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SPEAKERS
Madge Kaplan, Paul Batalden, Fiona Jones

Madge Kaplan 00:00
Welcome to the Power of Coproduction, a podcast series that explores the lived experiences of patients and professionals who are redesigning healthcare service to achieve better health through mutual respect, collaboration and science informed practices. Your host and guide is Paul Batalden, Professor Emeritus of the Dartmouth Institute for Health Policy and Clinical Practice and Guest Professor Jönköping Academy. The Power of Coproduction is produced in partnership with the International Coproduction of Health Network (ICoHN), the Dartmouth Institute, Jönköping Academy and the Health Assessment Lab. On Episode Four, “Allow me to empower you–the wisdom of self care,” Paul is joined by Fiona Jones, who tells us about a program in the UK that helps health professionals deepen their ability to support self-care. Here's Paul,

Paul Batalden 00:57
Welcome. Our guest today is Fiona Jones. She comes to us from the UK where she works in Bridges Self Management, and Kingston and St. George's University. She has spent two decades studying and trying innovative approaches to fit the needs of each person who is sometimes known as a patient with services that might help them. Several years ago, she led the formation and development of Bridges. Thank you for taking your time to be with us today, Fiona. So tell us how you describe what Bridges is.

Fiona Jones 01:39
Thank you very much, Paul, and thank you for that introduction. It's not an easy concept to explain. So I'm going to start with where we're at, at the moment, because Bridges has been developing for a number of years. And I think although it started off as an intervention that was about an approach, a way of working, I think how we describe it now is, it's more of a way of being. And what do I mean by that? A way of being is about the quality of the interactions that happen between patients, families, and healthcare practitioners. And it's easy for us to say, we want good quality interactions. But within Bridges, what we do is we really encourage people to reflect on the language that they're using, and how that language allows space and opportunity for patients to move into and to share their ideas, their strategies, problem solving, their goals. And through that approach, it can happen in one interaction, or ideally, it happens in every interaction. What we hope is and what we look for is that patients gain more confidence, knowledge, and skills in terms of their condition. And it's really moving away from being in a position where we're imparting information, you know, we're teaching, or we're managing

somebody's condition, their health care, to being more of a coach, you know, we're working in a reciprocal relationship.

Now, how we think about Bridges is it's not just about that one interaction. But it's also about when you get lots of people working in this way, you start to build capacity within your team. So it's not only how you interact with patients, it's also about how you interact with each other, as well. And so, using open questioning, being curious, creative, and not sticking to doctrines in terms of your care, but really seeing that person in front of you, and being interested in them from the start. And really looking at what the possibilities are with everybody that you work with. It's hard to describe because it's not, you know, a tick list of techniques. It's more of a way of being, which is why we describe it in that way.

Paul Batalden 03:58
Fascinating. So how did it get started?

Fiona Jones 04:02
It’s interesting because reflecting back on how I first started with Bridges, it does come back to my clinical background as a physiotherapist. I trained in physiotherapy a number of years ago, and I was always really interested in people that had some of the most profound complex conditions like stroke and brain injury, motor neurone disease, Parkinson's, multiple sclerosis. And I found that people in my profession at that time were very, very focused on their own technical skills. So it really felt to me as if it was a “you-were-doing-to-somebody.” And I think I was probably always around people that encouraged me to question and I think that I started to question well, why did we presume that we know the answers? Why do we presume that we're the experts in the relationship? And when we're thinking about 30 years ago, when I first had some of these ideas, it was very, very much a directive didactic approach to care. And this was really about questioning, I guess, from my own perspective within my profession. But there was a light bulb moment, Paul, and it was really when I moved from a very structured environment of hospital into working with people in their homes, and I started to hear ideas, creativity from people who were finding ways around things, you know they weren't hanging on my every word. They weren't waiting for me to lay hands on them. But actually, they were coming up with their own ideas. And I just felt well, what if we combine forces, you know, I have some ideas, you have some ideas, that if we try to switch things, so that we're learning from patients and families, and we're building that in, I mean, I just remember many, many patients that described all sorts of creative ways that they managed, you know, in their wheelchair, doing their washing, getting up the stairs. And the other thing, just to add a little bit more insight to that, was that when we think about goals, and what the goal of rehabilitation is, often we're thinking of it from our own perspective. And I don't think we ever really asked at that point, what's most important to you? And it was incredible; when you started to ask that question, people, first of all, weren't used to being asked that question. But gradually, they were coming up with some really great ideas, and also admitting that some of the goals that we had identified 2 Transcribed by https://otter.aiweren't that important to them. Anyway, there's such a lot in that because it's also about being much more efficient, and much more powerful with your interactions and the time that you have. It’s that you utilize that time <that you have.> And it's oriented around what's

important to the person. And I think that the other thing, just to add to that, is how we use storytelling, and how critical storytelling is within our services now, so we always encourage teams to work in a way where they share stories, critical bits of information about patients, not just if their arm is paralyzed, or they can stand for 10 seconds…it's about what sort of person were they? What did they enjoy? What did they like doing? And through that, you start to understand what motivates people as well,

Paul Batalden 07:20
Such fundamental insight into the coproduction of health service. As you think, in the concrete lives and ways that these people have helped you and brought these things into reality, is there a person or an example that comes to mind that makes it vivid for you, and that you frequently find helpful?

Fiona Jones 07:47
Absolutely. And it's actually hard. We have so many examples, but I like to always begin thinking about the person that most inspired me. And that was somebody called Eileen, that had multiple strokes. She happened to be the same age as me. So I think her situation just resonated with me so much. And I just felt that lovely phrase, “If not, now, when?” You know, when are we going to actually start to work differently, because I found that she was coaching me most of the time. And she began to be somebody that was coaching me through thinking about my research ideas. I would share ideas with her and when I set up Bridges, she was one of our original advisors. And I got such inspiration from her because she'd had multiple strokes. And it was as if these, just these most incredible words of wisdom came out of her mouth, they just used to fall out and they were absolute gems. One of the things that she told us was when she had a stroke, and she had another setback, what she did was she went back to a place where she felt comfortable. So what felt easy, that she could regain her confidence doing, and then she started moving forward. That's such a simple concept. But it's so beautiful in terms of what that means, because it's not setting yourself up for failure. But coming back to a place where you feel comfortable to start to build your confidence again. And when we've done our research, we always think about what's our theory of change. And we do refer a lot to self efficacy and the idea of having that belief in your own capability, but it's really how is that going to happen? And what Eileen was describing was building her self efficacy again, in practice. I do still think now what would she have said, what she would have done in this situation.

I remember one story when I was setting Bridges up and we had multiple events, and we were doing lots of work, it all seemed to be colliding. And she said to me, Fiona, what's your first step? What's the first thing you need to be thinking of? <As Fiona reflected, she thought,> Eileen, you're doing Bridges <our methods> on me. So she got me to reflect, she got me to think about what were my priorities, and I think this is where you know, if we work with patients in this way, we can build such fantastic relationships with people.

Paul Batalden 09:59
What an amazing story! My sense is that she was inviting you to what Ed Deming used to remind me about, he said, “Focus on the “zeroeth order.” Now he was a statistician. So X to the

zero power is always one. And that it's always sort of starting at the very beginning step. And that's what she was doing in this beautiful story. You obviously work with many places, and settings and people in those settings. But if I were to walk into a setting, and it was working in the ways that you offer and teach, what might I see?

Fiona Jones 10:37
There's a couple of examples that come to mind here. It could be how we're hearing colleagues talk to each other. And I think it's also about the language that we see in its written form as well, in terms of the processes. So my work is in rehabilitation, and we're very focused on outcome measures, assessment tools, getting those baseline measures, and actually a lot of that we questioned.

So, Bridges teams question, “Why are we doing it? Who is it for?” And you might look at the paperwork and see a question like, “What are your hopes and fears?” So you're sharing information between each other about patients’ hopes and fears, or you're finding out about a person's day, and what's important to them, rather than coming at it from the point of view of the deficits, what's wrong.

Teams are trying to really refocus on the individual in the language that they use. And I think what we hear about is how this way of talking, <using language much more carefully has helped us realize that> actually teams are really quite open now to thinking critically about their communication. And recognizing when they do goal setting, they can often go in with their own preconceived ideas. But there's a step back from that. So we would hear a different language, I think, Paul, we would hear less directive language, and a lot more questions that start with “what” or “how”. We always encourage people to not just listen, or as a really dear colleague of mine always says, but “super listen”. So you really have your antenna out for all the really important things that people are telling you. So the interaction that you might hear might be less of the professional talking at, rather than creating space and time for people to move into.

I mean, if I might just give you one example here with paediatric service, that we hadn't really done much work in paediatrics. And I met somebody who was leading the paediatric team who came on some workshops that we did for adult services. And she said, “Could this work in our paediatric setting, because our caseload is growing and growing and growing, the staff are feeling really overwhelmed with the level of work?” And so we worked with the parents, the children, and the staff, and we co-designed the workshops, and what the learning should look like for them. To cut a long story short, what they did was things like they got rid of a lot of their assessment tools. They found that when they really asked families what was important to them, actually, there were things that they hadn't shared with the therapy team at all; they felt very much that they were just being guided and told what to do. And the thing that was most revealing <that they told us about> was that when they mapped out a day, (and these were parents that were struggling with not just one child, but they would have had many children, may have had more than one with a disability and they were trying to get on with their normal day, as well as be a therapist), there actually wasn't time to fit in the therapy. There just wasn't that time in the day. So seeing it laid out together, you know, they problem-solved it together. How is this

going to happen? How can we use the bath time? Or how when you're walking back with Granny from the school, could you go into the playground and do something that would be therapeutic? So it opens up their eyes: < and made them wonder,> Is there was another way of working with parents and children?

Paul Batalden 14:14
I'm reminded as you tell that story about a senior evaluation researcher who once was talking to a group of junior evaluators and said, “You know, sometimes you just have to show up (as a person) and drop your tools.” I think that that was such a succinct way to sort of invite people into the authenticity of the relationship, which is exactly what you've done so beautifully. And I think they were so open, and they were ready for change.

Fiona Jones 14:41
So this was a service that felt they couldn't see their way through in terms of how they could make their work more enjoyable and the waiting times and the case loads dropped. And actually they enjoyed their work more as well because they had a different relationship with the parents and the children. And they felt as if they were always fighting against, you know, trying to get parents on board with things, you know. And that's exhausting for both sides.

Paul Batalden 15:11
So, if we imagine a room full of people who have had the chance to reflect on these things and practice them, and so on, and then some new people came into the room who hadn't had that experience. And so the new person was listening, overhearing the conversations, that one person who had had this practice in this teaching in these experiences, was now talking to another person about it. And the new person asked, “So can you tell me about the changes that you've made in your work? I hear you talking to each other about things, but how do you talk about what changes you've made in your work?”

Fiona Jones 15:51
I think it's really interesting, because I think one of the phrases that professionals often use, practitioners often use, is that we're doing less fixing, and sorting for people. So we're working much more closely with patients and families as a better quality relationship. But also we're getting a greater understanding, if you'd like. There's consistency then. I mean, the ideal thing is, in the, you know, Bridges approach, we do this through, (we're a little bit against the word training,) it's more of a, we're coaching. And we're advising and we're supporting, we're going alongside these teams. So we've seen these teams over a number of months to work with them. And of course, the other thing, Paul, is that all of our delivery is done together with people that have lived experience of health conditions. So they're hearing very powerful stories. (And I think that we're not discounting the evidence based research.)

Everything else that actually the evidence is, is that when people work in this way, hopefully, they're going to see that patients are more engaged, and they gain confidence quicker in the interaction. I think it's actually what people describe; it can be quite cathartic. So it sort of feels like I don't have to fix everything. And there was an example of a team that was working with

people with chronic pain. And they would have everybody coming in week after week to sort of talk through how they were doing, it was a group-based approach. And both the physiotherapist and the OT admitted to us, they just dreaded it, because people will come in and they would feel that burden of trying to fix the problems because people came in and it was like people sort of sunk down into a feeling of despair. But actually, by changing their language, how they started off the session, they started off by saying, “What's one small thing that you've managed to do this week compared to last week? Who can start us off?” I remember her describe it, it was like a ripple effect. And then other people said, “Oh, I haven't thought about that. I might try that.” And then other people would then come back, “So, I tried that.” And they said, I mean, she was, she literally was in tears telling us about the impact that this had: to sort of walk away from that group and not feel like, for the rest of her day, like she should have done more. And what could she do for these people? She was actually sort of relinquished of that feeling that she had to come up with the answers for everybody as well.

Paul Batalden 18:16
Just a perfect illustration of what it means to enable, to enable to give someone the ability, perfect. I'm really attracted to what you're saying. But doesn't this take too much time?

Fiona Jones 18:29
Yeah, it’s a question that people ask. We did a project, we were funded to look at how we could codesign this approach for people with acute brain injury. I think if we could have picked a more challenging setting, we couldn't have done <so>, because we were trying to go into acute neuroscience environments with people with brain injury and <where> everybody always says, Yeah, but this works with people that are really motivated, and this works with people that are health literate, or people that have good cognition. It doesn't work with this patient, it doesn't work with that patient.

So, we've got groups of people with brain injury to codesign the resources that we used in the training for professionals. And then we also provided lots of films of them talking about how it felt when practitioners worked in this way. And the small things, the small changes that practitioners could do in their everyday interactions, that would make a huge impact on them. And of course, the other thing is that if somebody is early after brain injury, it's not just about the person with brain injury, it's about their family as well. So it's also about how we work with families and friends and supporters. So I think that you're thinking about it taking more time. That's always where I think that's the environment where people said it couldn't work. We haven't got the time. It's a fast moving environment. These people are in and out. If they can walk, they can go home. I told you the best example I saw was with a neuroscience nurse that I'm still in contact with now. She was one of the busiest people in this neuroscience unit. But she built this way of working into everything that she did. And it became her way of being. And she would zip about all over the place, seeing all these patients that she would have remembered small things that they ever said that were important to them, encourage them to write things down. She would have worked with family, you know, so she just had a way of being out. We always felt that we needed to clone her because she just got this approach really well.

Paul Batalden 20:27
I am reminded, as you tell that story of a story in Norway, where a group of neurosurgeons got very interested in the problem that patients with brain tumors didn't know who was in charge of their care. And so they decided to put pictures on their business cards that would allow people to sort of recognize the person who was in charge of their care. And I thought to myself, my God, they're working with people with brain tumors, for crying out loud, and people who've had brain surgery. And it transformed the way they worked, because they now were identified to people as people. And people could in fact benefit from that just exactly the way this nurse that you describe.

And I think it's…what we see a lot is it's actually about, like I say, about a way of being, but it's also being very open, that it's not the patient's fault if they're not engaging, you know. So it's actually about how I can create opportunities in this space for people. So we tend to think of self management support as being this continuum…and if the very least that you do is you ask somebody what do they love, and what's most important to them? And if that's all, then that's the start point, because it helps you understand what motivates that person.

And just coming back to the question that you asked about, doesn't this take more time? What we find is, like I said, with that paediatric team, actually, it can save time. You know, that one of the best things that a professional told me about was when patients said to her, “When are you “locked off? You know, when are you gonna finish? Because I don't need rehab anymore. You know, I think I'm all right.” And they were hanging onto this patient thinking we could just work on this, we could just work on that. And actually, he was getting on with his life again, you know, and I think the thing is that sometimes we impose our ideals and our ideas on people, our sort of plans on people rather than checking in. I had an example today, when I was working with a team, where somebody said, “How much do you really want to do this?” You know, that he said this about a goal. And he said, “Not really, I don't think I really said.” “Should we not do it then?” he said. “That's fine by me if it's alright with you,” he said. “Well, let's work on the things that are important to you.” And I just thought that's such a lovely just checking in, you know, sometimes patients just assume that they can't just say what they really, really want to do.

Paul Batalden 22:52
So with all of these experiences, you must periodically go for a walk and reflect on this time that you've had and the experiences you've had and as you think about that, what is it that actually brings you joy?

Fiona Jones 23:06
I tend to really focus on the small things that give joy. So it's those incidental conversations that people tell me about…that I think, yes, people have that epiphany where they suddenly realize…and we had a lovely example of somebody saying that they were struggling at work, feeling overwhelmed…and a colleague just sat alongside them and tried to get them to think about what was going on. At the end of the discussion, or the end of her listening, just said, “What's one small thing that you could do?” And then she turned to a colleague and said,

“You've just “Bridged” me.” And I just thought, that's just wonderful, because it's also people starting to share things that they're doing in their own lives as well and helping each other. For me, it's those small things. It's a very flexible, creative approach…Bridges. And the more that we can have these little gems of examples, the more that people can start to get a sense of what it's about. The other thing that really brings me a lot of satisfaction is how open and honest and trusting professionals are when they work in this way. It's those professionals that aren't afraid to say, “Actually I've realized I've been controlling everything, and I need to take a step back.” It, you know, can be very experienced practitioners that are showing that humility. I think that's the thing that brings me joy.

Paul Batalden 24:31 Wow. Well, thank you very much, Fiona.

Fiona Jones 24:34
Thank you, Paul. Thank you for inviting me.

Paul Batalden 24:41
In the coproduction of healthcare service, a patient-person's health is not really “outsource-able” to another person. And while self ownership of health can take many forms, self care is key to the health of any human being. A professional-person can support that self care in many ways.

By creating a safe trusting setting, professional-persons may gain insight into potential vulnerabilities, as well as potential resources that are accessible and available to the patient-person. Use of language that invites rather than puts off contributes to the creation of that safe space.

Professional-persons may also gain insight into the patient-person's desire for learning, matching that desire with methods that fit a given patient-person's preferred learning style. Specifically, professional-persons can summarize useful information from the relevant scientific literature, or their own prior experience with the disease or condition or the illness that the disease creates, as well as the services that others have found to reduce the burdens of disease, illness and treatment. They can also help create shared goals, designs for self care, and identify and offer orientation to the technologies that can be helpful.

Coproduction experienced persons have to be careful not to objectify their knowledge and get carried away. The objectification of knowledge invites runaway categorization and schemes of classification that just add to the frenzy, reinforcing the common perception that there just isn't adequate time and daily work to use and apply all this knowledge.

Inviting clarity, and a shared focus with questions such as “What matters to you?” can be helpful in diminishing time spent on potentially less important areas.

Madge Kaplan 26:59
Thank you for listening to Episode Four of the podcast series, The Power of Coproduction with Paul Batalden. On Episode Five, Paul, will be joined by Sonja Batalden and Diane Banico.

They'll discuss the Diva Mom's program in Minnesota that's using coproduction principles to address historic racial inequities. All podcasts in the series, including an overview of coproduction are available at ICoHN.org/podcasts. The website is where you'll find supplementary materials, guest bios and brief profiles of the production team. You can subscribe to the podcast series wherever you get your podcasts. Thanks for listening.