amazing project to be part of. I mean you can say that as well Sally, it has been a fantastic project hasn't it?

S There have been so many different, exciting aspects to it. I'm still excited right now.

L So we in Living Life To The Fullest decided to kind of use digital tools to enable our research. Would you like to explain some of those tools we used Kirsty and how they've benefitted the research?

K Yeah. So we've used a variety of online platforms. We've got a very lively What's App thread where we communicate a lot. We've used email, we've used Facebook, we have a closed Facebook group for the project where we generally, I think, more used at the beginning of the project to connect with each other. We also have used Facebook Messenger for interviews, we've used Skype for interviews both with young people and with parents. We have a really active blog on our website which has been wonderful in terms of making space for co-researchers to write but also in terms of...I think with co-production it's still quite a rare process but I think it's really important that we document publicly what we're doing as we go along, and I think the blog has been really useful for people to learn about what we're doing and people constantly get in touch and ask about the project and ask how they can do similar work. So I think online spaces enable that connection I guess with a wide audience, well multiple audiences. And again I think it was only meeting you and

thinking about how online spaces and social media can do that work to connect people and stuff that really made us think about how it could benefit a project. And I think there's also something about online spaces which for many disabled people, though not all, online spaces are really accessible. So we found in the project that we can do things at a different time of the day, or researchers can take breaks in interviews and do interviews bit by bit. And it feels like there's more flexibility I think in terms of ways that research can be carried out.

L And how successful do you think that the co-production in Living Life To The Fullest has been? I mean for me it's been very successful, but what do you think?

Time 9:11

K Oh it's been – I'm possibly biased – I think it's changed the way I practice as a researcher for ever. I can't imagine now going back to doing research as a lone researcher, to me that's not what research is any more, it's always collaborative. I think it enabled us to, I hope, make a real difference in the lives of young people and their families and I think we're still yet to do a lot of that work because we're in a particular part of the project where we are starting to think about that. So I think we've done it really successfully and I think we've communicated a lot, I think we've been quite experimental. I don't always think we knew what we were doing at each stage but we just went ahead and we did it, and I think we found real successes. And one of the legacies of the project is a co-production toolkit, so what I want to do with that is for us to document what we've done and how we've done it so that other researchers, practitioners, teachers, can use it as a kind of best practice model of how to do research, not for young people but with young people.

L Yeah. And what have been your highlights of working through co-production with young people?

K Well I thought about this question a lot, and I think there has been so many. I think, again, changing the way I think about research has been very powerful for me as an academic. I think a lovely bi-product of co-production and the way that we worked is our friendships, I think all of us have become really good friends and I think that's a really lovely opportunity that can come out of collaborating with other people. I think we're about to – well we know we're about to write a book together, which is really special. And again I've never seen a book written with researchers and young people and co-researchers together as a collective, so I think that's a really innovative legacy of the project that we can all look back on in years to come and also share with others. So I think there's been loads of highlights, I could spend all day listing them. But yeah for me it's just been about totally changing the way that you work and getting to work with lots of different people, and also working together with disabled young people about what they want their lives to be like, or what they want....I suppose to bring about the change they want to see. And facilitating that and supporting that is a real honour.

L And it has been, for me it's been a real honour to be part of it, to work with young people, to work with researchers. But to have you invest so much in us as people, we're not just tools for your research but people contributing, I think that's a really powerful..... Often in research, I know I feel, you become a subject, you

become a bit of data, you become an interviewee, but you don't become a person. But I think Living Life To The Fullest has been very true to the people behind the project rather than just subjects.

K Yeah I know and thank you for that. And I think one of the things that is a key criticism still of engaging young people in research is that it is relatively tokenistic, as you've just said. And I think one of the things we've always tried to do in the project is really make it meaningful, to really do collaborative work together, to acknowledge you guys not just as subjects but actually as key leaders in the project – and you guys have quality skills and knowledge that we need and we need to work with you in order to do research. So for me there's something...yeah, just very meaningful about valuing what you bring as researchers based outside of the academy and how that enables us to do quite innovative research I guess.

L So Sally, you're one of the members we recruited to become part of the Co-Researcher Collective, why do you think that co-producing research with young people is important?

S So I guess I'm coming at it from a different position, I'm coming at it from where I've been invited into the Collective, and I think that was something that I never thought would be possible before. So for me co-research has really leveled the playing field, it's broken down barriers that I didn't realise could be broken down. So previously I thought that kind of research and academic work was quite exclusive and excluded disabled people a lot, and by having other disabled people including myself involved in this Collective and all being equal and all being researchers, it's really showed me that actually we do have things to say and we can communicate them. But more than that I think it allows a kind of two and fro, a movement of ideas that really helps inspire each other, so in co-production it's not just one person's perspective, it's many people, and that kind of like sharing of ideas and that ping-ponging backwards and forwards actually leads to creative development of ideas and helps us to develop our own thoughts and bring them to fruition. So it's really exciting and I think that the fact that we are kind of running the project together means that we've had an opportunity to have our say or have our input kind of every point in the project. So the questions that we should be asking of young disabled people, we've helped develop those. The things that might not have potentially been asked, the areas that are most important for research according to young disabled people, we've been able to inform all of those things, and we've also been able to say what we really want the outcomes, how we want to present the outcomes and what those outcomes might be. So yeah, for me it's given me an opportunity to kind of get stuck into something that I didn't think was a possibility for me any more.

L And what have you enjoyed most about being involved Sally?

Time 14:52

S So definitely a return to academia, which I haven't been involved in for a really long time, that has just....that's been fabulous. Yeah as I said, I didn't think that I had very much to input, I didn't realise that I would be able to get back to this kind of way of thinking. But more than that, I guess there's an aspect of suddenly realising that the experiences I've had have some value and have some worth and that they can

be translated into outputs of research and they provide rich data. I thought I was just having life experiences, and particularly negative life experiences, in being an unwell young person, but actually those things have gone on to inform some of the things that we've done in the project. And that's really uplifting and I think, yeah a wonderful outcome. But something I've really enjoyed is also just meeting other young people who have had similar experiences to me. We are all different and we all have different journeys and have different stories, but we are all united in a certain way and coming together with people in that way has been really uplifting.

L Yes thank you, and I can definitely say that camaraderie, that support, that networking, I have benefitted from that. And it's those deep and meaningful relationships, both on a personal and a professional level, that are really important.

S Absolutely. And meeting people who kind of understand where you're coming from, even if it's not the same details, it's not the same story but there's just something there that has developed that's really special. And I think that that has been really beneficial to the project as well. As you say, the camaraderie that we've developed has actually informed the project.

L So what roles have you played in the project Sally, what kind of things have you done to be part of this project and to enable this project to be what it is?

S So I was thinking about what roles I've played, and that seemed very formal. But then I thought about all the other things that I've done, and actually there are quite a few things that I've done. So I think when we first started we were looking at co-production and thinking about things, and one of the first things that I got really excited about was about collaborating on papers. So we had some Google documents and one of the first things that I did was to start just having some input on things that had been written, and for the first time I thought 'wow, people are listening to me, I have something to say'. So we've written a number of papers together now, and that's something that I'm really proud of, to have my name written down on there and to have actually inputted. But then I've also been to conferences and presented and conferences talking about the Living Life To The Fullest project and answering questions about co-production and the project itself. I myself have written some articles both for the media but also for some academic journals, which has once again just been a real highlight, loved doing it. I'm so excited and so privileged that I've been able to do that. And then I've also been doing quite a lot of research too, so I've carried out interviews via the digital methods that we've discussed, but I've also had an opportunity to analyse the data that we've collected, and that has been absolutely fascinating and also a real privilege.

L Yeah, and I can say it's really interesting, taking yourself outside your own experiences and reading these interview questions and then interview answers, and thinking about we've got such rich experience. And that's what Living Life To The Fullest has harnessed, it's harnessed that rich experience to benefit the project. And I just hope people will learn so much from Living Life To The Fullest and what we've done. I do see ourselves a bit as pioneers, you know we've done some great pioneering work and I hope it will have an impact on other research projects, in a way leading the way for other people to see that this can work - and not only work but actually lead to the best possible outcomes for the project.

S Absolutely. And I think that the questions and things that we asked, which were informed by our experiences have led to data that, yeah as you say, is really rich. But perhaps outside of our own experience, yeah we've been able to collect and harness more information than we thought possible but starting from our own experiences. And that's powerful.

L So how would you both say, obviously talking together, that co-production has enriched the project?

Time 19:14

K Well I'd like to jump in to echo what Sally said, that I think there's something really important about the ways that co-production enables us to value different lived experiences. So again, thinking about the interview schedules that we wrote together, I think the questions that we asked on those interview schedules are very different to the questions we might have otherwise asked if we weren't working with you. So I think all of you brought your own lived experiences, both good and bad, and you could read those in the questions. And I really think that the interviews that you did with other young people then....I don't know, there's a real acknowledgement or understanding that you guys have and the way that that came out in the interview transcripts that we then read and to analysis. And I think Sally will agree that the analysis retreat that we held – so we had three days together while we sat and essentially did the analysis together – that our own lived experiences are so rooted in how we then read those transcripts, and we had a real understanding I think of other people's lives based on our own backgrounds and our own histories and our own experiences with disability. And again, I think by doing research with other disabled people, which our model of co-production does, it's a way to gain really rich stories but also a way to really understand those stories in a way that we can then take forward to make real positive change for people and their families.

S Absolutely. And then having multiple people in the team, it being a Co-Researcher Collective, has been great. Because as you say, when we were sat round that table there were several of us and we were all bouncing our own experiences and our own ideas off one another and that led to kind of further thought and further analysis. And so there has been something really special about having a group of us who all have a shared experience in that we are all young disabled people that have all had our own unique journeys. And kind of putting all those into a pool has meant that we've been able to kind of pull out threads from everyone else's stories who we have interviewed. And I think that that's something really special.

K And just to add to that, I think it does something really meaningful to data as well. So many of the conversations we had at the analysis retreat were really emotional conversations.

S Yeah.

K And I think we were connected to the data and the stories in really emotional ways, ways that fed into our own feelings and experiences. And again that shows how our model of co-production takes something that is presumably quite technical –

and it's not data, these are young people's lives and stories that we're working with – so again for me it really embodied their politics I suppose and the power of what it means to ask people questions about their lives and really understand it. So it took research from something that can be quite technical, disembodied, to something that was really emotional and lived and felt as well.

S Absolutely. And it kind of qualifies. It's not just data, as you say, it's not just research that we've done, by using co-production and us all being young disabled people we've kind of leant an authenticity to the research that we've done because it is lived experience, it's authentic and it's real, and we've been able to pull out that from everyone's story.

L Do you both think the project would have achieved what we've achieved without co-production and doing it the way we've done it?

S I think that it would have been less valid in some ways. I think how Kirsty was talking about tokenism, and I mentioned about being excluded from academia, I feel like without the input of multiple people with lived experience we just wouldn't have got the same results, they wouldn't have felt so real and we wouldn't have asked the questions that we did and come up with the answers that we have. So I don't want to speak negatively of any other projects but I feel like it would have been a lesser project if it hadn't have had so many voices who've had lived experience in it.

K I totally agree. I think that it would have been a completely different project. And I think, again like Sally said, not to denigrate the work of others, but there's lots of research around children and young people's lives in the context of disability, and a lot of data. And our findings are quite different from that, and they're different because of the involvement that the Co-Researcher Collective have had. And I can't imagine what our project would have looked like without it. And I think that one of the things that's lovely for me again as both a disabled woman and a disability researcher is, that there's also something powerful about the process of research. So it's not just about our findings and what we're going to do with them, it's actually as you said Lucy around pioneering new ways that research should be happening, and that research shouldn't be kept within universities, you know to people who are supposedly qualified to carry it out. Research is much more than that. It should be a public enquiry. It should be something that everybody has access to to read about, you know. And although we've published in academic journals as a project, we've also blogged, we've also written accessibly elsewhere, again because research isn't something that's ours, it's something that is other people's and it's our responsibility as researchers to make sure that our work is accessible and meaningful to other people. So I think it's a very different project than it otherwise would have been.

L What would you say, both of you, are the greatest achievements? So what would you say are the top three greatest achievements that we've had at Living Life To The Fullest?

Time 25:00

K So my one would be disabled women as leaders.

S Oh yeah.

K I think not only is it incredibly rare in the ablest culture that we live in, it is very rare within the research context where disabled people alone are rarely leaders, let alone disabled women. So I think the fact that I've had the privilege to work with five, six, brilliant young women all of whom have taught me so much as a researcher and academic, is one of the key strengths of the project I think. That's my number one.

S So I think it's the goal, the aim of Living Life To The Fullest, which was to look at the lives of young disabled people. I feel like we have asked questions and invited the opinions of people who are not normally given a voice, and I feel like we are almost helping represent the forgotten. And I think it's really important that we tell those stories that would normally be untold – or perhaps even misunderstood. So I feel really passionately about the fact that we have gone in and asked questions which are important and need to be heard, and we are giving a voice to a lot of other people around us who are in similar situations. And I absolutely love the project name 'Living Life To The Fullest' because I think it represents the opinions and views that we have found. So that's one of my greatest achievements, my top, was just that we have been able to illicit the opinions and the understanding, the ideas of people who wouldn't normally be able to represent themselves.

K And I would echo that. Again we know from previous research that while particularly in social research and educational research over the last 10 or 15 years there has been a move to include disabled children and young people, rarely those young people with life limiting or life threatening impairments, so there's a real kind of neglected area of focus that we've really included in our project. And I think one of my other things that I'm really proud of as a legacy to the project is that disability in the context of Living Life To The Fullest is something really valuable and that it has changed the way we've done research, it changes what research means. I think we live in a society where disability is something that's considered to be inherently negative and problematic, and actually in Living Life To The Fullest it's something really unique, really special, really important, it's a tool to understand the world. And again I think that's something that we've done that really values disabled people and their intimate knowledges of their own lives and the world in really special ways. And I think that comes out in our data and in our findings and the way that we've done the project, and I think that's quite unique.

S And I would say as a researcher, it's not only done that for the people that we've asked questions of, but it's done that for me and I think probably the other researchers too, it's helped me look at the way I live my life and asked myself the questions that we've asked others. So it's actually been quite transformational for me as a person.

L It has for me as well, I've really learnt a lot about myself, about the world, about how things work. But also I think there's that other feeling of 'I'm not alone'.

K Mmm.

S Yeah.

L A lot of people that feel the same way, think the same way, have the same problems. You know it's not just me in the world on my own, that actually there's this whole community that when we join together we've got such power, we can effect change, we can make an impact if we just join together and work together.

S Yeah, the sharing of voices has been something that's really powerful. And something that I've also really enjoyed is that, as you say, we've come up with these thoughts and we have shared ideas, and then thinking about them and actually theorising, and then somebody who knows a little bit more – like Kirsty – will say to me 'well actually that's a theorist like so-and-so, and so-and-so'. And I'm like 'oh wow', so what I'm feeling is something that has already been described but I've never had access to and never understood. So it's kind of validated the way I feel in a certain respect.

L ??? research accessible isn't it? It's making....to us as the co-researcher, I've learnt a lot, learnt about research and theory, it's made that accessible for me as a disabled woman.

S Absolutely. I wouldn't have known about many of these things if I hadn't have been invited to join this group. And now I'm in the group I'm so excited to do more.

Time 29:25

K And just to lead on from what Sally said, I don't think it's about me necessarily knowing more. I think it's about that again, within Living Life To The Fullest, theory means something quite different. Theory is something that is collaborative, that's shared. Theory to me just means thinking about the world, it doesn't necessarily mean knowing stuff. It's a desire to explore the social world and people's locational place within it. And I love that the Co-Researcher Collective have been theorists alongside us, and we've shown that through the way we think, the way we talk, the way we write together. Again I think it's really unique. We know from other research with disabled young people that they're often only given access to particular parts of the project, but one thing we've been really keen to do is that as people are contributing time, energy and investment, you should have as much right to the full research process as we do as the academics on the project. So you know again, young people are quite typically excluded from writing, from conferences, from analysis, and those are the key areas for us where we wanted to include the Co-Researcher Collective, also enable it to lead those processes as well. And I think we've done that pretty successfully.

L How would you advise other researchers about co-production? I mean what would you say how they can take what we've learnt and apply it in their project? Kirsty?

K I would say look at our Living Life To The Fullest co-production toolkit that we're going to produce. But I would just apply it. But I would also say just listen. I think academics and researchers need to listen. I think if you're going to do research with or about marginalised people then you have to value and appreciate the knowledge that people have in their lives and actually again.... essentially what we've done in this project is just listen to your expertise. All of the co-researchers

have made really valuable contributions and we've been really lucky in that, but I think you know on our part there's an ability to kind of let go of the process a bit, that it doesn't mean having control. We share the project and we distribute the work quite equally and everybody contributes a bit in quite different ways. So I think I'm really proud of that, that yeah our methods of co-production are equal and balanced and fair and really value people's knowledge and our ability to listen to each other.

L What would you advise other people about co-production Sally?

S My first thing would be to say just do it, co-production seems to be a fabulous way to do research, I don't know why you would do it any other way. But also, probably not to make assumptions about people's capabilities. So I've learnt a lot about myself and my own capabilities through this project and I've learnt about other people's capabilities, and actually if you are adaptable, willing to do things in perhaps the unorthodox manner, a new way, then people are capable of great things and achievements which they might not have realised they were able to do to begin with. And so just have that openness to doing things in a different way. So we were talking about the tools that we've used to carry out co-production. Something that's been really helpful for me is the fact that when we have met together as people that we've had an allowance to bring our carers with us and there's just been like an understanding around the fact that we may have care needs and we need time for that and to look after ourselves. So it's just understanding that the people in the co-production team are all going to have different needs but all have different capabilities too, and that we need to kind of really cherish those individual things.

L I totally agree with that. And it is about, you know it's taking that time to invest in people, and you'll get so much back if you invest in the person and not in the data.

S Yeah.

K Absolutely. And I would say that I think really meaningful co-production does take time. It takes time to build friendships and relationships and intimacies. It takes time to consider or develop different ways of doing things, I don't think that necessarily comes automatically, that's taken a lot of time for us to work out how to do things and how to do things differently. And yeah I think good co-production should take time. I think good co-production has to take place on a different timescale when you're working with disabled people, but actually that teaches us really important things about research and its process as well. So again it's that space where disability becomes a really.... to challenge and how we think about research and what we think research is and how it happens.

S Yeah, it's exciting to me that disability is able to teach other areas of research about ways of doing things. I think that's fascinating that's it's actually an advantageous tool, and I never thought of it in that capacity before, so that's been fascinating. And I think we didn't mention when we were talking about tools the use of Google Documents. For me there's been something really magical about seeing kind of a group of people writing things down on a document and seeing everyone making their own adjustments to it, adding their own opinions, and it all kind of coming to life on this screen. I never realised that we could do that in a digital environment, we could have this real conversation about real things affecting real

young disabled people's lives and it all kind of coming together all collectively and all equally. I love that our voices are being heard equally and that we are representing the voices of young disabled people equally.

Time 35:00

K And interestingly, before we began work with the Co-Researcher Collective we'd never used Google Docs before. And again that's what I mean, so we used it as a way to enable people to write at different times, to show writing as a developmental process, and people could go in and write at different times and add comments or not. And actually that's fundamentally changed the way we work on other pieces of work, that Google Docs is something we've learnt through working with you that now has changed much of the rest of our work and our teaching and stuff like that. So again I think it's been a lovely process of learning together, and Google Docs has enabled us to counter much of the able-ism of what we think writing is. So we've learnt that writing isn't sitting alone in a room for 8 or 9 hours writing a journal article, it's much more distributed than that, it takes place over different timescales and happens in different ways. And also acknowledges people contribute in different ways, so a few comments by the side of a script can be as meaningful as someone writing 1,000 words. It's just again it's a different way of working and engaging with the written word and how we think and write about theory as well.

L The thing about co-production, it's not about having all the answers, it's about learning together and having that process. So it's sharing that power, working in a balanced way and learning as you go. And I think that's what has been really powerful. You know we haven't had all the answers right from the get-go, but we've worked hard as a team.

S Yeah, I feel like it's almost an evolution, the project and the pieces that we've written have all been this beautiful evolution, we've started in one place and you can actually see the transformation as it goes. And so we started in a particular way of doing things and actually we've adapted as everyone has their own ideas. And I think it's amazing that we can actually kind of like track that journey throughout the project.

K And I hope we're going to write about this in a book, as you said. I think a lot of what we've done has been quite accidental maybe, experimental, we tried things, some things have worked some things maybe haven't worked. But again I think what's really important for me about co-production is talking about it, because I think when researchers do do it they're never really explicit about how it physically happens. And I think one of the things we've tried to do in our writing is talk about the kind of literal 'what have we done, what did we do, how did that work'. So I think I'd like us to talk about that in a book because I sometimes think people think co-production is this mysterious process, and it doesn't have to be, the more we can tell people about what we've done and how we've done it the more likely other researchers will, people who want to do research, can learn from us I guess.

L And we'll go on to our last question. So what is true co-production in the context of disabled children and young people's research? How does that look like,

how does it apply, and what would we do – if we could change the way of funded research what would we change?

K So jumping in, mine would be leadership. Leadership is something, again it's communal, it's collective, it enables everybody to have a voice, an opinion, it means listening, it means challenging the normal way that academic research is carried out, who controls it, who manages it, who funds it. I think to a certain extent it means pushing back against some of those forces. And yeah I think it involves a lot of trust actually to work together in new ways that again often feel quite experimental, but yeah enable us to share responsibility of a project that we all care about.

S And for me I think if we're thinking about it in the context of specifically disabled children and young people, then we need to recognise that young people are the future and these young people are living longer lives and they do have stories to tell. We have stories to tell and we want our voices to be heard. And so to neglect youth and young people from disability research would not only fail to recognise like a huge sector of disabled people, but also fail to accommodate for the future. And so if co-production allows young people to have a say in how their lives go by doing research, analysing the results and then having an impact on the way policies are made etc, then why wouldn't you do it? We need to include disabled children and young people and give them a say.

L It's about unheard voices being heard. Because that's the thing, it's the same voices we hear over and over and over, it's not these new voices, these hidden voices. And we are as a society very exclusive of disabled people and often we're on the margins, like Kirsty you used the word marginalised – we are marginalised and we are misunderstood. And it's about showing that we have potential, we have power, we can do things, we can achieve things, but also that our voices aren't forgotten as society moves forward, that we don't get further and further marginalised, rather we go the opposite way and become more and more and more included.

Time 40:00

S And that we get to dictate our own opinions and we have our voices heard, that we don't have people speaking on behalf of us. Because that doesn't have the same value, it doesn't lend the same authenticity, and as you say it marginalises us further.

L And it is about 'nothing about us without us', you know the big disabled people's movement was all about 'you can't make decisions about us without us being there'. And it's about bringing disabled people to the table and bringing our voices to the table. And that has a multi-faceted approach, it's not just research, it's about research and activism and advocacy and campaigning and lobbying, we need to be embedded in all of that. But if research is done about us rather than with us, that side of our lives are getting missed and the research isn't actually factoring us as people. And it's getting research back to....research is about benefitting people, we do research to help people, but if you're not capturing the truth and you're not capturing the real lives and the real voices, then research is not very useful in a way because it's not true to life.

K I agree and I think for me as a researcher, research is about change, it's about ways to find out about people's lives and make change in positive ways that make things better for people. And I think you're right that by doing that, by doing the research with disabled young people and their families that any interventions or impacts that come from our project are going to be much more meaningful and relevant to those families than if we hadn't have done it that way, that we can bring about a different kind of change based on the voices that we've included in the project.

L So thank you both for coming on the show, it's been really great. And I think Living Life To The Fullest, the name says it all, we're just about living life. It's about capturing people's lives and experiences and their voices, but actually we don't want special treatment, we just want equality so we can live our lives to the fullest. And I encourage people to check out our website, so www.livinglifetothefullest.org and we've got some great blogs and items on there, and just keep up to date with our research. So thank you.

We've now come to the end of this fascinating episode of the Lucy's Light podcast. I hope you have found it interesting and maybe your thoughts about co-production or about how you can co-produce research with people has changed. This is not just applicable to young disabled people but any sub-group of the population, especially marginalised communities. I hope it's opened your eyes to the possibilities of how research can move with the times and how rich, accurate and true to life research can be when you involve people in all aspects of a project as equal partners and not just as subjects. As we've said in the podcast, this is not data, these are real people's lives and stories. We hope you will keep up to date with Living Life To The Fullest through the aforementioned website, which in case you missed it is livinglifetothefullest.org, including our outputs of the projects which, beside the research finding themselves, will include a co-production toolkit and a book about our research, our findings and our use and impact of co-producing research with a Co-Researcher Collective. Please do share this podcast with your friends, family and colleagues. And also follow us on social media so we can get these stories and the topics and issues covered to a wide audience. Please also comment, share your views and let me know what you think. Do not hesitate to email me or contact me via my social media. Maybe you have a suggestion for a topic to cover or an issue to highlight, or maybe you would like to appear on the podcast, or you may know someone who would be a great guest to share your stories, your work and issues close to your hearts.

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have been your host, Lucy Watts MBE, and thank you to our two fabulous guests today, Dr Kirsty Liddiard and Sally Whitney. Until next time, goodbye.