STELLER Podcast transcript – Concepts of Recovery

An interview with ***Helen Glover*** *and* ***Dr Barbara Tooth****, co-authors of seminal lived experience research paper:*
Tooth, B., Kalyanasundaram, V., Glover, H., & Momenzadah, S. (2003). Factors consumers identify as important to recovery from schizophrenia. Australasian Psychiatry, 11(Suppl1), S70-S77.
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Interviewer: Max Mamo
Introduced by: Dr Anne Honey

Anne: Hello, and welcome to the STELLER Podcast. This podcast is about the different ways that people can think about mental health recovery. It's based on lived experience research that was published in 2003 in a journal called Australasian Psychiatry. The research has since been replicated internationally in Colorado, Wisconsin, and Trieste in Italy, with the last study published in 2011. The Australian research is based on interviews with 57 people who had lived experience and the writings of nine leaders of the Lived Experience Movement. The published article was called 'Factors Consumers Identify as Important to Recovery from Schizophrenia', but actually the findings are relevant to recovery from any kind of mental health issue or challenge. The actual diagnosis isn't important. In this podcast, Max Mamo interviews two of the authors of the paper, Dr. Barbara Tooth, and Helen Glover. The first thing he asks them about is what was happening in the mental health space back when they started this research, which inspired them to do it.

Barbara: Well, back in that time, recovery was just starting to be spoke about, and it was mainly mental health consumers that leaders in the field had spoken about what it had meant for them. But no one had actually asked people and done a study on what they thought recovery was. And so we set out to find out what people found useful in their recovery.

Helen: And I think at the time the mental health sector didn't have a firm focus on supporting people's recovery because they didn't actually know people that had recovered. So therefore it was really important for this research to bring to the surface and highlight the reality that people are and do and have been recovering from illnesses such as schizophrenia and other mental health conditions as well.

Max: Because I think this falls nicely into my next question. I've been told this study falls under the category of lived experience research. What does this mean and how does it differ to a standard research on schizophrenia?

Barbara: Lived experience research has to be coming from people who actually have the experience and learning from them rather than coming from a professional or a researcher perspective. It's understanding people's stories.

Helen: I think also if you had a professional research looking at the same question, they would look at things around whether symptoms were present or not, or what clinical support helped or hindered a person. Lived experience research as such isn't so much interested in that stuff. It's much more interested in how people make sense of their experience. Some of the environmental factors that assist or disable people in their journey that they don't... Lived experience research doesn't actually see the person's distress as a problem to be fixed, but more a problem to understand how it actually manifests itself.

Barbara: Yeah, so there's very much a tension between professional and lived experience.

Max: A tension?

Barbara: A tension, a tension between that of I'm the expert here as a professional and so therefore I put my lens on that of what I can do to fix or help that person rather than learning from the person; what they need and what they see as important.

Helen: And I don't know whether you'd say, Barbara, but from a professional research perspective, they may be coming in looking for something in particular where lived experience research appears and seems to be much more open for what emerges.

Max: Okay, so it's more about we're going in, we don't know what we're going to find, we don't know what we want to find, we're just going to ask them and see what happens.

Helen: Exactly.

Barbara: Yeah, we're curious.

Helen: Yeah, much more curious and much more seeing that the person that they're inquiring with is the expert.

Max: Yeah.

Barbara: Yeah. They have the wisdom. They've lived it.

Helen: Yeah.

Max: So the researcher has lived experience as well, is that right?

Helen: Yes.

Barbara: Yes.

Helen: Yes.

Max: In the report, there seemed to be a consistent theme amongst participants of ‘self-determination’ being the most common factor in helping their recovery with 74% saying so. What was the significance of this finding?

Helen: Well, it aligns with what other research has said around recovery in general as well as other researchers looked at recovery from schizophrenia. But for me personally, what I was really heartened by was that it reinforced... that self-determination along with some other factors is an internal process. You can't be given self-determination. Someone can't say, "here, take three pills of self-determination a day." It's something that rises up within you and usually rises up when there's something important that a person wants in their life. You know, “I'm self-determined to achieve that.”

Being the number one or the most frequently spoken about qualities is not surprising in hindsight, but I think it's under recognised in our health system that most people wouldn't see a person's self-determination as the major kind of influence on their recovery.

Barbara: Yeah, and also if you think about it as human beings, what do we do when we have challenges? You know, is this finding an inherent strength that people have within them to be able to do that rather than seeing them as an illness with symptoms to be fixed? So to be able to draw on that capacity of their own knowing and their own ability to take this on. “Yes, I can do this”, that “there is hope.”

Helen: And I don't know. When I was unwell, I don't know that I would have used the language ‘self-determined’.

Barbara: Yeah.

Helen: But I wanted something different to what I was experiencing at that time and I wanted something almost to reclaim a dream, a lost vision, something that was more than what it was. I remember thinking about... Someone asked me a question once. You know, “what is it about you that's been able to recover where many other people struggle?” And I thought about this question; it's a really important question. And I realised even in the depths of despair, I wasn't put on this earth to be a mental illness. So therefore, this self-determination, it's always there even if we don't appreciate that it's actually working for us.

Max: Another consistent answer was ‘taking responsibility and managing your own life’. What does taking responsibility look like for someone in this scenario?

Barbara: Well, that's for them, it's experimenting a lot and finding what works and then realising that, "hey, it's me. I need to take ownership of this. No one can do it for me." And that's a real transformative experience if you think about it. Once you start to think, "hey, all of these people are out there trying to help me" and you get confused and things aren't working and you realise that, "hey, I noticed, geez, I did that and I actually felt better and I can do more of that. I can take responsibility for finding my way of what works."

Helen: I think the ‘taking responsibility’ is a really interesting concept because most people, when we're diagnosed with a mental illness, there's an assumption by others that, that's something, you know, we're not responsible for things anymore. We can’t… we're not responsible for our thoughts. We're not responsible for our actions. And-

Barbara: And you can't be trusted.

Helen: You can't be trusted. I think one day it came to me that I realised if I'm not responsible for me, who do I think is? And I couldn't answer that, and realising that even though you might have difficulty, we are still responsible and that's a really important part. And therefore if we're having difficulties, who do we actually have to ask to assist us in that?

So even asking for assistance, we're still holding onto that responsibility. If you think of the word “responsibility”, it's our ability to respond, which most of us want that. We don't want to lose control of that stuff. And when we think about what makes it difficult for us to respond, then it highlights what might we have to do differently in order to respond.

I'm probably not saying that as eloquently as what I want, but ability to respond is different from trying to get someone to take responsibility. If I could respond, I would, so something must be in my way if I'm struggling. Helping me find out what's stopping my ability to respond is probably the most helpful conversation someone could inquire with me.

Barbara: Yeah, and it's also very much to be reminded of, even though we have a plethora of people who are well-meaning professionals, but this notion of coming in and doing something for people and actually taking the responsibility does strip away that of constantly being told, "you can't do this.” “You can't do that.” “You have to do this."

Helen: Yeah. I think if personal responsibility was a muscle, we named it, and yet I didn't get to exercise it, then it would atrophy. And what people with a lived experience told us, it was really, really important to claim that back and to exercise it in order to live the best life they could, and interestingly, how our systems haven't created the right environments for people to exercise their personal responsibility.

Max: Yeah. Well, I was about to ask, you know, this study was obviously undertaken in 1996. It's now 2019. How has the system changed since the findings of this research came out? Do they have an impact?

Barbara: Look, I just want to throw out there a research by Dr. Richard Warner. He's now passed on, but he did this study. He was a psychiatrist. And he went over the literature in the last 100 years of outcome and he found that outcomes were no better now than they were a hundred years ago. And that's given the advent of medication, a whole range of things. So if we're looking at the response to this question within the context of that research-

Helen: But it depends when we're looking at outcomes, doesn't it? I mean I think if you ask have things changed, I think the acceptance of that people can and do recover is much more than what it was. And I think other people with a lived experience, maybe people even listening to this podcast may not know the intricacies of recovery and all the literature around it, but they probably have been introduced to it somehow. They probably have been invited somewhere about, you know, “this is your life.” “We're inviting you to take control here." You know, "we want you to not be limited by your illness, to limit you to what's possible", where if you go back 20 years, I doubt those conversations were happening.

So my hope is that while people still may have symptoms and may still use medication, may still have to access health services, the binary limitations that were usually put on people may hopefully-

Barbara: Have changed a bit.

Helen: ...have changed a bit. I think that the discourse or the people talking about the reality of recovery, my hope is that it's more prevalent. Well, you know, 20 years ago if I was to run a workshop around recovery, I'd have to pay people to come.

Barbara: Did you have a specific response you wanted…

Helen: Did the nature of schizophrenia changed or how long people experience…

Max: Or just more the process within the health care system; are health professionals more accepting of the idea of giving agency to the people living with schizophrenia?

Helen: I think it waxes and wanes and it's got a whole lot of things that will pull it to people to pull back the control back into the professional's control. But at the end of the day, I think if we look at over that hundred year history, people are no longer incarcerated in institutions forever and ever. They may have short, and very short periods of hospital, even shorter than what I had now where the people are still encouraged to not let an illness like schizophrenia or any other mental illness disrupt what's important for them in their life. And you know, people have gone on to have great careers. And we're not talking about recovery being "I no longer hear voices" or "I no longer have visions" or "I know longer have hallucinations"…

Max: Absolutely.

Barbara: It's not about getting rid of symptoms…

Max: Yeah. No.

Helen: It's about how to manage them or transform as a result of them so that they don't actually get in the way of my life.

Max: Yeah.

Helen: And this word 'recovery' is not the most useful.

Max: Well I was about to say the report mentions that people are often uncomfortable with the term 'recovery'. How do you think you can make this idea more approachable and more comfortable for people?

Helen: I think we have to change the language.

Barbara: Yes.

Max: Okay. Yeah.

Barbara: Yes, definitely, we have to change the language.

Helen: And if we know what we know now, back when this term was coined in relation to mental health, I don't think we would have chosen the word ‘recovery’.

Max: What do you think a more accurate term would be? Is there one word or is it something that can't be quantified into a box?

Barbara: “Getting on with your life.”

Max: Getting on with life?

Barbara: That's what people told us was one thing.

Helen: I like words much more that have got ‘self’ in front of it. Like my ‘self-writing capacity’, my ‘self-management capacity’, even the concepts of ‘self-leadership.’

Max: Because that's what it's all about in the end, isn't it?

Helen: Yeah, me leading me. Yeah. And finding ways to do that. And it's not so much that I'm always on top of stuff. It's more important that I know how to pick myself up. So if I know how to pick myself up, I actually can take a challenge. I can take a risk and perhaps stumble because then I know how to get back up. But if I’ve lost that confidence and ability to do it, I won't take a risk. I'll stay small, I'll stay, you know, kind of this closeted world of illness. And I think what we're seeing now is that people are daring to create those environments where, you know, they're not so risk averse as what perhaps they were.

Barbara: Yeah, and I think it's really interesting too about the transfor-

Helen: -mation.

Barbara: ...transformational nature of these experiences. People often talk about this, "oh God, this is terrible. This is really bad." But yet when you talk to people, they say that "actually I'm coping much better now than what I was before."

Helen: That part of the research, and I know I shouldn't have fallen off my chair, but that part of the research that “actually I'm far better now than I was before I was diagnosed”.

Barbara: There's growth.

Helen: ...although I had that in my own life, I didn't think other people would say that and this growth, this transformative growth that happens from adversity and which seems to suggest that the experience of distress and the experience of overcoming it has been life-giving rather than life-defeating.

Barbara: Yes. Very much.

Helen: And most people walking down the street probably wouldn't agree with this.

Max: Well, that's the beauty of this research isn't it? Is that we've got it in paper, in academic writing, that people do feel this way. It must instil hope for people. Absolutely.

Barbara: Yeah. Well, if you think about it, the bigger the challenge we have, then the more you have to learn and find out and so therefore if we hadn't had that experience, then we don't develop all of those skills and that self-awareness and knowledge and start to really think about, “what is important in my life?” “What do I want?” “What can I do?”

Helen: And I think our systems have been built and still are kind of being generated around a faulty concept that this is a self-defeating experience, that once diagnosed with schizophrenia, you need to kind of have all this protective layer around it, which I think we need to change the discourse and think about what would services look like if we truly believed that people can transform through this.

Max: [Music playing] That was part one of the Steller Podcast. To hear part two, keep listening. Otherwise, now's a good time to take a break, stretch the legs and get some fresh air.

BREAK

Max: There was a lot of negative response towards health professionals in the study with 61% of participants saying interactions with a health professional were actually detrimental to their recovery. What role should doctors or health professionals have in helping those with schizophrenia on their recovery journey?

Helen: From the research, I think it's probably not so much the health professional per se. If you looked at the difference between the health professionals that were named as helpful versus the health professionals that were named as unhelpful, it's the relationship that was created.

Barbara: Definitely.

Helen: So they still got the same training. They still got the same kind of job role and all that sort of stuff. So someone named as helpful, someone named as not helpful. And when we listened to what people said was helpful, it was that they actually gave a damn, they went beyond their normal responsibilities, they saw me and not just responded to the illness. They cared. This isn't rocket science. And yet the ones that were named as unhelpful were quite sterile and quite seeing the person as an object.

Barbara: There's also this notion that people who are able to do that were rulebreakers…

Helen: Exactly.

Barbara: ...that to see the person like just going, "oh, let's go for a coffee" could break the rule.

Max: So there was a certain stigma around actually talking to-

Barbara: Of what professionals really had to do with boundaries.

Helen: …professional boundaries. Yeah.

Barbara: Boundaries gets in the road of... And another thing that I found really is… not that I found was surprising, but it was the fact that when we asked people about what was it about them, how were they able to recover, no one had ever asked them. Professionals had never asked someone, "what is this like for you?" So if we think about that they're not asking those basic questions to understand the person's experience.

Helen: Or wanting to understand it.

Max: Yeah, it's just there is that huge disparity between what health professionals define as what is recovery versus what a consumer might think is recovery.

Helen: Exactly. And to even for someone to be curious enough to try and understand that world says actually you're letting that expertise down a bit in order to understand the person's expertise.

Barbara: Yeah, you do. It takes a lot. You know, as a health professional, you spend a lot of years studying and you think you come out as an expert and you understand this stuff. And if you go in there and being the expert on someone else's life when they've got serious mental health challenges, it doesn't work so well.

Max: Are there certain conversations or methods that people living with schizophrenia can use with their health professionals if they might not have a wide range of choice in developing a relationship to get to that point?

Helen: I like to kind of expect it was a health professional that would be thinking around what to do, but I think it's around coming in as saying... I mean, I always think now when I see a health professional, “am I assessing… can I assess you as to see your relevance in my life in that if I was to recruit you to my team, what would I be looking for?"

So quite often we go cap in hand to a professional instead of thinking, switching the tables and saying, "I'm wondering what you see you can add to my life?” “What skill set do you bring? What values do you align with that also align with mine? Are you signed up to the vision that I want for my life? Because if you can't, if you can't, then I can't afford to have you on my team.”

So these are the things where I don't think we're game enough to ask yet, but at the same time, if we were, I think that would start to shape health professionals thinking about, “why am I showing up in this person's life? Is it the same understanding that they have? Are we actually on the same pathway together?” One of the turning points in my life came when I realised that the health professionals I had in my life were on a different track and I was expecting them... you know, I was a bit of a princess. I was expecting them to get me from here to there and I'd just sit back and wait for them to deliver my life back to me.

And then I realised that they actually were planning a whole different scenario. At that point, I thought, "why am I looking to them to get my life back when they've got a different vision?"

Max: It goes straight back to responsibility, doesn't it?

Helen: And my responsibility, my responsibility, yeah.

Barbara: And self-determination.

Max: Self-determination.

Helen: ...to actually say, "hang on, I've sat here passively expecting them that they know best. They're taking me in the same direction, but we'd never had a conversation about that," and that was a really important learning for me. Now and my life from that point didn't go every day in every way I'm getting better and better, but I changed the position of how I showed up in my own life.

Max: I wanted to touch quickly on the topic of medication within the report. It seems both necessary for recovery, but some participants spoke about it negatively at the same time. What insights did you find from this study about how people responded to medication?

Helen: I think for me the word, the term that we... It's not that they liked it… it's that they learned to accept it. And I think there's a big difference between, “yes, I see this as the most helpful thing and I couldn't survive without it” to actually have to develop a relationship with it. I might not love it, but I can accept it so I actually can do other stuff in my life.

Barbara: Yeah. “How can I use it so it works for me?”

Helen: Yeah. And even with the… like in this research, people that we were inquiring with were on some of the older medications and you know, there was some thinking that maybe it's because of that particular kind of generation of medications produced horrific side effects. But when this research was also repeated in the US in new modern medications, the same challenges, the same kind of, "I don't like the medication, it causes side effects. It makes my life more difficult" emerged.

Barbara: Yeah. And to say that we did replicate the work in Boulder, Colorado in the US and also in Trieste in Italy and found the same things and that was in the 2000s.

Max: That's fascinating, isn't it, that no matter where you are, the same patterns come up over and over again?

Helen: And I think part of it's not necessarily... Yes, the medication is hard. It produces some really difficult side effects. It's more about the prescribing of it being done to you as “you will take this, and there are no other options.”

And I think from a lived experience perspective, we want to explore other ways of managing it and medication not necessarily being the only thing. And if we don't have a good relationship with our health professional, that we're free to kind of raise this. How much are they willing to experiment with this, then feel like we're kind of a slave to it.

Max: Yeah. You lose that sense of agency in the process, don't you which-

Barbara: Yeah. And people just stop taking the medication anyway.

Helen: There's a psychiatrist that I did some work with in recent years and he had a wonderful phrase of saying to his patients, and I call him one of the very recovery-oriented psychiatrists, and he'd say to someone, especially men, he'd say, "I've got a truckload of medication here that can wipe out every symptom you've got, but it'll also give you many side effects that you don't want. So we need to have a conversation about how many symptoms you're prepared to tolerate and how many side effects you don't want. There's nothing that is going to wipe it out and not give you side effects."

Barbara: And there's no one medication for one person. It really is a trial and error. You need to be all that because what works for one person isn't going to work for the next and so people have to be approached as individuals with medication.

Helen: I used to think that recovery for me was being off medication. I thought that was the indicator of success and I've learnt that it's not. It's much more about how I see myself as using it to aid my ability to lead and live my life rather than its presence or absence in my life.

Max: Listening to all of this, you can really see why ‘self-determination’ was such an important factor in terms of recovery.

Barbara: And finding the coping mechanisms-

Max: Yeah…

Barbara: …that work for you.

Max: What role does the stigma of schizophrenia play when it comes to beginning that journey of recovery? Because obviously it can be a very overwhelming feeling with a diagnosis.

Barbara: Well, is it stigma or is it discrimination? It can be… recovery and lived experience is all about human rights. We have a right, you know, to live in a community that provides support and live a life like everyone else. So is it stigma or is it discrimination?

Helen: And I think this is a really complex phenomena because I think we anticipate being discriminated against. And so we internalise this sense of being different, which is what stigma is about. “I'm different to you. And the way that I'm different is not socially valued.” So I get a sense that, you know, “I can't go out” or “I can't do something” or “I won't be welcome somewhere.” So I participate in that myself.

Barbara: …so the ‘self-stigma’.

Helen: The self-stigma is... And so at the end of the day, I… I was a little bit surprised that 49% of people only spoke about stigma because we're all told, "oh, it's stigma. It's stigma. It's stigma that stops people." But only 49% of people talked about that.

And I thought about that for while. Why is it that people, you know, only 49% of people thought that, that was an interesting thing to raise? And a difficulty is because probably by the time they got to talk to us, they were already in this active part of their recovery and they'd already negotiated their way around discriminating people and discriminating environments.

So it wasn't the first thing that comes to their mind about their recovery. If they had probably been asked earlier when they were first diagnosed, it may have come up. But I think you get to a stage in your recovery journey that you don't take on the discrimination. You're stronger about that and you don't even see it by the time we get to a point. Therefore you're not projecting it either. You're not going out and saying to people, "I have schizophrenia" as the first way of introducing yourself. You have a different way of engaging in your community and in your relationships, so people then don't relate to you as different.

Max: Because it is in the hands of the public, isn't it, to really eliminate stigma or even discrimination because a lot of these signals aren't able to change. It's the response to those signals which need to change.

Helen: And I think it's even not the community.

Max: No. Right…

Helen: I think it starts with what we call professional stigma or institutionalised stigma. So you think about it, you know, we get a diagnosis, we're given that by a professional and then we enter services and everything in that service subtly, very subtly, reinforces that we're different from other people.

Max: Right. Yeah.

Helen: So we start to swallow this, that “I'm different, I'm different, I'm different”, we go to different groups, we go to different places. We kind of get different privileges because of an identity with this. And so subtly over time we start to internalise, “I am different.”

Helen: Then we go and you know, I might go and join the local netball club or the local football club and I've got a sense that I'm different. So I'm popping up in that environment saying, "hi, I'm different." And then we're surprised that the community treats us differently.

Helen: I think it shows up in the community, but I think it starts-

Max: Begins even further back, all the way from the beginning.

Helen: ...it starts way back all the way from the beginning. So we're tackling the wrong end.

Max: It's a really deep rooted problem isn't it?

Helen: Well, I'm wondering if you're talking about problems and redesigning it.

Max: Yeah.

Helen: I think we've been tackling stigma and discrimination from the wrong end. I think we need to start where it's actually born.

Max: Flip it on its head.

Helen: Flip it on its head.

Max: Never thought of it like that before.

Helen: It's because no community anti-stigma campaign has ever worked.

Barbara: No.

Helen: If anything, it's actually reinforced a sense of difference.

Barbara: You need to look at the role of media and how it's-

Helen: Yeah.

Max: Yeah. Especially in pop culture.

Helen: Exactly.

Max: Yeah.

Barbara: Things are portrayed.

Helen: So because we're tackling where it shows up as opposed to where it starts.

Max: Do you think there was a single biggest outcome from this research, whether it was the significance of conducting lived experience research or a result that came from the findings of the survey? Was there something which really stood out and sort of echoed through the mental health space?

Helen: I think for me, and Barbara might differ because I'm not a researcher by all the bells and whistles behind it, but for me, when you stand back from the results and you look at even the top 50 themes that came out, something spoke really loudly to me. It was that the ones that were most frequently talked about, you know, ‘self-determination’, ‘understanding my illness’, ‘finding meaning’, ‘taking responsibility’, even that bit about, you know, ‘having a purpose’, they all come from internal. They're not something that can be created by someone else or by a service. And the things that we think help people weren't named as frequently, ‘support groups’, ‘family and friends’, ‘health professionals’, ‘medication’. They were mentioned, but they weren't on the top of the pop list.

So for me it actually shows that we're also focusing in our health systems on the wrong energy. How do we resist impeding some of those internal efforts and how do we create environments where they get an opportunity to strengthen and to flourish? If we're just thinking about well we've just got to send someone to a support group, or we've got to get them on medication, we've got to get them to take responsibility, just faking on the external application of recovery, we will never ever change the status quo.

Barbara: And so I agree with everything Helen said. And I also think it's in terms of a research perspective, it's about thinking about, well who is the expert here and who does hold the knowledge and how do you find it? And it's really important about being very clear about the questions that you want to ask and taking that curious stance of who is the expert here and who are you going to learn from? Clearly the people in the study, they're all very clear about what was important to them. They held that knowledge and it was different to what-

Helen: Professionals thought.

Barbara: ...what professionals thought. And that really stood out.

Helen: And I think the other thing that stands out for us is a bit humbling, is that we tried to come up with a thematically defined, research-defined definition of ‘recovery’, and we didn't, and we failed. And why did we fail? I'm going to go back to the uniqueness of it. Up until then and probably still now, people have only tried to define ‘recovery’ from their own perspective, like an individual, “this is what I think recovery is”, and then you look at some of the definitions out there that are still popular, they're written by one person. We tried to get a collective statistically informed definition by 60 or 57 people, and we failed because the highest... one component that what people said it was, was only at 37%. If we look at like our Australian politics, 63% then say it didn't say it was that.

Interestingly the thing when I ask people, when I ask professionals about what do you think people think recovery is about, the highest thing that they say, they say, "oh, you know, having friends, having hope, being happy," they name all this stuff, but the 37% thing that people said, 37% of people said was ‘taking responsibility’.

Max: And that's all we have time for today. Thank you so much to our guests, Helen Glover and Dr. Barbara Tooth for taking the time to come on the podcast and speak to us. It's been a real privilege and it's been really insightful to learn about how consumers define what recovery is to them. And I think there's a lot we can take away from today. Thank you very much.

Helen: Thank you.

Barbara: Thank you.

Max: Thank you.