Supporting Community Connection for People with Mental Health Conditions Outside of a Funded NDIS Package
Webinar – 29 May 2019, 10:30 to 11:30 AM

WEBINAR REPORT AND TRANSCRIPT

Presenters

- Tina Smith, Principal Advisor – Sector and Workforce Development, Mental Health Coordinating Council
- Irene Gallagher, Chief Executive Officer, Being | Mental Health & Wellbeing Consumer Advisory Group
- Jonathan Harms, Chief Executive Officer, Mental Health Carers NSW Inc.

Participants

- 164 people registered to attend the webinar
- 78 people attended (48% attendance rate).

Welcome, acknowledgements and introductory comments

TINA SMITH:
Good morning. My name is Tina Smith, and I'm Principal Advisor, Sector and Workforce Development at the Mental Health Coordinating Council of New South Wales. MHCC is peak body representing community organisations that support people with mental health conditions in New South Wales. Before beginning today's webinar, I'd like to acknowledge the traditional custodians of the land, on which this event is being held, and pay my respects to elders, past, present, and emerging. I also acknowledge the importance of people's lived experience of a mental health condition, in shaping services and communities that are increasingly inclusive and healing. Before telling you about the CEEP project, I'll explain that acronym soon, we have a brief live web poll that I'd like to ask you to respond to. How familiar are you with MHCC's New South Wales ILC CEEP project? Not at all, a little, somewhat, very. I'll just give you a minute to lodge your response to that question.

I encourage you to lodge a response to that question. Ahh, OK. OK, so 88% of you are saying that you're not very familiar at all, which is not a bad outcome, because hopefully, that will change across the course of the next hour.

Full results of webinar pre and post live poll: How familiar are you with MHCC's NSW ILC CEEP project?

	Pre-webinar	Post-webinar
Not at all	66%	18%
A little	19%	26%
Somewhat	10%	28%
Very	5%	28%

The CEEP project, the Community Engagement Education Project, is all about supporting people with mental health conditions outside of an NDIS funded package. When you think about what we're setting out to do, think develop learning materials, to help people, both paid and unpaid, that support people with mental health conditions to be more connected with their communities, whether they have an NDIS package or not.

This is important, even for people with NDIS funded packages because being connected with more than funded services and supports is what recovery is all about. Joining me today, are our two project key partners, Irene Gallagher, who is the Chief Executive Officer of the Being Consumer Advisory Group in New South Wales, and Jonathan Harms, the Chief Executive Officer of Mental Health Carers NSW. Thank you for being engaged with this important work and being here today. These guys represent people living with mental health conditions, and their families and carers in New South Wales. Our intent today, is to briefly orient you to the project, but mostly, we're going to be consulting with you about what those learning materials that we're developing look like and using your feedback to further refine those materials. There is a project website, and in the Resources button on your screen, you can go in and have a look at that, now or later. And on the Resources button on the screen, you can also go in and download the CEEP framework that we'll be talking about today. But you don't need to have done that in order to participate in today's webinar. The New South Wales ILC project is funded by a National Disability Insurance Agency New South Wales ILC Jurisdictional Grant, and MHCC thanks them for this important opportunity to strengthen community connections that support people in their recovery journeys, both within and outside of NDIS packages.

If you have questions, comments, or examples of things that we're going to have conversations with you about, please type them through. We won't be able to answer and respond to all of those today, but we will gather all of those up, and make a transcript, so that everyone's comments and questions and observations are helping to build the learning materials.

So, what are the project outcomes? I'm not going to read these outcomes out to you. But again, it's about helping people with mental health conditions, have access to the same community activities as everyone else, and the information that they need to make decisions about how they want to live their life in a community of their choice. While the ILC Outcomes Framework can feel kind of complicated, it's essentially about working with people to undertake particular activities, to contribute to achieving certain inclusion outcomes.

So, the people that we'll be working with for this project are Community Workers, mostly non-mental health specific Community Workers. Although the mental health ones have shown a lot of interest also. Volunteers, whether they're mental health volunteers or other volunteers in organisations that see people with mental health conditions. And peers, people with lived experience and their families, whether they're in paid or unpaid roles. That's who we're building these learning resources for. The activities that we're going to undertake are to develop, trial and make available to others, the learning material. The trials will be occurring in the August through October timeframe in Dubbo and Sydney, with a group of about 20 to 30 learners. And this is the first of three webinars that we'll undertake, across the course of the project, as we co-design, build, refine. And then we've been asked to think about ways of scaling up the uptake, the use of these resources, both in New South Wales and nationally. So, we'll end up with a good practise guide and a project report that helps to facilitate that scaling up.

We started co-design with a bunch of questions about increasing access to mainstream and community services because that's a really important part of the ILC. Co-design told us very quickly, that people with lived experience did not resonate with that language at all and were really having trouble articulating what that meant exactly. So we refined our key research question to be about, well how do you support people to have a good life outside of an NDIS package? And interestingly, the second round of co-design people came back and said, you know what? I've never had a good life. I really have not had a good life. It's been quite an awful life. And they found that use of the word 'good' triggering of some of their past traumas and experiences. So, we're moving forward hearing that message loud and clear from them.

Consumer and carer perspectives on the importance of the CEEP Project

OK, that's my introductory remarks. While we're waiting on some comments and questions to come through, I do have some questions, one for Irene, and one for Jonathan, that I'd like to ask you to respond to.

Irene …..

Consumer perspective

IRENE GALLAGHER:
Miss Tina. (LAUGHING)

TINA SMITH:
How will the CEEP project help people living with mental health conditions to be more included in their communities, and why is this important to recovery?

IRENE GALLAGHER:
There's two things that come to mind there for me. Two words, recovery and inclusion. When we think of recovery, it's really important to think of recovery in the broader sense, and the interpretation of recovery for people with mental health issues. What we're talking about here, is not just a clinical aspect of recovery, but a more inclusive personal aspect of recovery. That means, what does recovery actually mean to the individual? As we know, recovery is a unique journey for each individual. It has different meaning, it has different purpose for each individual. So if we think of some of the principles that underpin recovery for example, things like having choice and control, self-determination, self-agency to be able to define a life that people would like to live, we also need to think of, what else underpins that? And that's where trauma informed practise comes into it. We can't really, have recovery without ensuring that we have trauma-informed practise.

TINA SMITH:
Absolutely, absolutely.

IRENE GALLAGHER:
So that's a real key.

TINA SMITH:
Yep.

IRENE GALLAGHER:
And we really need organisations to integrate trauma-informed practise within their services, and MHCC have got wonderful suites of information beyond just the CEEP program as well. So, let's give MHCC a bit more of a plug there.

TINA SMITH:
Yeah, thank you.

IRENE GALLAGHER:
To bring it back to the question about inclusion, this is how people are going to feel included. Cause people will feel included if there is a sense of belonging. If there is an opportunity for people to feel safe, if there's an opportunity for people to heal. And maybe the language we need to start using, is how can people heal? And even in the circles of the survivor movement, there's many people who don't particularly like that term, 'recovery', and do consider that word, 'heal'. How will CEEP benefit those people that it's targeted towards? Well, through the training, it will assist organisations and workers, volunteers and peers, to have a better understanding of, A, what recovery is, B, what trauma-informed practise is? And not just from a theoretical aspect, but how to actually implement that within the organisations, and how people can work from that framework. And I think that's the key.

We know a lot of people who are looking to work in that way from a trauma-informed perspective, often struggle with, what does this look like? What does this model actually look like? I think you mentioned language beforehand, and I think that's really important for us to consider. Maybe we need to change our language around, from a traditional biomedical model language of, what's wrong with you? To, what's happened to you? And start asking those questions and exploring and finding ways to connect with people. And I really feel that's what the CEEP program is going to shine (with), and really help people to have a better understanding of.

TINA SMITH:
Yep. There are some fabulous community workers, volunteers, and peers out there, working in wonderful ways with people affected by mental health conditions. But still too often, for a whole range of reasons, some can decide to go, “Oh mental health, too hard. Go to the hospital". And the hospital will kind of go, “You're not unwell enough”. And the person will go, “Well, I don't want hospital and meds anyway." “I want housing, friends, something meaningful to do with my time during the day”. So, the resource is about helping us to do more of that the former, yeah.

IRENE GALLAGHER:
Absolutely.

Carer perspective

TINA SMITH:
Jonathan. How will the CEEP project help people, that support people living with mental health conditions, to understand that individual choice and control is central to recovery?

JONATHAN HARMS:
Thanks, Tina. For mental health carers and other informal supporters of people who experience mental illness, understanding that building a person's capacity for autonomy and independent decision making, and independent living, taking the place in their community of choice, in the way in which they wish to interact with that community. That is the content of recovery, in many ways. It's very hard sometimes for carers to understand, that autonomy is something you can't just give to another person. It's something that you've got to work with them to build. Giving them the benefit of the dignity of taking some risks, just as we would any other person. In many ways, I see the CEEP project as helping us to understand what the mental health ramp looks like. We understand in other areas of disability, if someone that has a wheelchair, we can put a ramp in, we know exactly what that looks like. But in mental health, we don't understand very often, the nature of the barriers that people experience when they attempt to access mainstream services. But we do know that about 80% of the support a person needs, have got nothing to do with clinical treatment. They have to do with things like, housing, access to recreational services that help build their community connections. And those things which keep people well.

Carers often have a great understanding of a person's individual preferences, and their individual history of trauma, which can be triggered when they start to try to interact with mainstream services, if those services aren't sensitive to the signs of a person reacting from their history of trauma, rather than necessarily, from what's going on in the here and now. That can be confusing to carers, as well as other services who need to reach out and interact with people, but who might not have that background information. So I think that the CEEP program, will be of great assistance to mental health workers, but also to non-mental health workers, in understanding how we need to support a person's decision making, rather than to take it over, wherever we can, because building that ability to make good choices for ourselves, is the content of recovery, just as being able to act in our community as a worker, as a team member, as a participant in any sort of community activity, in the way you want. That's another huge part of, not just recovery, but keeping us well and safe in the community.

TINA SMITH:
Yep. Self-determination, choice, control, being supported to make decisions that are your decisions in your life. OK, so, this technology, it's daunting me a bit. Bear with me. We have one question and one comment that have come through so far. I think you'll get more in the groove about sending in questions, comments, examples, as we move on to talk about the framework, and the six learning modules, that it consists of so far at this stage.

So, the first question is, what will the learning materials that are being developed look like? Now I think I'm going to answer that one. We don't know. That's not 100% true, because we are committed to true co-design here, with people with lived experience, and other stakeholders as we move through the project. We suspect that there will end up being a range of online video, and other e-resources that people can have microlearning opportunities around, because in the current environment, we're just so time stretched and time poor, for education and training. But we think we'll say, there will be some of the more traditional stuff, like learner's guides and PowerPoints, and facilitator's guides. So that, sort of like a smorgasbord of resources, will be available that individuals, and groups of people can kind of pick and choose from, depending on what their unique individualised learning needs are. Yeah, I'm almost afraid to throw this comment there in the two minutes we have left for this section. And I am going to ask both of you to comment very briefly. We could spend a whole hour just on this one. Sam asks, or states, CEEP is a worthy project but it isn't covering the deficits and shortcomings of the NDIS.

IRENE GALLAGHER:
Hmm. Wow, two minutes. (LAUGHING)

TINA SMITH:
One minute each.

IRENE GALLAGHER:
One minute each.

TINA SMITH:
Oh! 30 seconds each.

IRENE GALLAGHER:
30 seconds each. Can you read the question to us again?

TINA SMITH:
Yeah, CEEP's a great project, but it won't … it's a comment. It won't cover the shortcomings and deficits of the NDIS.

JONATHAN HARMS:
Well I think that's true, given that the requirement for permanence means that a lot of people can't get into the NDIS very early, but has to be some sort of handover from mental health services after the disability becomes established as permanent. For psychosocial disability, there are elements that need to be rethought, and also the carer respite aspects. And this will help mainstream services get better at supporting people who are in, or maybe should be in, or aren't but have significant disability support needs. But yes, it's not going to fix the whole system.

TINA SMITH:
The NDIS was never intended to be the solution to all problems, for people affected by mental health conditions either. It sits within a larger disability strategy, and a larger mental health reform strategy. Where it does work, it works really, really well. And the NDIA is working very hard at strengthening the psychosocial stream of the NDIS. So, it's getting better and better all the time. I think that's about all we could probably say on that.

IRENE GALLAGHER:
Yep.

JONATHAN HARMS:
Yep.

TINA SMITH:
That's –

JONATHAN HARMS:
We have great hope –

TINA SMITH:
That was a tricky comment, thank you.

JONATHAN HARMS:
We have great hope at psychosocial pathway, when that's developed.

IRENE GALLAGHER:
Yeah.

TINA SMITH:
Yeah. Absolutely, a specific pathway.

JONATHAN HARMS:
Yeah.

IRENE GALLAGHER:
Yeah. Absolutely.

Introduction of the draft CEEP learning materials framework

TINA SMITH:
Can I have that clicker please? I seem to have misplaced mine. OK, so we're going to move on now to introduce you to the CEEP framework. You can see the six key learning modules there. I won't read them out. What we're going to be doing at this point, is spending just five minutes each, on each of those modules. We've got a question we'll be putting out as a conversation starter, that we're hoping that you might respond to with examples, to help us build the resources. But happy to also continue to take comments and questions.

- **Module 1: Recovery**

The outcome that we're looking for in the Recovery Module, relates to people understanding better medical and social model approaches, to working with individuals. It's that notion of clinical recovery, versus personal recovery that you mentioned earlier, Irene. And we're asking webinar participants, can you share an example of experiencing a better life, while living with a mental health condition? Irene, I'm going to invite you to respond to that question.

IRENE GALLAGHER:
The first thing that came to me, when I saw the question, was actually very similar to your comments in the opening, around the language that we're using here, "good" and "better". And for me, as an individual who lives with mental health issues every day, I'm not sure that I can really relate to that particular language of good or better. I think for most people with mental health issues, and also for workers working with people with mental health issues, we need to think of what may be language that assists to elicit a conversation, to create those healing environments, because language is incredibly important. So what resonates to me, is language such as meaning and purpose.

TINA SMITH:
OK.

IRENE GALLAGHER:
So what brings meaning to my life? So, if I was to ask someone, rather than saying, what does a good life, or a better life look like? For many people, they may say, well, recovery may not be possible for me and there may not be a better life. So if we go back to meaning and purpose, and think of it from that perspective, for me, meaning and purpose is about living a contributing life, being able to give back to my community. And a lot of people with lived and living experience, we're now seeing this emergence of peer workforces, not just in the mental health sector, but in other sectors as well. And there's some statistics that actually show, that it's the fastest growing workforce across Australia at the moment, because of the uniqueness of bringing that lived experience to the forefront. We need to consider that. We need to think about what meaning and purpose actually is for the individual. And start asking those sorts of questions.

So the example for me, as I mentioned is, it's important for me, rather than to consider what's a better life, or a good life, because I can't resonate. That doesn't resonate with me, is to consider, what really brings me purpose? And for me, purpose is, my family and my loved ones, and my friends, but also the work that I do as well.

TINA SMITH:
Yep. So thank you Irene, and we have a question from someone watching. They're asking, did you include people who are socially isolated, unable to leave the house in the co-design process? We did not include people unable to leave the house, because co-design, the first round of co-design working groups, were done as group work. But we did really target people that were very disabled as a result of their mental health condition, whether they were getting a package or not. So the co-design participants were primarily, people with lived experience, but we also encouraged paid and unpaid supporters, to come along to support people that might not otherwise have come into the room, so to speak. Yeah, OK.

IRENE GALLAGHER:
Can I just say, I think that's actually a really good point, so thank you to the person that's actually raised that. It's definitely something that, I think all organisations need to consider. We've got significant information that's available now, around ensuring that people are included, how we engage, how people participate, and we know that co-design is integral to best practise within services. But we do need to find ways to be able to reach those people who are not able to be there face-to-face. So thank you for that.

Module 2: Community Inclusion

TINA SMITH:
Yeah, thank you Ayesha for your question. And certainly the Project Advisory Group is really pushing us to stay on task, about co-designing with those people, that are arguably most disadvantaged by their condition, and working to support that group, not those that are further along perhaps, in their recovery journeys. We are going to move on to community inclusion. The learning outcome here is, the importance of supportive environments in recovery. Audience, can you describe a situation that a person living with a mental health condition could experience as supportive? Jonathan, I'll ask you to briefly comment.
(LAUGHING)

JONATHAN HARMS:
Well look, I think it's a great question. There's been work done recently that I think back up what a lot of carers have suspected in saying that, interpersonal relationships suffuse all aspects of mental wellbeing and recovery, including experiences such as hope, identity, and empowerment. So the way that we are treated, and who we think we are, comes from the relationships that we have. And this is why having good nurturing, supportive relationships that are informed about trauma, and don't retraumatize you, and effectively reinjure you, are so important.

So, I was talking with a carer, actually yesterday, who's loved one had gotten NDIS package, and she had worked very carefully with the ambulance, with the police, with the local support services, to get really specific plans in place that addressed her trauma. That has made a massive difference to her quality of life, to the extent that now she's singing again, and engaging in those other community

connection activities that she hadn't been able to do before. But she isn't accessing that much mental health treatment apart from some medication. And I think that that really shows that if we can stop traumatising people by the treatment we give them, if we can tailor the experiences they have to their particular needs, and their particular experiences and desire for the place they want to take in our community, then we can really push that recovery along, building their autonomy and their ability to participate, to the extent they want that.

TINA SMITH:
Yeah.

IRENE GALLAGHER:
Yeah.

JONATHAN HARMS:
Because there are a range of activities, and while some people think of nothing better than becoming an activist, and certainly we all need those people to get active. There are other people we're just maintaining a good standard of life, of being able to participate in the local choir, or whatever other activity. That's enough, and that's a perfectly fine, and reasonable goal for us to be striving for.

TINA SMITH:
We have a comment here before moving on to the third learning area of the framework. Sean states, “Better isn't any better than good. I'd go with fulfilling”. So it sounds like he's on the same page with you, Irene.

IRENE GALLAGHER:
Yeah.

TINA SMITH:
In terms of meaning and purpose.

IRENE GALLAGHER:
Yeah.

TINA SMITH:
Yeah.

IRENE GALLAGHER:
And a great example that recovery journey is individual, and language is individual for each person.

Module 3: Supports and Services

TINA SMITH:
Yeah, absolutely. So, the third learning area is Supports and Services. We want the learners to understand that there's a whole lot more out there for people living with mental health conditions, than just mental health services. In fact you could argue, a person has a pretty poor quality of life, if they only have mental health services in their life. You could argue it. I would.
(LAUGHING)
The conversation starter, tell us about a non-mental health community service or support that could help a person to have a more fulfilling life. Sean. Irene.

IRENE GALLAGHER:
Yeah. I guess considering new approaches. I mean, there's so many organisations that I can think of, and, you know, way too many to mention but considering new approaches when we're talking about... Although recovery and trauma-informed practise has been around for so long really, it is quite new to some degree. It's new for organisations to really get a grasp of what that is particularly because it is an individual journey. Particularly because it is so personal.

So, it's about organisations considering new approaches to how they work with individuals, how they can integrate those practises and those principles and ensure that their policies and their directives within the organisation support those practises as well. So it's not just in theory. It's not a tick box that actually staff have an opportunity to practise from that perspective as well.

I mean, I like the fact that we're also, with CEEP, that it is... that it is quite specifically targeting non-mental health Community Workers and volunteers but also peers at the same time. Because the one thing that I hear consistently is that a lot of people with mental health issues don't actually want to talk about mental health.

TINA SMITH:
No.

IRENE GALLAGHER:
If we think of personal recovery there's so many other aspects that make up an individual and the determinants and you mentioned some of them before Jonathan. So, organisations also really need to embrace having conversations with individuals and people with mental health issues and carers that are not just mental health specific.

TINA SMITH:
Yeah.

IRENE GALLAGHER:
But are actually about going back to what is meaningful, what is purposeful for you. What is fulfilling? What is the fulfilling life for you?

TINA SMITH:
Yeah.

IRENE GALLAGHER:
If you could have one wish. If tomorrow looked different, what would it look like?

TINA SMITH:
Yeah. Thank you. We have a comment here from Natalie. Natalie says my son is now living supported by people who don't define him by his medical mental health diagnosis. They treat him as an individual and collaborate with him on his goals, hopes and dreams for his life. This is a first in 12 years of different supports. They are open to learning about how to best support him including learning about trauma-informed recovery work.

IRENE GALLAGHER:
Yeah.

TINA SMITH:
I'm really pleased to hear that that's what's happening for you and your son, Natalie, and we want to see that happen for more people whether or not they have NDIS funded services and supports. We're at a time of unprecedented change with Commonwealth mental health programs winding down. The Psychosocial Support Measure and Continuity of Support measure ramping up through Primary Health Networks. But even with those changes they will never, and arguably should never, be enough mental health services without also increasing community inclusion of people across mainstream services and in their communities as well.

Apologies for the short break. I'm having a little trouble multitasking. Wendy says, "I'm sorry, but I can't understand a lot of the language you were using." Thank you. I did get into psychobabble land, didn't I?

Aisha says uni and employment can be non-mental health community services.

Wendy says," What I can identify as needed in my local community is grief support groups, domestic violence support groups, community centres where varied activities are available at affordable prices."

Also, counselling is desperately hard to find". Yeah. There are a lot of support services and supports available outside of mental health and NDIS funded services and supports and we need to help people and workers to understand better what those are. OK, we're halfway through the framework.

Module 4: Mental Health and the NDIS/ILC

The fourth area relates to that reform in the mental health and NDIS environment that I just alluded to in my industry speak. This was an interesting one for co-design because there's a sense that Community Workers, volunteers and peers need to know some of that. And originally people with lived experience in co-design kinda said 'no, they don't" but as they worked through it, it seemed to be more a question of how much or how little people - Community Workers, volunteers, peers - need to know about that. Jonathan, how much how little?

JONATHAN HARMS:
Well, this is a very interesting question. To some degree, a person doesn't really need to know more than about their own experience when they're engaged in some aspects of co-design. They need to understand what support they received or didn't and how that support could have been tailored better to meet their needs or to prevent obstacles or barriers arising to receiving that care. But when we start to look at slightly more complex issues such as how care needs to be supported across settings. So, when someone's being cared for in hospital. It's done by a particular organisation. When someone's discharged back to the community. It's hugely going to be taken over by a different set of supports if any at all. Understanding some of that framework could be of advantage when we're getting into some of the more complicated areas around wrap around individual supports that persist across settings giving a consistent level of support where records are routinely asked for say from the general practitioner when someone goes into hospital and the plan is given back to the general practitioner when someone's discharged. Those sorts of... There a lot of issues around that with information sharing and funders and different corporate entities having access to different levels of information but there's still one person that needs to be able to navigate that setting with the assistance of their families and carers or formal paid supports. And so understanding how that can work and how that can be designed could be of some significant advantage. Knowing what each system is meant to provide.

So the National Disability Insurance Scheme is meant to provide supports to live in the community. It's not necessarily intended to deliver clinical services to people. Or housing interestingly. That's generally meant still to be the responsibility of the state government's public housing authorities. So we... having some understanding of that landscape can be of some advantage when we are looking at how we make services seamless and person-centred. But I would also think that for others just understanding what they needed was not have to tell their story six times, not to get their medication changed just because they turned up to a different venue. Those sorts of basic support needs, basic good medical practise as well as basic good psychosocial support. Those elements can be very helpful for people to have some understanding of but I also think that the peer activists and... or good peer organisations can help people to understand some of those niceties and maybe shield them from some of the burden of the bureaucratic labyrinth that we have to navigate to get important reforms implemented so that the person receiving care receives it in a simple, logical way and not one that's a bit mystifying due to all the intricacies of the funding bodies and the rules between different governments.

TINA SMITH:
Yeah, the co-design people like I said started off with no, no. Too... too overwhelming. And yet if it's overwhelming for them you know. Workers need to be able to help support them to navigate that change.

JONATHAN HARMS:
I think it's reasonable to expect that workers in the sector understand how it should work and where you should go next but it's not always the case and it's because it's genuinely complicated.

TINA SMITH:
It is complicated.

JONATHAN HARMS:

Yeah. Yeah.

IRENE GALLAGHER:
Yeah.

TINA SMITH:
The co-design participants were kind of saying “is there some way to just do a diagram that maps those changes”, and that's a really exciting challenge to think about whether there's some way to make a diagram.

JONATHAN HARMS:
There are a number of atlases and there's been health service mapping done at a number of levels. I know the Primary Health Networks have got a responsibility to help map the relevant services in their jurisdictions and many of them such as the Central Eastern Sydney Primary Health Network are working closely with the Local Health Districts in the area to do... combined planning around some of these issues. Proven because of... impetus even by the peer advocates often. So there is reason for hope but this is also the sort of the part the conversation that some people are going to be scratching their heads and going, do I really need to know this? I just need to know that I can go somewhere and get the help I want and need and that it's not going to be really complicated or a disaster for everyone.

TINA SMITH:
I think what the co-design participants seem to be saying is they want a one-page mud map. That talks about that change in environment that's occurring in particularly outside of an NDIS funded package whether you're ineligible or for whatever reason choose not to apply. I have a comment that relates to the last services and support area of the framework. This is from Sharon who says, "I work at a community college and this is an area teaching foundation skills and leisure courses that I believe in enriches the lives of people who experience mental illness." I agree with you Sharon. Education and employment pathways through recovery are incredibly valuable pathways. And people often say they want a job, don't they?

JONATHAN HARMS:
Absolutely.

TINA SMITH:
And yet others think they're incapable of working... and right, wrong or otherwise... don't respond meaningfully to that sort of goal or aspiration a person might have in their life.

IRENE GALLAGHER:
We just have to look at the... The... what's the word? The... the establishment of the peer workforce and the growth. The growth of the peer workforce. People wanting to share their lived experience and wanting to work, wanting to be educated. The cert four in Mental Health Peer Work as well that MHCC... facilitates. You know, there's many people that want to contribute in those ways.

TINA SMITH:
They certainly don't want to be poor and they want something meaningful to do with their days and they don't always have enough opportunity in their lives for that.

JONATHAN HARMS:
And you shouldn't set up supported work systems that are worse than some sort of 19th century (LAUGHS) factory either.

TINA SMITH:
Yeah. So, just another comment before we move on to the fifth area of the framework. And again, I know that these five-minute soundbites aren't optimal but we are collecting all of your comments, questions, examples and you'll be able to read those on MHCC's website along with the webinar transcript and a permanent webcast will be available for people not participating live today. This is from Sandra who says, "I find there is a great demand from mental health consumers and the public trying to find out how to navigate the NDIS. As a Mental Health Consumer Advocate in conjunction with clinicians and the

team, we are struggling to help them as we are unable to grapple with it ourselves'. …a nice comment in that session on…

IRENE GALLAGHER:
Yeah.
(OVERLAPPING SPEECH)

JONATHAN HARMS:
Yeah.

Module 5: Healing Environments/Trauma

TINA SMITH:
Yeah.

OK. Healing environments trauma. We went in (to co-design) sort of going 'people need Community Workers, volunteers and peers need to be trauma-informed... and practising according to the level of skill that's required for their role'. What we heard in co-design was a lot about healing. Not just trauma but healing. And certainly, if you look at first nations across the world, not just here in Australia, that this is a conversation that's very much occurring for them. Yes trauma, but healing needs to sort of be taking us forward. So, the conversation starter is 'can you share an example of a safe and healing environment for a person living with a mental health condition'? Who am I up to?

IRENE GALLAGHER:
Me.

TINA SMITH:
You.

IRENE GALLAGHER:
Yep, I'll give that one a go.

TINA SMITH:
OK.

IRENE GALLAGHER:
Thank you. Healing environment. Well, I guess there's a number of different examples that we can draw on that create a healing environment but I think first of all we do have to think about trauma and we do have to think about where trauma can possibly occur. So we know that there is childhood trauma and... but we also know that people are traumatised by the very services that they're accessing because services are not necessarily trauma-informed. And I don't want to state that as being a blanket, that's every service, because there are some organisations that are doing fantastic work out there. But this is the feedback that we're hearing. That people are actually not just recovering from their mental health issues but are actually recovering from the services that they have access and the treatment that they've accessed as well. An example of environments where people do have an opportunity to heal … I think we need to shine a light on peer work and the values that underpin peer work. That lovely mutuality and reciprocity that equal sharing of power that we see particularly in peer support work is a really great example of potentially what's needed within organisations.

Because imagine if organisations weren't all about mitigating risk and... and looked towards how do we have power dynamics and look towards how do we eliminate those dynamics of power? Those differentiations of power? How do we ensure that people feel like they can contribute and belong and feel part of. These are the sorts of environments that we're going to ensure that manifest healing opportunities for people. I think the peer workforce is a great example. Another that we can think of is the Safe Haven Cafes. Once again where peer workers and also clinicians will be working together. So we know that one has been established in... at St. Vincent's in Melbourne and it is a model that comes from overseas and there's also been an investment by... by our government here in New South Wales to open

Safe Haven Cafes. What's the difference? It's the principles of trauma-informed practise and healing. There's a focus on healing people.

TINA SMITH:
Yeah. Yeah.

IRENE GALLAGHER:
That's OK.

TINA SMITH:
So we have a comment from Graham who says, "Working in nature. Gardening can be a healing environment." So authentic, reciprocal relationships, nature. Yeah, these are notions of not just trauma-informed but healing.

IRENE GALLAGHER:
Healing. That's right, yeah.

TINA SMITH:
Acknowledging trauma.

IRENE GALLAGHER:
Yeah.

TINA SMITH:
Past and possibly even current.

IRENE GALLAGHER:
Yeah.

TINA SMITH:
But helping people to heal.

IRENE GALLAGHER:
Yeah.

JONATHAN HARMS:
Respectful, nurturing, supportive environments are the sort of thing that we need. We know that carers often try and create that in their homes. But when you think about say an emergency department or even a general hospital what where people can be time-poor. They can inadvertently or maybe because they don't see the importance of it be quite pushy and aggressive. Those sorts of things that can retraumatize a person can really be an impediment to progress because people who become subject particularly to involuntary mental health treatment are at high risk of being traumatised because losing that control, is inherently traumatising particularly when things are then done to you rather than with you and this is why having the culture of our mental health services focused on recovery-oriented, trauma-informed practise so we don't reinjure people. And give them the best opportunity to heal themselves is an absolute priority for health reform and requires the engagement of people with lived experience and their families and carers are often the repository of the history of trauma for individual people on how to work with that trauma.

Module 6: Self-management

TINA SMITH:
Yeah. Thanks guys. So Sam has a comment. “I don't believe any environment that a person does not have some control over can be a healing environment." So, that's, thank you Sam, a very sound comment, to move to our last proposed learning module which is self-management. Our goal here was to help learners better understand that self-management is a key recovery tool. Now the co-design feedback we got back is that people with lived experience don't like the term self-management. They find it to be industry speak. There was some feedback that well, if you're not managing yourself that's

because you're not working hard enough and not seeing the problems that a person's having due to their mental health condition that make up psychosocial disability that they actually need support around. A bit of blame the victim stuff. So, the question conversation starter here is ‘how might a person living with a mental health condition describe their journey of reimagining their life’. Their journey of recovery if you will. I think it's your turn Jonathan.

JONATHAN HARMS:
Well, I feel that Irene will have to comment on this one. But look for carers, in particular, taking back some control and autonomy over their life as opposed to their caring duties is an important element of recovery and so consumers taking back as much control over their lives as reasonable when possible is also very important. We don't oblige any other people in our community to only make really good decisions about their health and welfare unless they become subject to involuntary treatment and then we set... start to impose a standard on around their decision-making which is not exactly the same as we impose on everybody else at the same time. And we do that for good well-intentioned reasons but the fact is autonomy and the ability to make good decisions, to manage our own risks, to accept, to understand, what's a reasonable risk to make. Those capacities are a very important part of recovery and that's something that we need to work with a person to develop. Understanding that sometimes I want to make decisions that we won't agree with and that can be very hard for carers when they are trying to motivate someone to stick to the recovery journey which can be a big part of what a carer can do when a person gets discouraged or is down. Feeling downtrodden because of the experience of symptoms.

But building that ability to understand and manage risks. Building that shared understanding of the nature of your illness and disability and what you can do about it with or without the assistance of your families and carers and support workers. That's how we maximise a person's autonomy and that self-management, and that's actually how we help them to reimagine their life. It's important that they are the ones doing that reimagining and that no carer or support, no matter how well-intentioned, colonises that process because that detracts from that very autonomy that we are trying to nurture.

TINA SMITH:
Yeah. So, some of the preferred titles for this area of learning have included self-empowerment, self-determination. If anyone out there has views about what better language might describe this unit we'd love to hear it. I do have a question from someone that asks “how will supported decision-making be embedded across the learning modules”? And at this stage, if you look at the draft framework most of that content will sit within this module as opposed to being embedded elsewhere but it won't just be supported decision-making. It will be decision-making, independent, supported, substitute et cetera. The range of decision-making choices that a person has to pick from. Yeah.

JONATHAN HARMS:
I should say that a lot of carers delighted to hear that they should back off and let people make some choices.

TINA SMITH:
I'm sure it's quite a relief to you.

(CROSSTALK)

Closing Remarks

- **Promotion of reimagine. Today mental health and NDIS e-resource**

OK, we're in the last five minutes of our webinar. So please bear with us. The use of the word reimagine in that last question was intentional. I'm hoping that some of you participating today will be aware of the reimagine.today?

(LAUGHTER)

If you're not, I'd really like to encourage you to look at that resource and we do have another web poll that we'd like to undertake with you.

And I believe it might be going up on the screen in front of you. Although I'm... just struggling to get to it here. OK, are you aware of reimagine.today? Yes or no?

Have you used reimagine.today? Yes or no?

If yes, have you found reimagine today to be a useful resource to you? Yes or no?

So we're just waiting on some of those responses to come in. While that's happening we'll keep - excuse my back - moving through... the remainder of our closing session here.

Live webinar technical problem meant that results were not available and they are provided below

Are you aware of reimagine.today? Yes 37% No 63%?

Have you used reimagine.today? Yes 32% or No 68%

If yes, have you found reimagine today to be a useful resource to you? Result unavailable

- **Next Steps for the CEEP Project**

Next steps for the CEEP project. Well, we'll take the learning from today to further develop the framework then start building the materials. Videos will be part of that. We're going to be filming them late June. Trials August through October. I've mentioned the webinar transcript and webcast on our website and we're aiming for the final learning resources all of which will be up on our website free of charge along with the trial resources from early 2020.

So now we'd like to repeat the web poll that we did at the beginning of today's webinar and... we're asking you once again how familiar are you with MHCC CEEP project? Do you feel like this webinar has informed you about what we're setting out to do and achieve and how we're going about it?

And I'm not getting any live polling results coming through on this delightful little piece of technology.

But we will ensure that they're included in the transcript for this event. It is a shame. I really wanted to see if that... now 86% not very familiar at all had turned around. We'll do something to draw that out on the website after the event.

You will soon be invited to take part in a post-webinar survey where a few more questions time permitting will be asked of you that link to the project evaluation - the project evaluation and trial evaluation the latter of which is being undertaken by the University of Sydney - and I encourage you to complete that survey. The more feedback, the better a product we can end up with. So, thank you for your participation today. We anticipate the next webinar maybe early December. Stay tuned. Irene, last comments before we wind down?

- **Final Comments**

IRENE GALLAGHER:
Just really excited to see how this unfolds. So appreciative and grateful that MHCC's approaching this from a true co-design process. Yeah, so very excited to see how the whole program unfolds.

TINA SMITH:
Yeah, it's a bit daunting sometimes.

IRENE GALLAGHER:
Yeah.

TINA SMITH:
Make the world more inclusive for all people with mental health conditions by June of 2020!

IRENE GALLAGHER:
Yeah.

TINA SMITH:
But again this is one of many, many, many ILC projects happening all over Australia at the moment that are going to create greater inclusion for all people with disabilities and differences. Diverse people of all types as we move forward into the future. Jonathan.

JONATHAN HARMS:
Oh, I just think that if we actually can help train mental health workers and general social services workers to understand the difficulties and the barriers that people face when they attempt to access those services because of their mental health issues or psychosocial disability then we're going to help the carers of New South Wales and Australia a great deal as they get assistance and support to help support their loved one in a way that actually works for them as opposed to them being effectively excluded by services who don't know how to deal with that complex history of trauma that keeps so many people from getting the vital support that they need. So the carers will benefit enormously from getting their understanding shared by the other people who need to support people with experience of mental illness.

TINA SMITH:
Thank you, Jonathan and Irene. Thank you, webinar participants. Thank you, Redback for your support of our event and thank you to the NDIA and New South Wales ILC Jurisdictional Grants for the funding of the project. That's it from us and we'll see you at our next event. Bye.

Webinar Chat: Full list of participant responses to requests for questions, comments and/or examples

- How did you include people who are socially isolated/unable to leave the house in the co-design process?
- Some individuals wouldn't understand the word recovery?
- I love the ideas though in XXLHD - those in practice (delivering services - seniors aren't involving those who are coal face/living aren't being engaged)
- Support outreach community activities/clinical support, so people don't have to attend 'clinical' or traditional mental health spaces that have previously created trauma
- Some NGO's tend to want people to have NDIS packages to provide services to them. This seems to be a barrier to some people who have a mental illness but not of significance to qualify for the NDIS. Is this going to be addressed in this project?
- How do you plan people with mental health disorders to be supported in the community without being funded by the NDIS when the sector is shifting to an NDIS model? As a provider we are seeing people with mental health coming 'through our doors and we don’t want to turn them away based on their NDIS status.
- Will there be lobbying for more mental health funding for community providers?
- Hi, My name is Ana, Recovery for me has been access and interaction with Peer Support Workers and sharing experiences and chat with someone who understands.
- 'Better' isn't any better than 'good'. I'd go with 'fulfilling'.
- I think one of the most important things is to have is meaningful activity. Everyone needs a purpose and hope.
- Acceptance of the " issue" understanding the outcomes and how it makes me think/feel/act. Less guilt and shame around those outcomes. Bringing my experiences to work as disability support worker, family support worker and counsellor.
- One of the best things that happened to me was to get a job.
- Chris, the role of the project is to train community workers to help people get better access to existing mainstream and community services.
- Is anyone else having a HUGE lag in the webinar???
- I 100% agree on how we must somehow change retraumatisation via mental health services. I feel that trauma needs to be more understood in our world, For example There are some great interactive youtube clips for Autism, Im hoping that more can be created as "experiential"l" understanding for all people in our communities. e.g. videos about mental health ED experiences
- Self-empowerment!
- Yes
- Cant see the answer dialog any more
- Questions have not come up yet
- Know about re imagine via the network - have shared as a resource to the network
- Please repost the questinnaire
- There not up1
- I can't see the poll.
- Not seeing the poll, or the last after the 1st
- Was the url reimagine.com.au?
- reimagine.today
- @sean, tnx
- http://reimagine.today/
- Thank you
- Thanks.
- Thank you.
- Julian you can also find Reimagine Today on Facebook. www.facebook.com/reimaginecommunity/
- Will do.
- What is ILC?

- Hello every one, please hit the blue hand top right of the screen to send questions and comments to the panel.
- Also I think having ongoing counselling/therapy available is vital.
- My son is now living supported by people who don’t define him by his medical mental health diagnosis they treat him as an individual and collaborate with him on his goals. this is a first in 12 years of different supports. they are open to learning about how best to support him including learning about trauma informed recovery
- Thanks! Supportive situations are positive interactions with staff, in the small and large interactions. I agree with Jonathan
- To support me to have a 'better' life & when my life was 'better', includes having active friendships, being part of my local community across many areas especially key areas of community inclusion, staying out of hospital.
- Sometime its the issues of engaging the individual associated with the stigma - shame associated with the diagnosis. Being part of the community when they have disengaged
- Also to have employment
- How will supportive decision making be embedded across the learning modules
- Scouting
- Jonathan, you are very right. Participating in your community is very important. I am on board with community based groups. They made me feel part of something bigger
- Uni and employment can be non-mental health community services
- Connecting with local networks - via Local Council Services - Library - Men's Shed etc
- Hello every one, if you have a question or comment for the panel please use the blue hand, rather than this chat platform.
- Hi my name is Sharon and I work at a Community College and this is an area (teaching foundation skills and leisure courses) that I believe enriches the lives of people who experience mental illness.
- Is this webinar available to watch offline at a later date?
- Hi Tracey, sure is!
- Thanks
- Can we get it sent to us, the lag makes it impossible to get a flow in conversation!
- Hello Sharon, Im not sure if it will be sent to all registered attendees, alternatively it will be available on the MHCC webpage.
- OK thank you :)
- Am I reaching too far, if I want to do a start-up (business)?
- Jonathan can you be careful not to hit your stop hitting his microp
- Julian, no - I'm a consumer and I've started up a business, There are plenty of resources to assist you start up a business.
- tnx, Sean.
- Working in nature, gardening can be a healing environment.
- Clency - the Trauma service Heal for Life' run really effective 'non re-traumatising residential courses which we should at least knoe sbout
- The environment of Cumberland Hospital - is the mature garden settings is one of the unique healing environment
- @Leslie, I remember many calming moments there.
- What about self directing rather than self management

Webinar Chat: Questions, comments and/or examples asked of the panel (not all were forwarded on to the panel)

- I find that doctors, psychiatrists, psychologists, nurses and health professionals seems to be quite confronted by a person who tries to 'drive' their care, and seem to be quite taken back if the person is informed and knows what they are talking about. Comments I have received are that I am tiresome, unreasonable, difficult and how dare I challenge them, as they know best, because of their qualifications, experience and/or standing.
- Still got to explore re-imagine as I have only recently found about it.
- Hi, I'm just trying to imagine what the service will look like. Will people meet in the office, or is there flexibility around location (i.e. where they meet), amount of time etc?
- The questions are not coming up
- I can't see your survey?
- test
- test 2
- Ayesha Khan says: How did you include people who are socially isolated / unable to leave the house in the co-design process?
- Ayesha Khan says: Uni and employment can be non-mental health community servicesblank
- Hi my name is Sharon and I work at a Community College and this is an area (teaching foundation skills and leisure courses) that I believe enriches the lives of people who experience mental illness.k
- Corinne says: How will supportive decision making be embedded across the learning modules
- Maybe have more government funded groups to address the principals of anxiety & depression management in the communityn
- Natalie says: My son is now living supported by people who dont define him by his medical mental health diagnosis they treat him as an individual and collaborate with him on his goals. this is a first in 12 years of different supports. they are open to learning about how best to support him including learning about trauma informed recovery blank
- Sean says: 'Better' isn't any better than 'good'. I'd go with 'fulfilling'
- Graham says: Wrking in nature, gardening can be a healing environmentlack
- CEEP is a worthy project, but isn't it covering for the deficits and shortcomings of the NDIS
- This is more of a comment. Instead of asking 'what has happened to you?', could you ask 'what have you experienced?'. The former frames the person more as a victim, and I think the latter is more broad and human
- What is ILC???
- Can you read out the power points for those who are visually impaired?
- Living with mental illness, I would consider living my 'best' life is living My life on my terms. I am a person not a diagnosis though sometimes symptoms raise their ugly heads.
- I'm sorry, but I can't understand a lot of the language you are using.
- Are you going to have 'resources' to assist people with a mental illness deal with anxiety as this seems to be one of the primary reasons for isolation and some lack of community involvement?
- I find there is great demand from mental health consumers and the public, trying to find out how to navigate the NDIS. As a mental health consumer advocate, in conjunction with clinicians in the team, we are struggling to help them, as we are unable to grapple with it ourselves.
- Thank you for presenting my comment on navigating the NDIS. :-) I don't know if the below question, that I believe I submitted, is relevant to this webinar: Sandra says: Some NGO's tend to want people to have NDIS packages to provide services to them. This seems to be a barrier to some people who have a mental illness but not of significance to qualify for the NDIS. Is this

going to be addressed in this project? But if so, time permitting, could you please address? If not, where else may I get this addressed. Thanking you.

- I hope the transcript is de-identified before it is published.
- I don't believe any environment that a person does not have some control over can be a healing environment.
- Important not to forget safety as a key principle
- When were redesigning services - there is a onus on the responsibility of GP centred care - when they are pushed. What about those who require the high (17-24hrs supervised care) at a time when were closing those services - increasing the gaps - patchwork quits acronym.
- first2care.com.au has good resources including diagram of process
- ...sorry that is for NDIS funded clients
- A safe and healing environment is one where there is no swipe card entry systems that can retraumatise someone who has been scheduled / restrained by security. Clinical spaces that do not look like traditional mental health services where trauma has occurred.
- Sandra says: Some NGO's tend to want people to have NDIS packages to provide services to them. This seems to be a barrier to some people who have a mental illness but not of significance to qualify for the NDIS. Is this going to be addressed in this project?
- Google connections Broken Hill, they are doing AMAZING work in social inclusion!
- What I can identify as needed in my local community is Grief Support Groups,,,,,, Domestic Violence Support Groups, and Community Centres where varied activities are available at affordable prices. Also, counselling is desparately hard to find.
- How will supportive decision making skills be embedded in the modules?
- Catch phrases like 'what does this look like?' and 'ramping up' are distracting as they mean something different.

Webinar Survey Results

Eight people completed the post-webinar survey (three people rated the webinar as excellent, 2 as very good, 2 as just about right and 1 as poor).

Question: What enablers and barriers do you identify in relation to community engagement outside of a funded NDIS package for people living with mental health conditions?

Enablers:

- You are 'free' to make your own entertainment
- More access to information about available community services.
- More Peer Support Advocates.
- Willingness of participants to engage

Barriers:

- No access to Day2Day Living Centres day programmes, excursions & holidays.
- No access to the personal networks and connections I established when I did have access to D2D centres.
- No access to physical health supports, that would otherwise be funded by NDIS, eg, dietician, exercise physiologist, CPAPP machine purchase assistance, podiatrist
- No access to mental health supports funding, eg pay for your own psychiatrist & Psychologist visits
- The cumulative effects of long-term social isolation on confidence and motivation to engage community supports
- Lack of awareness of available organisations, activities etc.
- Lack of one-one-one support to find and attend services/activities which is done by support workers for NDIS participants and was previously done by PIR & PHaMs.
- Lack of digital literacy and access, particularly since organisations increasingly communicate and post events online, and registrations/tickets are often online as well.
- Not enough Head Space and Safe Haven Cafe's.
- Lack of supports housing
- Engaging with people who do not leave their homes, the end of the Ability Links program, and not enough alternatives to medicalised forms of service
- Not enough trauma informed training and understanding, these create great barriers
- huh?
- Can you please use plain language?

Question: What are you hoping Community Workers, volunteer and peers will learn from the education package?

- How to calm and 'coax' a mentally person towards taking control of their lives.
- How to more effectively support people to access non-NDIS supports in their community, or initiate their own support groups, services, and networks if none are available locally.
- How to support people in a trauma-informed way.
- Resources and activities available to them.
- Assistance in recovery journey.
- Education, training and employment.
- New approaches are considered and welcomed.
- How to better support person with mental health issues to engage
- Better use of language provide supportive encouragement
- To be flexible to the needs of people, and let them decide on the direction of their journey
- How best to understand trauma informed practice and person-centered planning and advocacy and be trained in these areas.
- What package?

Question: What aspects of the package do you think might be most helpful/least helpful?

Most helpful:

- Module 1 Recovery
- Module 6 Self-Management
- A trauma-informed approach.
- Education and training.
- Individual needs are respected and acknowledged.
- Online resources.
- Respectful principles around co-design, empowerment, self-determination etc

Least helpful:

- None. All intervening steps are needed to get to the last stage.
- Overall, I can't see anything that is not helpful. Given that the project is about supporting people outside of NDIS package supports, learning module 4, 'Mental health & NDIS/ILC' may arguably be the 'least helpful'. with that in mind, module 3 'Supports and services' may be the 'most helpful' especially if the content involves navigating non-mental health support agencies like 'Centrelink' and 'FACS'.
- What package?

Question: What is missing?

- Possibly, 'gaining of medical insight' in the patient. May be being covered by Step 6, but I'm not sure.
- How to handle relapse - do you go back to the beginning, or can you back up a bit?
- It's not necessarily 'missing' as it may already be incorporated into module 3 and/or 6, but I think the program may benefit by including specific information about accessing supports around drug, alcohol and tobacco use; gambling; financial management; homelessness; domestic violence; and other recognized 'non-mental health' determinants and co-factors of psychosocial disadvantage and distress
- More practical tools or community-based initiatives
- From what?

Question: What are your perspectives on what would enhance the package going forward?

- Implement at small scale
- Lessons learned
- Refine
- Test and verify
- Next step
- Till you reach completion
- Lessons learned
- Validate
- Scale up to next iteration
- Repeat the cycle, till complete
- Periodic reviews
- See previous answer
- List of services available
- Further clarity on what the program will look like, and how to access it.
- What package?