

Equal Exchange of Ideas: From Conversation to Collaboration

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Speakers: Lauren Cox, TJ Clark, Rich Crisp

00:00:07 Lauren Cox

Thanks for joining this episode of Gerrin' On Wi' It, hosted on the Research and Innovation Podcast at Leeds University Business School. I'm Lauren Cox, the Yorkshire Policy Innovation Partnership, YPIP, Comms and Engagement Manager. I'll be speaking to Rich Crisp from Sheffield Hallam University and TJ Clark from the YPIP Community Panel.

They'll be sharing how one conversation has led to a collaborative piece of research looking at the adult social care system, particularly the overlooked area in research and policy around how people use personal budgets to employ their own care through personal assistants. Rich's work on the YPIP project has been looking at what good work means and how we can create good jobs in the local economy.

Together, they've explored what good work could look like in this part of the sector. Welcome, TJ and Rich. Thanks for joining us.

00:00:55 Rich Crisp

Hi Lauren. Hi TJ.

00:00:57 TJ Clark

Hello.

00:00:58 Lauren Cox

You're both involved in the Yorkshire Policy Innovation Partnership, YPIP, which is a huge regional collaboration. So please could you tell us how you first met and started working together? What was it that sparked your interest in one another's perspective?

00:01:13 TJ Clark

Yeah, it was during the initial training that we were having for taking part in the YPIP panel. I'd already been quite interested in work package 2A - "good work". As somebody who's quite disabled and employs their own PAs, I also have found over the years that I employ a lot of either disabled people or often single working mums and they need quite a lot of support themselves, either in reasonable adjustments or flexibility, and I've been quite focused on trying to provide that in the small amount of employment that I provide. And we had a very interesting mutual understanding of this because of some of the things in Rich's personal life.

So, when it came to inclusive recruitment and reasonable adjustments, I'm already trying to build those and also we had a conversation around how it feels like we are always overlooked, that there is nothing out there about us. Everything from wider organisations to the COVID guidelines that just

absolutely missed us. There's just no awareness at all. So yeah, that was what led me to the conversations in York.

00:02:35 Rich Crisp

And what really struck me when we had that conversation was when TJ was talking about being an inclusive employer, when they were talking about making reasonable adjustments. And I thought that was fascinating because adult social care is often seen as a sector where there's lots of poor practice, where there's bad employment, where jobs aren't necessarily good, even if they're meaningful to the people that do them, for lots of reasons.

And yet there's this whole part of the adult social care sector where actually there are employers working with their PAs to make that relationship as productive and as positive as possible. And I thought it would be fascinating to explore that in more detail and to learn from those practices, learn from those experiences and those relationships.

I went to the event with my colleague, Belen Martinez, who is also on the work package team, and so we already broadly knew we wanted to do something around good work and we called it "better business" as well. So how can businesses be more inclusive? How can they support their employees better? How can they create good jobs and so on? And so we were really interested in finding out what the interest and the expertise and the experience of the community panel was and whether they would be able to, or want to, engage with us on some of the activities within that work package.

Now, if I remember the sequence of events correctly, we'd already started to speak to Sheffield City Council, who are a key partner on the project, and we were thinking of doing some work around the foundational economy, which sometimes that's called the everyday economy. So, it's those parts of the economy that are essential for everyday life. So, the people that come up with the ideas sometimes talk about safe and civilized life. So, it's things like health and education, but also the stuff that makes life fun. So it can include stuff like retail and hospitality as well.

So we've been thinking about doing some work on adult social care with the council, but at that point it was very much a half fleshed out idea. We weren't sure exactly what we were wanting to do or how we were going to do it. I think the council were keen for us to look at residential care. So that's obviously things like care homes for elderly people or people that have specific health needs or disabilities, as well as the home care sector. So that's where people are being cared for in their own homes and care workers are doing house to house visits.

But what really sparked my interest and my enthusiasm when I spoke to TJ was thinking about that part of the adult social care sector where individuals are using their own personal budgets to employ carers, to take on their own personal assistants or PAs, as they're often called. I knew from personal experience that this can be quite a unique relationship. So, I have a brother-in-law who had a brain injury in later life. So, he needs full-time care and has his own PAs and has done for a number of years. And I knew from seeing that relationship that when it goes well, it can be fantastic, they can build a really strong relationship, but also when it doesn't work so well, it can be really tricky as well.

And I think as the conversation with TJ progressed, it was really fascinating. I think between us, we started to think about, well, what does it actually mean? What does good work mean in this part of the sector that's unique in many ways because you have the person who is employing the PA, but also has care needs themselves, who is managing that relationship and who is the employer? What does

that look like? What does “good” look like in that context? What scope is there to be a good employer? And I think crucially, what scope is there for other parts of the sector that research and policy typically focus on, so residential care, or home care, what could they learn from looking at that relationship?

So from that conversation, that single conversation with TJ, that developed into a whole strand of work within our overall piece of work on what good jobs look like in the adult social care sector.

00:06:10 Lauren Cox

Great. So how did you get this work off the ground from that initial meeting?

00:06:15 Rich Crisp

So, we had the conversation with TJ at the event. We took that away. We spoke again to Sheffield City Council about our ideas for the research and it was really interesting. So, the lead contact of the council who we've been working with, when I told them about what I discussed with TJ and our ideas around looking at PAs and employers in that part of the sector alongside residential care and home care.

They were really engaged, they were fascinated, they were excited.

They said it's an area that they don't really think about as much. Obviously, as a council, they're involved in funding care in that part of the sector, but it's not an area that they thought of in terms of good work and what can be learned from the relationship between employers and their PAs. So, they were definitely really keen for us to look at it and it felt like a gap that we could explore in the research and, obviously what I've been working since, the team's been working since with TJ to develop that particular part of the research.

00:07:09 TJ Clark

So, from my point of view, we had a really very interesting conversation that looked like it was going to go places. And then the wider YPIP process kicked in and we just had to wait because I needed to be nominated for the work package and that had to be agreed by everybody on the YPIP panel because that's how things work on the panel.

So, there was a long wait, but I was put forward with a couple of other people to be the representative from the panel on the work package. And that's when we started meeting and talking and looking a bit more in depth about why I felt that this particular part of social care needed to be looked at.

Although I have input from the council, I have a social worker who reviews my package, I do have supports in place. The package in Hull is, I think, personally quite well designed. Outside of that bubble, it feels like we're quite invisible. When you go to other places and you discuss the kinds of situation you're in, that you're employing your own PA, that your PA is going to come with you. There is a lot of misunderstanding that that isn't somebody from a care agency. It's also misunderstood when my PAs go to help from the DWP or somebody needed help from Access to Work, because I actually, I employ quite a lot of disabled people myself. I try and make as many reasonable adjustments, and we had our first person need Access to Work.

Access to Work struggled hugely with the idea that I was an employer who wasn't part of the business, didn't have an income myself, and who wasn't a care agency. I'm still not sure that the

support worker that was working with my PA ever fully understood the situation and it makes you feel invisible in a way that we just aren't recognised and we aren't seen and it is completely misunderstood.

00:09:28 Lauren Cox

So where did all of this kind of working together and getting these ideas off the ground, where did this lead to next?

00:09:34 TJ Clark

We discussed interviews and that the most important part of the actual working relationship that you have is the relationship you have with each individual PA. The relationship that you have with each individual PA is completely different because it's a pairing, or at least in my case where I have one-to-one care, it may be different for people who have two-to-one, but in my situation and the situation of the people that I mostly know about, it is a pairing and each pairing is different. So, although I remain the same, the actual working relationship and the pair is different every single time you employ somebody.

And we decided to look at that and what that looks like when it's working well, which meant that the interviews, we had a long discussion about whether they could be done as a pair. And I actually asked my PA, who works with me the most and has been with me the longest, whether she thought that was appropriate. And she was very happy with the idea of a paired interview because we work so much in conjunction with each other, she felt like that would give the best example of what a paired relationship like ours looks like. Although we were aware that might not work for everybody and that other people would need separate interviews.

00:10:54 Rich Crisp

Certainly from our sort of perspective as a research team, it wouldn't have happened that we'd done the paired interviews if it wasn't for TJ's input because we thought that it would be a fascinating thing to do.

We thought it'd be really insightful in terms of understanding what makes for a good working relationship between PAs and the people employing them. But we weren't confident that we could necessarily do that without overstepping ethical boundaries. Obviously, you've got to think about, technically, you've got an employer there, you've got their employee. Often there can be a power imbalance there or a power dynamic. Maybe PAs feel they have to say certain things, or they have to cover up certain things in that context. So, actually, as a team, I think we'd reached the point where we were thinking this can't really happen and that it would only really be appropriate to interview PAs and employees separately.

But then really interestingly, I thought, well, let's run it past TJ, we've got someone who's obviously got personal experience of this. And that was what changed our mind, exactly as TJ said, it was coming back and suggesting that it would be possible and it would be feasible and it could be done sensitively if we did it carefully. And if we phrased the questions in the right way, that it would be appropriate to bring PAs and employees who were willing to do it together, obviously, into the same conversation as part of our research. So that's something that we did.

TJ also put us in touch with a disability support organisation and through the various contacts that they provided, we're able to do, we've done 2 paired interviews so far. We've also done additional interviews with a PA and an employer separately where they've chosen to do it separately. So obviously it's a choice, it always remains a choice.

But drawing on the lived experience that TJ has and drawing on the understanding and the perceptions of their PA, we were able to change the design of our research to do things differently, and from the interviews that we've done, I'm really glad that we did. I think it makes for a really, really meaningful conversation.

And one thing we did do is that we wanted to do things a little bit differently and make them a bit more interactive. So, there's a book on good work by an activist called Hilary Cottam. And she uses prompt cards around different aspects of good work, whether you have a good relationship with your boss, whether you feel you're well paid, whether you feel your work is meaningful and so on. And it seemed like, firstly, an effective way of talking about good work in a way that isn't just firing a string of questions at people, because you could give people cards and say, to what extent do you feel that you get this within your job? Do you feel you experience it a lot, a little and so on? But also, because that was an exercise done by the PA, it felt a little bit like it handed power back to the PA in that particular context, in the sense that they were the ones who were kind of really setting down how they felt about the working relationship. And then we invited the employer as well to comment, but it felt like we were definitely trying to address any sort of imbalances within that particular research setting.

And we also tried to make the research as inclusive as possible. So, one of the respondents has just provided written responses. That was the way they preferred to interact with us. So, we just sent 'em a list of questions and they sent that back. So, it's really trying to open up as many opportunities for people to take part as possible.

00:14:03 Lauren Cox

Thanks. And I think obviously, having both grown this kind of relationship and kind of working together approach, I'm sure you're kind of dying to know what each other's perspective and experience of this process has been.

Rich, would you like to ask TJ kind of anything from their point of view?

00:14:26 Rich Crisp

Sure. So, the one thing I wanted to ask TJ is whether the process felt like it was a genuine process of co-design and whether TJ feels like they're meaningfully engaged in the research.

00:14:38 TJ Clark

It's honestly felt very organic from that first conversation. It's very much felt like, I'd say, an equal exchange of ideas from the beginning. My experience and my ideas being considered carefully and used by you to inform what you're doing. And sometimes I have challenged you and you've accepted that.

I have never heard that we can't do something or that we just don't do things like that. It's always been an open conversation, which has actually in some respects included my PA as well. Since that first conversation where we made a connection through the kind of mutual experience of, or

knowledge of, people who employ their own care, their own PAs. It has definitely felt like an equal exchange of ideas.

I feel like the things that I have said have definitely changed the research that you were originally going to do. They've definitely made a difference and what we have is definitely a collaboration between the two of us. I don't see that this would ever have been done without us having had that initial conversation all the way back in York.

00:15:57 Lauren Cox

Thanks, TJ. And is there anything that you'd like to ask Rich?

00:16:01 TJ Clark

Yeah. What would you have done differently? What would you change to make this based even more on the principles around co-design?

00:16:12 Rich Crisp

Yeah, it's a really good question. And I think it's important to say at the outset, it's very reassuring to hear, TJ, that you felt like it has been a genuine process of co-design and collaboration.

If we were starting again, I would say that what I would like to do is bring that in at an earlier phase of the research. And this is partly about the way that the project was funded. So, we had to have some ideas to put forward to the funder. So, it meant that we came to the panel with some ideas about what we wanted to do. And although they weren't fully developed, I still think it would have been fascinating and more engaging potentially to sit down almost with a blank sheet of paper with the panel and work through what a series of research projects could look like.

And I think we've very much done that in terms of the specific piece of work that we've done, but I think for it to be genuine co-design, it would ideally be built in from the outset. As I say, it's nobody's fault. It's just the way that the project worked. We had to get the funding first, then we had to set the panel up and we had to have some ideas that we were going to work with in the meantime. But one of the things I've learned, I think, is that co-design works best when it starts as soon as possible. And that makes everybody feel like they're involved and engaged from the outset rather than ideas are being brought in or imposed from the outside.

00:17:27 Lauren Cox

So, what's next for this work and where do you hope it will go? What would be helpful for others to learn about this collaboration for their own practice?

00:17:36 TJ Clark

I'd love for this to be seen as a blueprint or a pathway for how to do the collaboration. Not necessarily any particular process or policy, but more about the attitude, the genuine openness and curiosity and respect that's been part of what's been a relationship between me and Rich in this process that we've been going through. There's been a definite willingness to learn and to share knowledge.

Anything that I have been uncertain about or unfamiliar with or just confused about has been explained thoroughly in a way that I've been fully able to engage. I've never once heard we can't do

that or that's not how we do things, not as a first answer. I mean, apart from YPIP process, which is essential and important and had to happen, but that's the only area that that occurred in.

From Rich and Belen, it was always, I hear you or I'll have to think about that. And that's been the core part of this, the flexibility and a real genuine investment in what we were trying to do to build something that was a real collaboration.

00:18:53 Rich Crisp

It will be interesting to carry that forward now into this part of the research. So, we're nearly finishing up our interviews, or we will do by the summer within a couple of weeks or within a few weeks. And it will be great to sit down and start to think through some of the findings and what they mean and what their implications are. And I think crucially, what are the key messages? So that's the messages for PAs, the people employing them, for councils that are commissioning this type of care, or funding this type of care, wider support organisations and policy makers. So, I think it'd be really interesting to see what that looks like from your perspective and how we can craft messages that best work for the different audiences that we want to influence.

It's great to hear your comments about the openness, the flexibility, the curiosity, the respect. That's all something I felt from my side as well. And it's really challenged the way that I do research. I've always hoped that I do research in a way that's inclusive and that's ethical. But what I've realised from this experience is often that's a closed shop. You do that with other academics who there's an ethics panel at the university. So you submit a proposal, how are you going to do it? They respond. They might ask you to make some changes. But that never goes outside of the university. And then you go out and do the research to the group of people that you're working with. So it very much feels like we've been marking our own homework actually.

What this experience of working with you, TJ, has made me realise, and this is perhaps embarrassingly late, that research participants should absolutely be at the heart of that process. And it's been brilliant to have you there as a sounding board that I can test things with or suggest things to or ask for comments or invite changes or for you to insert questions or for you to tell me about how you think we can do this research in the most meaningful but also the most sensitive way with the different groups that we've been working with.

And I think that's not just about engaging participants because that's the right thing to do. I mean, clearly that's really, really important, but I think it also makes the research a lot stronger. And it's given us confidence as a research team to do things differently in a way which I think will ultimately enhance the quality of the work that we produce and the outputs. So, in terms of the learning, I've learned a huge amount from working together, but the message I would hope for other researchers in this space is that co-production should absolutely be front and centre in their research practice if it isn't already.

00:21:19 Lauren Cox

Thanks both so much for your time and for joining us on this episode. You can really see the kind of mutual respect and value that you've both brought to the table and will continue to do as the research goes on.

And yeah, hope that others are able to take inspiration and learning from what you've achieved. So, thank you both so much for being on this episode and wishing you all the best for the next stages of your research.

00:21:46 Rich Crisp

Thanks, Lauren.