

E07-The-web-i-tend

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SPEAKERS

Madge Kaplan, Paul Batalden, Cristin Lind

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 a Guest Professor at 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 Seven, "The Web I Tend," Cristin Lind joins Paul to discuss the interconnected daily experiences of long-term conditions that coproduction must address and help. Here's Paul,

Paul Batalden 00:56

Welcome. We continue our exploration of various ways that empirical knowledge building and thinking informs the everyday practices of the coproduction of healthcare service. Cristin Lind has led the development of knowledge about living with the condition her son, Gabe, has. She developed tools for her own insight, and has shared them with countless others who have benefited from her insights. Thank you for being with us. And welcome, Cristin.

Cristin Lind 01:32

Thank you. It's a real pleasure to be here.

Paul Batalden 01:34

Is there a story that helps us understand how you approach this challenge of understanding the practical realities of living with a long-term condition?

Cristin Lind 01:47

I think that a good story to share is maybe about the first time that I was asked that same question. Ten years ago, back in 2011, I was asked by a group of primary care physicians to come and speak with them about what it's like to be the parent of a child with complex healthcare needs. And as I was

preparing to speak with them, I was really thinking a lot about how I could share those practical realities, as you say, of the health care appointments, the hospital stays, home visits, you know, a very long journey to finding a diagnosis, the struggles to find resources that our son needed to thrive. And I was really struggling to do that in a way that kept Gabriel a person for them, you know, not a diagnosis, not a list of symptoms and services. And that kept our family honest, kept the picture that I was portraying our family to be, honest, that we were sometimes resourceful, sometimes struggling, and you know, thinking about how to share the fear, and the love that I carried with me almost all the time. I'm kind of a visual person. So, I often use Mind Maps as a way to organize my thoughts in preparation for a task like this. So, you know, I pulled out some blank pieces of paper and colored pens and sat down at my kitchen table. And instead of mapping out, you know, the structure of a talk of what I might say, this time, I started by just simply writing the letter G, in the middle of the piece of paper, and circling it to represent Gabriel. And in a circle around that G, I made a bigger circle, and I wrote our family to represent me and my husband. And from those two circles in the middle, I began to draw a Mind Map out from that center, which I guess would maybe be called our system of care, different domains, different areas of support, starting with healthcare, you know, that came to mind first, because I was speaking with healthcare, and drawing out not just primary care docs, but the specialists, the medical secretaries who helped us with scheduling and paperwork, the insurance company, the suppliers of medical equipment, and they're even the drivers who, you know, we had relationships with. I drew out school, not just the teachers, but the assistants, the physical and occupational and speech therapists, the special ed gatekeepers, the school nurse, the bus drivers, and, you know, recreation, community services, both organized and informal, inclusive and adaptive programs, personal care attendants and the Department of Public Health Services. From there, you know, it didn't feel complete without adding pieces of information about advocacy and leadership and places where I was going to grow myself and my own capacity to lead and find and navigate in this system. And then of course, there was the natural support, you know, this, the supportive family, friends, neighbors, support groups, therapists, support for our other child. And when I was done with this, and I filled the entire sheet of paper, what was there was about 70 bubbles on this mind map. Seventy people, organizations, agencies and partners, who helped to support Gabriel to be healthy, and to learn and to live with dignity. And when I put the pens down, at the end of that exercise, I knew that in my gut, I had, you know, found a way to communicate something in a few square inches, that would probably take me hours of stories to tell.

Paul Batalden 06:08

Wow, as you did this, what surprised you?

Cristin Lind 06:13

Well, a lot, actually. I think that my first reaction was just kind of awe at the complexity...and the challenge. I think that for me, it was almost as though I was seeing myself clearly, for the first time, myself in this role as parent of this level of complexity, of really seeing it. And, you know, what had been kind of a, just a messy knot of information and details and people who we had encountered over the past 10 years, it suddenly became, instead of just a knot, it was like a web. I began to be able to make sense of you know, why things were the way they were, I could see strengths. That surprised me for sure. Because I often didn't feel strong, you know; I felt like I was for the most part struggling or, you know, embarrassed that I was struggling. But I could suddenly see things that were working, I could see problems that we had solved, doors that we had opened, I could see imbalance. People will have the

chance to look at this care map, this mind map, if they want to. They can see for themselves that the part of the map that represents healthcare is awfully big in comparison to the part of the care map that represents recreation and community. While I don't think that any of these bubbles are proportionate in that way, it got me thinking about, you know, what is Gabe's life like? What does he experience all these people to be? What roles do they play in his life? And I think that I also could see, after thinking about the strengths that we had, I also thought a lot about other families. I worried about them and wondered what it was like for families who didn't necessarily have the strengths or the resources that we had. And I think that, you know, if I'm honest, I really wondered about Gabe's future. And who would be there to do this for him, if I ever couldn't?

Paul Batalden 08:19

It's amazing to me that this characterization, or this making visible what is usually invisible, has these various kinds of encouragements and so on. As you raise the question for yourself, I wondered about the recreation, or the kind of sources of joy that Gabrielle was experiencing. When I showed this picture of the map that you made and put on public view, it immediately caused the person to say, "Oh, and in this other family, the parent has come to an understanding about the things that give joy to her child. And here's what they do." So what happens in the picture that you've made is you allow people to see the lives and the experiences of others. And I'm sure that now that you've shown this map to many, many, many other people, and you've gotten feedback from them, you've seen how this process of mapping, not just the making of the map, but the process of making of the map has actually been a helpful process. Is that right? Have I got that right?

Cristin Lind 09:47

If I look back on all of the assessments and assessment tools that we've used over the years, you know that the questions that we've been asked, they've been helpful, and they've played their role and they've mostly always been evidence based and by well meaning people. But I think that what this map did for me was to create a way to begin having conversations that I wasn't having before: conversations with myself, conversations with my partner, with my parents, with my friends. And so when I think about the practical reality that you asked about, opening this conversation, I think that that's probably for me, what has become a question, that's really calling me. It's really calling me to do this work—to help make visible some of these issues that don't show up on those instruments.

Paul Batalden 10:45

It seems to me that what you've done is a little bit like what Parker Palmer talks about when he says that good teachers create space within an idea. And they set some boundaries on the space of inquiry. And they offer some hospitality to those who are engaged in the exploration of that space. And what you've done, it seems to me, is to open a frame that invites people to an insight of the reality of the whole of living with a significant life-altering condition. It's only a part, even though it's quite complex, but it invites people into that way of thinking about the situation. And so you've grounded it in the lived realities of the family involved, and you've welcomed others to try it. And so this, to me, is the sign of a master teacher. So thank you for that. And thank you for helping me understand this, and so many others. I'm reminded as well of the observation that Dwight Eisenhower, when he was the commanding general of the European forces for the US, said about planning and plans. And he said, "Plans are worthless. Planning is essential." And the map is only part of the issue here; the process of making the

map and having an interaction with the mapping of the map is actually the thing that offers this additional insight, as you were saying, and I'm sure that must be the case for others, as they have done the same.

Cristin Lind 12:23

Thank you for your kind comments. And I think that if this has awakened in you memories of Parker Palmer and Eisenhower, that feels really good to me. So I like that idea that it's the planning that's important. And what I think as well, is, it's the reflection that's important. Equally important, as planning is to pause and listen in: "How did that go? How is this going?" I don't know that I was making a lot of space for that in my life. And so this became one of the first places for me to kind of stop and just pause and reflect on where we were, what we had built, and where we might be going. And as you say, it's just a partial view of this, of course. It's, you know, a static picture from one day. And as soon as I finished it, it was out of date. But it gave a window for me. And that wasn't the window I planned, you know; it was something I thought I made to share, to be seen by other people, to share myself with other people. But I think that what I got out of it most was that I could see myself.

Paul Batalden 13:39

Your characterization of this as a web, rather than as some kind of a fixed wiring diagram, I think is a very helpful frame. Because anybody who has looked at a spider's web in a breeze or after a rain knows that the web itself is in motion, or is very dynamic, and it's stretching, it's moving and adapting in some way to the forces that are there. Just like what you just said about the nature of a picture once the picture is there. It's out of date. And so then the challenge becomes this insight into how the realities of living with a condition, the burdens of an illness or the burdens of a treatment, all those burdens, in fact, jump out at you, can change as you represent them, and as you try to find a way to fit them into the web.

Cristin Lind 14:36

Well, it's interesting that you caught on that word web because when I made this, our family was living in Boston, and we now live in Stockholm in Sweden. And when we first moved to Sweden, there is this idea of being the spider in the web of a person's healthcare. And I think in those first few months when we arrived, there were three different healthcare professionals who told me that they would be the spider in Gabriel's healthcare web. And, you know, we know that with spiders, like, there's never more than one spider on the web, right? And what surprised me about that was my own insight that I didn't want anybody else to be the spider. I wanted to be the spider. You know, I think that also raises questions of like, "What would it mean to make this experience better? What would be helpful for me or for other people?" You know, you spoke to that already a bit in this idea of the burden of treatment, or the burden of caregiving. I think, for a lot of families, it's just the sheer magnitude of paperwork and bureaucracy and scheduling and rescheduling and informing and things like that. So what I saw when they said that "I'll be the spider in your web" was kind of like, okay, I appreciate the offer. But you know, how do you let people know that you want to, and I think we need to be the spider in our own web. And even now, you know, Gabriel has some really significant challenges. But our role now is to help him become the spider in his web, to the greatest degree possible for him, and that our role at least is to allow his values and what's important to him to inform all of the choices that we make on his behalf.

Paul Batalden 16:27

So this business of support and supporting and getting support and giving support and so on, also opens up this question about the differences that people have with respect to their resources or their access to resources or the entitlements that they have. And so as you've had a chance to talk about this with others, this issue of the differences and the inequities that exist as people tried to flourish in the face of conditions, some kind or another, how has all that gone? I mean, I'm curious. We're struggling, it seems to me on a worldwide basis, to deal with this growing recognition of these inequities, in part made more visible by COVID, but also just a general awareness I think in the world right now, about the challenge of dealing with these inequities. How have your conversations gone with people around these phenomena, as they have begun to see differences in how their mapping has gone? And what it has revealed? For them? And for you?

Cristin Lind 17:34

Well, I think that's a really good question and an important area for all of us to think about. You know, there's a paradox here for me, which is, I can feel kind of vulnerable in society, you know, in a society that's created for and by normative people, neurotypical people, people who function in a certain way. And I think that the earlier part of Gabe's years, I really was focusing on that vulnerability. With time, it's become clear to me that there are lots of different ways to be vulnerable. And I'm not vulnerable in all the ways that other people are. And I think that my experience of spending time in the disability community has not broken me, but has broken my heart open to what it means to be vulnerable in lots of different ways. There's a saying in Swedish, "man måste må bra för att vara sjuk", "you have to be well to be sick", kind of pointing to this. You know, the idea that the system asks so much of us to live with a chronic illness, you have to actually have some amount of capacity and strength. I think we're just beginning to understand what the system is asking of us, how we're communicating with people, so they don't have to find their way to the right resources, we have a really long way to go. And I think that as for me, in my role as a patient and family advocate, I think what that also has meant is leaving more space for other voices and understanding that, as much as my voice is maybe different from a healthcare professional's voice, it's not representative of everyone's experience, and that we need a lot more voices to be part of this conversation, and that it's my responsibility to make sure that those voices are heard.

Paul Batalden 19:33

You must have also had some reactions from people against this process and the examples that you've shared or that have arisen out of maybe their discomfort with what you have shared with them. Do any come to mind?

Cristin Lind 19:50

I don't think that I've had negative response to making a mind map, that everyone seems fine with. I think about in my own work in healthcare improvement, advocating for the inclusion of Patient and Family perspectives, you know, as we innovate and improve our systems of care, the negative feedback, that probably won't surprise you, is, you know, this costs too much. And we don't have enough time, you know. This type of caring, and these types of conversations are just too time consuming, and we can't afford them. And I respect the people I work with enough to know that if they say that's so, that's their experience, there's some truth there. But I've also heard from enough

professionals at this point, who said that we can't afford not to have these kinds of conversations. That the sort of revolving door of band aids and just patching people up, even with multiple chronic conditions, the unintended consequences, that looking at people as parts, is just something we also can't afford. And we don't have time for (it) anymore. And so I think that what it comes back to for me is, I always try to be respectful of the people I'm working with. I know that even before COVID, most of the people I worked with were working really hard and really fast, and with not a lot of resources. So I won't deny them that. But for myself, as a mother, that things are not going to change significantly for me when Gabe turns 20, or 25, or 30. I don't have a list of measures or outcomes that I can check off at the end of the day. You know, for me, I think it's going back to Parker Palmer; it's about what he might call faithfulness, instead of efficiency. And I think that healthcare has some values that it wants to be faithful to, as well, to see people as whole, even if they're sick, which you've alluded to, as well. I've noticed that you know, the word, *heal*, and *whole*, and even the word *holy*, share the same root. And I don't know how else we can be faithful to healing without being faithful to the whole person and the whole family.

Paul Batalden 22:22

What you have just spoken about is such a powerful characterization of the challenges today in healthcare service and healthcare activities, because there's this mix of these activities, some of which seem like a product or an object. And then there's this other activity, which is much more like an interaction based on a relationship and action—a service. That is a different logic that's involved in the two different kinds of human work. And part of me says that we have to keep asking the question about well, is this mainly like a product or an object that we're engaged in making? Or is this more like a service that we're cocreating or coproducing in some way?

And so, it's getting that right, and staying open to the question, as we together deal with the challenges that we face that are really at the heart of I think this knowledge of the lived reality of the person and the family around that person with a condition that you have so elegantly opened up.

(And) I'm curious, as you reflect on this, there must have been people along the way here who have tried to take this idea of a map or process of mapping, which is so generative, and so helpful, and so inviting, and to use it in ways that are different than your experience or the way you might have intended. How do you help people sort of re-center or re-focus in a way that gets at what you think some of the real powerful insights are that have been true for you and for others?

Cristin Lind 24:12

I'm frequently approached both by people who are interested in using the image that I've created in order to support a particular argument or perspective in a paper or a lecture. And I'm also approached by developers who would love to turn this into an app or some sort of technical solution, technology platform, connected to electronic medical records—something that's dynamic and that can easily be built. First thing I have to remind myself and remind everyone all the time is I did not invent mind mapping. There have been plenty of people who've tried to depict the complexity of healthcare before me so if they want to do it, you know, if they want to create their own, go for it. I think that for the people who are wanting to use this image to support their argument, I often, I take the time to try to understand what that argument is. I feel like as Gabriel's caregiver, it's my responsibility to use his story in ways

that make sense for him and his life and his experience. And so that's, you know, my responsibility to do that. I always encourage them to find someone for whom they can encourage to make their own and to watch that person go through that process. Or maybe it's even them. It's so much more powerful when you have your own experience of trying to map out who are the people who care about me, who love me, who I rely on, and who want me to be my best self. I think we all could do a little bit, we could also all benefit from reflecting on that. And then as far as the app developers go, you know, there are things in the works. And it's easy to be, you know, protective of the idea. But at the same time, I'm also a person that uses you know; I need the electronic medical record systems to work well. So if there's something here that people find helpful, that's fine.

You know, what often takes a longer conversation are the folks who can see the potential of value for this kind of like sense making activity for patients and families, and so their instinct is to say, "Can you teach me how to do this so that I can do it for my patients and their families?" And there's something about the power of the person who holds the pen that is really, it's so important, whether that's literally or figuratively. I've had so many folks send me their own versions of their care map, and I'll be honest, sometimes I don't understand them. I don't know how they've put them together. I don't understand the relationships, I don't understand why they've grouped those people together with those people. And yet, it's like, great, if that's how you're seeing it right now, and that's how you need to see it, or drawing that out that way is going to spark a conversation with someone close to you, or who's on that map. If it's something that's going to help you make more sense of your day today, then who am I to say that you should be doing this in some other way. So I love it when people share their own care maps. And so if anybody's listening, and has their own to share, please, please share them. That makes me feel so happy and so much less alone, which I think is also something that's been important about this.

Paul Batalden 27:41

Well, I think you've helped us gain insight into why it's so hard for a spider to outsource "spidership" for the web that that particular spider is dealing with. It's been such a privilege to take this time to be together and to have this conversation, Cristin. So thank you for that and I appreciate so much your insights and the way that we can hopefully open them for others. Thanks.

Cristin Lind

Thank you.

Paul Batalden

When you're living with a medical condition, or dealing with the impact of a disease, the knowledge that you need is like a room which may be entered through different doors. For some, it begins with understanding the experiences of others, such as the historical sequence or contributory factors and commonly experienced outcome that have led to the situation they are experiencing with their condition or illness. For others, it begins by literally mapping in some sort of graphic display the web of connected factors, people and places; some people prefer to start with an assessment of the situation they're facing. Still others need to first take stock of the resources readily available to them. These different forms of inquiry all share an invitation to gain perspective on the situation that is being faced. With that perspective comes additional invitations for further clarification, for further reflection and sense making, and for further community and partnership building as the individual finds others willing to be helpful.

In my conversation with Cristin Lind, she made the fascinating observation that it's important to decide how many and which spiders should be involved in managing a given web. The suggestion by well meaning professionals that they were willing to be the spider for her web made Cristin realize that she didn't want to outsource the role that she and her son played in managing his condition and their experience of any threats to his ability to flourish.

After all, it is difficult to outsource the full ownership of your health, even to well meaning others for long; it's the process of mapping, not the map, she said. Her observation came in response to the provocation, "Tell us what it's like to be the mother of...." And as she thought about that invitation, Cristin saw herself more clearly, the connections at work more clearly, her own strengths and struggles more clearly. And all of this enabled new curiosities, and the possibility of new conversations with herself, or partner or family, her friends, and many others. So in very real ways, the process and the map are dynamic, always changing.

Other lessons that we can take away from Cristin include the importance of honoring paradoxical thinking. Some might say, as they do in Sweden, "You have to be well to be sick." Or others might say this information gathering costs too much, while still others would say we can't afford not to do it. Some may say my primary concern is for faithfulness, and others may say my primary concern is for efficiency. The truth that paradoxes open is made clear by strengthening both limbs of the paradox, not in trying to resolve it. Another lesson from Cristin is that the process of learning opens the logic of service creation, and helps one see the difference between the way a service is made and the logic that helps us understand the way a product is produced. Such a gift, many thanks, Cristin. I'm Paul Batalden.

Madge Kaplan 32:17

Thank you for listening to Episode Seven of the podcast series The Power of Cproduction with Paul Batalden. On Episode Eight, "Am I Allowed to Cry Here?", Paul talks with Morten Södemann about designing and creating effective services with an immigrant community in Denmark. Coproduction is key. All podcasts in the series, including an overview of coproduction, are available at ICoHN, that's 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.