

**Alex Swift**

Croseo, welcome. This is the exchange podcast. I'm joined by Anne Collis co-founder of Barod, a community interest company set up to support people with learning disabilities. She is also the author of the report Not Just the Usual Suspects which looks into the failure of social care policy in Wales to guarantee people with learning disabilities the ordinary life that so many of them want and deserve. Hello, Anne, how are you today?

**Anne Collis**

Hello Alex. Just one thing I'd like to correct, Barod wasn't set up to support people with learning disabilities. There were four of us who set it up together – some of us had learning disabilities, some of us didn't and we just set up Barod to prove that we could all work together to run a business really. So, it's not so much about supporting people, it's about just cracking on and doing stuff together.

**Alex Swift**

Thank you for that correction, that certainly makes sense. Can you start by setting out the main points you're addressing in your 'Not Just the usual suspects' thesis and the main challenges that are preventing many people with learning disabilities in Wales from leading an ordinary life?

**Anne Collis**

Okay, the starting point is that the reason that we know most people in Wales with learning disabilities aren't having an ordinary life is if you look at anything that is important for an ordinary life like having your own front door, being able to choose your friends, having a social life, having a job, having a partner, maybe having kids if that's what you choose. Most of those are either off the menu or incredibly difficult to achieve if you have a learning disability and you live in Wales. It's not just a Welsh problem, same problem in lots of parts of the world. What is surprising is that this is the situation even though we've had policies in Wales right back to 1971 before devolution, then a specifically Welsh policy in 1983, and all the years since then they've all been promising an ordinary life but it's just not what people are experiencing.

We don't even count how many people have a job but if its anything like England it's going to be less than 5% of people with learning disabilities having a job. A lot of people think they've got a job because they get told they're going to work but they get maybe £5

a day if they're lucky for working full time. That is not an ordinary life. So, 'Not Just the Usual Suspects' that was the report that I wrote right at the end of doing my PHD. The main points in the thesis are that most of the times that policy is made there is public consultation. Welsh government really do want to involve and engage and co-produce but there is this phrase of "it's only the usual suspects who get involved". So, what we were co-designing through the research was a way of involving and engaging people that went beyond the usual suspects. Hence the title, not just the usual suspects. So, the key points are life is not simple, it is not straightforward. It is not something that can be solved by coming up with a wonderful theory of change or a logic model, like a sausage machine where you put this in, stuff happens in the middle, and you can predict that these things will come out the other end – if only life were that simple. If we try to make policy in that way, it's never going to give people an ordinary life.

If we instead think of life more like a web where everything is interwoven, what one person does effects what somebody else does, a bit like billiard balls going off in all different directions where things are constantly changing, you can't pin things down, you certainly can't control things and you can't predict with any accuracy what's going to happen. If you think of life like that you need a totally different approach to policy making. So, in my thesis we came up with a way to think about making policy that stands a better chance of working in real life and a way of listening to and consulting the broadest group of people possible so that all of their knowledge, all of their ways of making sense of the issues, all of their wisdom could all be brought to bear and become part of understanding the problems and then making policies to try and address the problems.

### **Alex Swift**

This is an important thing that you're pointing to because a lot of the things that people presume to be normal like basic social mobility, going out and meeting people, these are not normal for many people., You can see that if you meet people with learning disabilities. What you're arguing is that people with learning disabilities are expected to change themselves to fit in with a model that's not at all built for them whereas what we need to do is change policy and change those elements of society which are preventing people with learning disabilities from leading an ordinary life so they can feel more welcome in their communities and be more involve in policy making and decisions that affect their lives.

## **Anne Collis**

Absolutely. That is 100% what the issue is because now we've got policies that don't work, services that don't work and more profoundly we have attitudes and expectations in wider society that are just so wrong, not just in relation to people with learning disabilities but anybody who doesn't tick the 'normal' box, for whatever reason. There's just this assumption that there are certain things that are normal and if you don't fit that you must get adjusted and changed so that you can use the services that you need and to crack on with life. It sucks, basically. So, the starting point if we're going to change things in Wales is starting to change how we value different people's knowledge, and ways of understanding things so we start to respect that people with learning disabilities can come up with very creative and very feasible solutions and plans and things that they want to do. It's just, people don't take their knowledge seriously.

## **Alex Swift**

And the reason they don't have their knowledge taken seriously as you point to in your report is this phenomenon known as epistemic injustice, which is when experts or leaders treat the views of people whose lives their work really impacts as not to be taken seriously. Can you go into more detail about what's meant by epistemic injustice in the context of what people with learning disabilities experience?

## **Anne Collis**

Well, the term epistemic injustice really goes back to somebody called Miranda Fricker who wrote the first book all about this topic. 'Epistemic' means everything to do with what we know, the language that we've got to be able to talk about and make sense of our experiences and everything about how we make sense of the world and of social issues, so that is all epistemic. Basically, we all get the idea of social justice. Epistemic justice is one bit of that because until we all listen to each other and value each other for the information we've got and how we make sense of the world and what we know, we will never actually get this social justice. So, one of the examples that Miranda used is that sexual harassment had been happening probably since the dawn of time but until somebody came up with the term, women who were experiencing sexual harassment in the workplace didn't have any language, they didn't have a way to communicate it. So, part of epistemic injustice is also not letting people have the language to express what's going on and quite often people with learning disabilities are still being shut out from

really important information, simply because it gets written in very complicated language, in ways that most people would struggle with, but would actually prevent people with learning disabilities from taking control of their own lives because they just can't get the information because people don't realise, can't be bothered, say they can't afford it, all sorts of reasons that are put forward.

It's not just a problem in policy either, it's also a problem in the academic world, so before I could even do any of the research we had to tackle some of this in the academic world to find ways that we could even do research that seemed just and fair and treated peoples knowledge fairly, so there's a whole chunk of the report that deals with some of the methods of 'how do you do research' that is epistemically just, even before you can think about 'how do we make epistemically just policy and services?'.

#### **Alex Swift**

I'm really interested in this point you made about language in that what isn't written and what there aren't words for can't be understood. If, in official policy documents by a government you don't have terms like neurodiversity or autism or learning disability, you're not going to have a very good understanding.

#### **Anne Collis**

It's even more powerful than that because I was talking to a person who was having quite severe mental health challenges. At that point she didn't know she was autistic, but there are those of us who can spot it in other people quite quickly. We can spot kindred spirits. I talked through the idea that everybody is unique – there is a whole diversity of ways of making sense of the world. That's the neurodiversity bit, but that the world is set up as if some ways of thinking are right and anything else is wrong or broken or defective and needs to be fixed whereas, we're fine as we are. We're not broken, we don't need to be fixed, we're just part of the diversity of life. I don't have a learning disability. If you could imagine, someone having to face all of this, all of those challenges and they have a learning disability as well which means that processing information is harder, dealing with language may be harder, it's not surprising that a lot of people with learning disabilities just get so fed up and frustrated with life and find it so impossible to communicate.

**Alex Swift**

Yeah absolutely. You've talked about some of the people you met while you were doing this work. I'm interested to know, how did you as someone who was writing a report for a university, make sure you were including the voices of people with learning disabilities in your work and that you weren't almost subconsciously using epistemic injustice yourself

**Anne Collis**

I think that there are two answers to that. The first one is it was never about 'including' because if I have the right to include somebody, I've also got the right to exclude somebody. So, I found it easier to use the language of co-designing and collaborating and co-working because that just set things up so that we were equals. It was one of the academic challenges was finding a way that we could actually work as equals, rather than me researcher, you participant who has to sign an informed consent set of paperwork. We found a way around it which worked. Basically, by making all of us researchers and participants, so I was probably the first PHD student who had to sign her own informed consent paperwork to take part in my own research, because it was a shared thing.

The other thing that stopped me was that I had a colleague Allen Armstrong, who was another co-founder of Barod and devastatingly, February last year, Allen died. It was a huge loss to Wales and a huge loss to the academic world because Allen had a learning disability and Allen had a very good way of keeping me in check. There were times when I would take liberties, or I would do stuff that it was not my position to do, and he was always gentlemanly about it but I would get the sideways look or the silence when I said something and I'd know that I'd overstepped the mark. We're all going to do it, we will all have biases, we will all forget, and we all need somebody who has the confidence like Allen to just feel comfortable to remind us and give us a poke when we step out of line and take too much upon ourselves that isn't our job to do. I miss Allen very much and I have suffered in my work since from not having him. I still imagine him sitting on my shoulder and just the memory of that makes me hold back.

**Alex Swift**

And you've dedicated your report to Allen as well.

## **Anne Collis**

Yeah, I did. The irony is he died at age 49. He would have been 50 last year, so all the years from 1971 to 2021. That 50 years of policy for an ordinary life. Allen achieved it but he had to fight. It took an extraordinary person to be able to fight and achieve that ordinary life despite all the good policies, and we've really got to change that. As part of Allen's legacy, we need to make sure that you don't have to be as extraordinary as him to get that ordinary life.

## **Alex Swift**

And the thing you've pointed to that was so wonderful about Allen and about this concept of co-production and co-collaboration is that you get this diversity of perspective that can keep you in check and provide these different viewpoints. A lot of boards in companies and cabinets in governments – they don't use diversity of perspective so much as they use diversity of background to check a box. So, they might employ a cabinet that's half male and half female to go "look, we've got gender representation". Whereas you point out how we don't just need that. It's not enough to have a range of different people. You need diversity of opinion and diversity of perspectives. Why is that an important distinction?

## **Anne Collis**

Well, if you go back to something I said at the start about how life is more like this web of interwoven things, the only way in which you will ever get a good handle on any situation is by making sure you've got people who are experiencing things from different parts of that web. So, that's what I mean by difference of perspective. If you take for example a social issue – Climate change, that's kind of a big thing at the moment. If you think you know what climate change is and you know what the problems are and all that you need to do is consult on solutions, you've already lost because it's not that simple, we don't really understand everything.

People across Wales are going to see the problem differently and they're going to see it from very different perspectives. So, if you have a refugee who has come to Wales partly because their country was being destroyed by the impact of climate change, they are going to have a very different perspective on the topic of climate change from somebody who's a farmer whose land is going under water regularly, from the long-distance lorry driver whose livelihood depends on him being able to continue driving. They are going to

make sense of the problem very differently from each other. When I think about diversity of background, it's not just background, its personal characteristics. It's things like protected characteristics in the equality act. One of the problems that you get is that if you have one of the protected characteristics you tend to rise to the top of the heap by learning to make sense of the world as closely as possible to those that are already in the elite make sense of the world. So, you could have a group of people where you have a black man, an Asian woman, a disabled graduate who uses a wheelchair, an older person, a younger person but they've all learned to think in very similar ways and that's how they've got to being high up and getting their voices heard. So, you can have that kind of diversity, which is great, you get visual representation of different people, and you will get different sets of knowledge but what you really need is these different ways of making sense of the world.

If you want to make policies that are going to work in real life, they're going to be used and effect real life people. Real life people have different ways of making sense of the issue. Your policy has to make sense to them and to their life and their world and their way of doing stuff. The only way that you're going to be able to make policy that way is if you have people with a diversity of perspectives. It's not just enough to have a diversity of protected characteristics. That is important, that is essential, that is a great first step but it's not enough.

### **Alex Swift**

Absolutely, I completely agree with you. In this section you also address the question of 'evidence-based policy making'. Now, the term evidence-based on the surface sounds great and it can be great that you're basing policies off real evidence and not just ideology. However, that of course raises the question of who decides what evidence is? and who decides who gets to be an expert?

### **Anne Collis**

You really have read the report haven't you Alex? That is the fundamental question. When academics do work, they have to meet certain standards. Then the work gets published and quite often it sits on a shelf. One of the challenges with policy making is that the evidence isn't going to sit on a shelf – it's going to directly impact people's lives. So, it should be at least as high quality as the evidence that gets published as academic research. So, absolutely it got to be evidence but unfortunately evidence-based policy

making has tended to value certain types of knowledge as if they are gold-standard and you can trust them in a way that you couldn't trust other stuff. Now, quite frankly, I wouldn't trust most consultation responses and I wouldn't call most consultations evidence because it is just the usual suspects who are responding and also because by the time consultations come out publicly, you only really get a chance to respond to what somebody else has decided the problem is and what somebody else thinks the solutions should be.

So, in the brave new world which I really hope may happen we would get this diversity of people. One of the things in the report from my research was looking at an academically robust way of sampling from the population so that you are hearing from people with a diversity of perspectives. I also worked on a method so that people could talk freely on their own terms about the topic, rather than have to answer questions or read reports. I think that evidence-based policy making is really important. I think that policy must be based on evidence. I think that at the moment the problem is that when you read documents about evidence and policy making in Wales they ignore and leave out anything that's to do with actual members of the public having direct involvement in creating that evidence. That's the bit that really needs to be addressed and challenged. We need evidence, but we need a different sort of evidence if we're going to get policies that work.

#### **Alex Swift**

That absolutely makes sense and I completely understand your approach.

#### **Anne Collis**

I'm glad you do because I spend a lot of time feeling very guilty that a lot of myself was the standard, one way, let's get information from people, see how they make sense of an issue and then we'll take away that information and do something with it. I spent a lot of time feeling quite guilty until the people I was working with said that they would never have agreed to get involved in focus groups or co-production or anything because they felt it would be a waste of time. Hopefully in the future they will feel that there is a point in policy making but until that point, we need to hear their voices somehow.



**Alex Swift**

Absolutely. Whether it's in policy making circles or in society at large what are the things we need to change in the short and long term to make for a Welsh society that favours epistemic justice and works to give people with learning disabilities an ordinary life?

**Anne Collis**

I think that we need to begin to interact with each other as unique individuals. I think that as long as we put people in boxes and assume that we know things about that person because of the label that we've given them we're going to be in deep trouble. One of the things that I loved with Barod from the months when we were working out if it was possible was that we weren't willing to accept that this is how things get done. We imagined a new future and we just decided to live that way work that way rather than do things the way that they were supposed to get done and I think that the more people who just work out how they want Wales to be and crack on as if Wales is already like that, the faster we'll get changes because sometimes we can use all of our energy trying to fight against stuff and there are times when we really do have to do it but there's also times when it is so important to just be a bit minded and know where we want to be and just try to act as if we're already there.

**Alex Swift**

So almost pushing against the tyrannical concept of normal and building a new way of doing things in the shell of the old?

**Anne Collis**

Yes, because on paper a social enterprise set up and run by a mix of people with and without learning disabilities without core grant funding, without contracts and without anything really. It just should not exist and we're now looking, eight years later that Barod has got six figure turnovers and loads of people working for Barod, but in order to get there we had to act as if what we were doing was normal and every day. The things that we need to see change in the short term are those us who get it to start to just act as if the future is already here, interact with people as unique individuals, expect people with learning disabilities to have an ordinary life and be surprised, shocked and horrified every time you meet somebody who doesn't have what society might consider an ordinary life rather than just take it for granted, so that's in the short term. In the long term, we need to

change how we make policy, not just in the making of the policy but also in understanding what the issues are that require a policy intervention. People need to be at the heart of it, people who've got all the different kinds of knowledge need to be able to be brought together in a way that their knowledge can be combined to come up with a solution.