

for co-design and *working with* enthusiasts

# with us



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# Big thanks...

Cover artwork by the wonderful **Nina Sepahpour**, a textile designer and freelance artist who works on projects across illustration, print and graphic design.

Exploring layers of motif, pattern, shape and colour, Nina is passionate about creating engaging and playful designs that bring stories to life.

She is driven by innovation, excited by nontraditional methods of work, community projects and collaboration.

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Big thanks to **Ellen Muller**  
For her editing + copywriting services

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High fives and huge thanks to all of the awesome contributors to Issue 1 of **with us**, and extra special virtual hugs to a very patient behind the scenes support crew who have provided moral support and gentle arse kicking to keep things on track. (you know who you are)



We acknowledge the Aboriginal and Torres Strait Islander peoples as the first inhabitants of this nation and the traditional custodians of the lands where we live, learn and work. We value their cultures, identities, and continuing connection to country, waters, kin and community. We pay our respects to Elders past, present and emerging.

We acknowledge and pay our respects to the voice of lived experience, their families and support people; to those who use their personal experiences of ill health or circumstance in the hope of shaping a better future for themselves and others. We thank them for finding the extraordinary strength and determination it takes to revisit often painful memories in order to make a difference.

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# The magic of *working with*

Welcome to the very first edition of **with us**.

A place to shine a light on co-design + **working with** lived experience done right.

If you have met me over at The Better Together Collective you will know that.



## **I have a co-design and great lived experience engagement dream.**

A dream where...

- real people are genuinely (and consistently) at the heart of the design, development and delivery of products and services meant for them. Where people + organisations work purposefully together to make lives better.
- it is standard that organisations seek to meaningfully embed the voices of lived experience across their work, in ways that aren't just transactional but transformative for all involved.

I dream of times where the dysfunctional siloes of our health and community services come crashing down. Where we take off our collective professional hats, ditch the hierarchy, labels and titles; remove the barriers, the power imbalances, and see ourselves in each other's eyes.

Of times where we purposefully build opportunities + spaces where people feel safe + heard. More chances to be curious and open about how things could be different. + to work together to make change real.

**Co-design, co-production, co-creation, participatory design... all the many names + ways of working with are far from new.**

**Working with** people who are experts by their lived experience in these ways is gaining traction and fast becoming both a requirement + expectation... especially within the health and social sectors, where there is so much work to be done.

But many of us who are out there in the trenches, know that what it looks and feels like in real life from place to place, project to project can be hit and miss.

Great work IS happening, and I truly believe that if we turn up the volume... and shine a light on the people, projects and change makers getting it right. We can amplify the good... we can make doing this well the norm, not the unicorn.

I figure that we do what we see, so in the spirit of **a person who is passionate about the value and power of working with people with a lived experience,**

**with us is...**

A FREE quarterly e-zine to shine a light on the many awesome humans who are out there doing great work amplifying and learning from the voices of lived experience and getting the culture of projects that involve **working with** right.

A place to celebrate + recognise the efforts of those who are out there having a crack. Doing it for real. Those who appreciate + genuinely want to do this work in the spirit that it is intended. Those who respect + want to learn from the pioneers who have brought us this far and are looking for ways to unite against the common enemy of tokenism, buzzwords + sh\*t co-design projects and build a future we can all be proud of...together.

If you believe in the power of doing with (not to), of sharing power, of building new (and improving old) things together.

I hope that you find **with us** to be a shiny little virtual disco ball of sparkle + hope... and that through it, you find ways to connect, conquer, celebrate and grow.

Most of all, I hope that you recognise the sweet sweet smell of possibility in the stories and insights shared and that you use them to inspire and inform your own **working with** adventures.

*Sue*

# Co-design beyond sticky notes

with Kelly Ann McKercher

Kelly Ann is a leader to watch and we are loving watching their co-design star rise. They have been kind enough to share some of their wisdom and magic in the very first edition of **with us**.





# Co-design beyond sticky notes

with Kelly Ann McKercher

Like a breath of fresh hopeful air in the co-design space, Kelly Ann's book *Beyond Sticky Notes* has become a must-read for anyone who believes in the power of working with not 'doing to'. It's powerful, practical, kind, simple + REAL all at once. - and has spoken to the hearts + minds of so many already.

In everything they do, their passion for great co-design as a social movement shines through unwaveringly. With a community of practice, a book club and growing following, their capacity for connecting and building community is nothing short of inspiring.



**You have such extensive experience across both Australia and New Zealand...**

**Can you tell us a bit about your story and the work that you are doing now?**

I grew up at the base of a volcano in Aotearoa, New Zealand with a laboratory scientist mother and wizard (no kidding) father. I wanted to be a fine artist or a funeral director – but was begrudgingly persuaded to pursue a ‘real job’ and studied design. Lucky timing,

I fell into Design for Social Innovation and Cultural Anthropology at Te Herenga Waka, which landed me a great job out of university at a design studio that felt more like a family than a workplace. I had great mentors that believed in my capacity to take on far more leadership than I was probably ready for (oh, hindsight!) After working on a series of insurance, banking, agriculture and bra projects (yes, really) I discovered that commercial design wasn’t for me and that I was much more interested in design for social and environmental outcomes. Fast forward roughly ten years I’ve worked across a bunch of industries, agencies, countries and levels of design (product, service, system, policy) before landing on Wangal and Gadigal Lands, where I now live. I’m currently working in the NSW government in a design leadership role and loving the challenge, teaching and hosting communities of practice that seek to create stronger connections and coherence across design for social impact in Australia.

**Why are you so passionate about co-design?**

Frankly – we all deserve better. We deserve to be better involved in the decisions that shape our lives, to be able to use our lived experience to help others avoid the poor outcomes we endured, and to more deeply connect with and learn from others who we wouldn’t typically work alongside. Many styles of design are very transactional – concerned with producing outputs and things. Amidst the climate crisis, increasing polarization across the political spectrum and communities that are made increasingly impotent by authoritarian services (McKnight, 1995) I think we have to move from transactional design, to transformational design (I explain this, soon). The mindsets and methods of co-design is the most powerful way that I know how to make those transitions.

### **Can you tell us a bit about the difference between transactional and transformative co-design?**

Designers and design processes have long focused on making ‘things’ such as products, services, brands and buildings. While those things matter, they often fail to shift relationships between people with lived experience, communities and professionals. By contrast, transformational design focuses on relationships and outcomes. While we shouldn’t do away with transactional co-design entirely, I think we need to shift our focus to how we design together (the process), not just what we make (the out-put). This book focuses on transformational co-design.

When people with lived experience, professionals and provocateurs work in equal partnership across the design process, it’s common to see new relationships and possibilities for different systems emerge. Often, co-design enables people to see themselves and each other differently. Transformational co-design can involve professionals discovering that people with lived experience do not need ‘empowering’ or to change in any way, but rather they must be listened to.

**A focus on things, ticking off tasks and racing to finish a process is what I term transactional co-design.**

Kelly Ann McKercher

### **Best advice for new co-designers. What are the 3 most important things to get right?**

- Focus first and foremost on relationships – build them, cultivate them, care about them. If you don’t have time for relationships you don’t have time for co-design.
- Don’t obsess over tools or a specific method. Instead hold methods lightly and curiosity tightly – look outside of design and inspired to be design-infused (as x describes) not design-led
- Find your place to stand, that connects with your identity and lived experience.

*Kelly Ann McKercher is a designer and writer living on stolen Wangal and Gadigal Land. You can find out more about their work, at: beyond sticky notes. Get Kelly Ann’s book here: <https://www.beyondstickynotes.com/tellmemore>*

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**Kelly Ann McKercher**

# The power of partnering with those who are most affected

## Morgan Cataldo

Morgan is the kind of leader to love. Strictly no bullsh\*t with a can-do, what-you-see-is-what-you-get energy & style. Knowledgeable and respectful of those who have paved the road to where we stand today, she is a change-maker to watch, who is forging her own unique path forward.

Passionate about nurturing and amplifying the voices and potential of young leaders with a lived experience through her role at [Berry Street](#), where she heads up [Y-Change](#) – a social and systemic change platform for young people with lived experiences of socioeconomic disadvantage. Her mission is to integrate lived experience driven approaches to Australian and international social systems through participatory practice and design.

Fiercely proud of and inspired by the people she works with, Morgan is a champion and enabler of all things lived experience, co-production and meaningful participatory practice (aka working with). Morgan was kind enough to talk to us about her story, the power of grassroots engagement, her approach and her hopes for the future.



Morgan has worked within the for-purpose sector for the past ten years in a range of policy, advocacy, and service development roles. Dedicated to transforming traditional ways of doing advocacy, her work centers the lived experiences of those whose voices aren't traditionally heard to influence social and systemic change.

She currently advises and supports organisations on the role of consumer participation and how to meaningfully partner with affected communities to design and shape better policies, services, and practice.

Morgan is currently the Senior Manager Youth Engagement at Berry Street, one of Australia's largest independent family service organisations. In her role here, Morgan leads organisational and sector discourse and development in relation to lived experience work, youth engagement and knowledge exchange practices with young people.

She also advises, coaches and works on strategic projects with other organisations through her consultancy practice and sits on the [Council to Homeless Persons Board](#).

**Can you tell us a bit about your story and the work that you are doing now? How did you end up in this space and working with such awesome humans?**

I like to reflect on how I got here through a 'trifecta of experiences' – being diagnosed with severe scoliosis at 13 years old and needing to undergo three stages of spinal fusion surgery, experiencing anxiety and deep clinical depression during my most formative years, and then leaving home at 21. I became a "service-user" of the health system, the mental health system, the homelessness system and many other intersecting systems.

I took away two key things which still guide me to this day:

1. Why aren't the people using services helping to design them?
2. If my experience has been this harmful, what must it be like for more marginalised groups of folks?

This trifecta of experiences, and my survival through them, helped me to access a fierce drive to support other people doing it tough. I've dedicated over ten years to learning, studying, collaborating and working with individuals and organisations to reimagine the capabilities of people who experience oppression from systems that were and are meant to help them.

My current work finds me as the Senior Manager Youth Engagement at Berry Street. I get to work with a group of phenomenal young people who are Lived Experience Consultants who teach, challenge and change me every day. The rest of my time is dedicated to supporting organisations better partner with folks with a lived experience and understand how to do this meaningfully and supporting folks with a lived experience get access to what they need and to strengthen and realise their many capabilities.

### **What makes you so passionate about the work that you do?**

Poverty and oppression is a political choice and people should not be experiencing it. I am so furious and tired of getting to know and work alongside remarkable people who just don't have access to what they need to do what they want to do in the world. I want to see folks who have suffered and continue to suffer get access to what they want and need and live lives of beauty, rest and repair.

### **What about it lights you up?**

Seeing people grow into the people they already are, uncovering the layers of shit that have been projected onto them from other people, harmful systems and toxic ideologies. Being witness to this process of discombobulation to integration and then metamorphosis – I don't really have language for it. It's beyond a privilege to come alongside folks who are carving their own paths. There's serious magic in the misfits and most people can't see it. I'm here to help bridge that gap, make the invisible visible.

### **What has taught you?**

My life experiences, mostly – WHO has taught me. People teach me, daily. Being in relationship, not being in relationship, relationships being repaired, relationships falling apart. Having my heart broken, opening it up again anyway. Truly believing that something else and other realities are possible. Believing that 'the othered' are here to create widestreams, not fit into the mainstream (nod to [Pat Deegan](#)). Consistently taking huge leaps of faith (nod to [Lauren Oliver](#)) and learning to trust people. My wounds teach me, my shadows teach me. Power is always teaching me..

### **When working with people who are experts by lived experience, what are the most important baseline factors that organisations need to get right from the outset and maintain consistently throughout?**

Stop thinking that folks with a lived experience are here to fit into a predetermined structure. That's co-option. Those who have chosen to work in professions where they are explicit with their lived experience have often done so at enormous risk to their livelihoods and don't make the choice lightly, and in many cases – don't even get to make the choice at all, they're so embedded in service systems already. It takes funding, resources and deep and critical reflection – on the part of organisations and on the part of folks with a lived experience. The difference is that organisations have resources and marginalised folks generally don't. So, it's a matter of spending privilege through taking risks.

I often talk about the iceberg analogy – there's so much going on in our practice under the surface that is unseen and so it becomes invisibilised and unfunded labour. For years, I took personal leave from my jobs and paid for myself to take part in specialised training that I knew I needed. I've been incredibly supported by many organisations and for that I am grateful – and – I've spent a lot of



time and energy trying to educate people about what is needed before I ever get it. We often say that our work is ¾ 'educating people' and then the real work can start.

For those of us who identify as the bridge-builders, this work is tough. Being a systems translator is painstaking but it's the only work I want to do. It gives me so much joy and when I see organisations begin to get it right or take those risks to move closer to meaningful participation – it feels worth it.

**Listening to – and working with – community means we get to learn from one another, we get to engage in conflict, we learn how to heal, we learn how to come back to ourselves.**

Morgan Cataldo

### **What is the ripple effect of getting those baseline commitments right?**

We get to see folks with a lived experience be supported and grown in truly inclusive ways – they blossom, they get to access decision-making power, they get to be active systems shapers rather than forced to be passive recipients or beneficiaries. They get to shape futures.

Organisations get to work closer to the ground, their work becomes more meaningful because the folks who are most affected have been brought closer in. I've had many people reflect to me over the years that this work 'brings us closer to showing up as whole humans' and I tend to agree. This doesn't mean it's not hard, that there's not days where I throw my hands up in the air and wonder why I'm doing this etc. but the shifts I get to witness in so many people through moving closer to their humanity – again, I don't have words for that. It is a gift.

### **You've had so much experience in this space. What frustrates you, and what do you find to be the biggest barriers to meaningful engagement?**

I think the key thing that frustrates me is the lack of analysis we have around [class](#). Seeing shiny new programs with lots of money and capital clean up, while folks who have been working tirelessly in community building real impact are often overlooked because they won't play to the mainstream. They don't have marketing teams or business development staff. They have community, guts, and unique maps they've drawn as a byproduct of surviving. Why isn't that enough?

The problem is not about what communities have to get better at doing, it's mainstream systems with loads of resources turning inwards to reflect on their supremacy. Are you someone who continually gets invited to speaking gigs? How about creating space for folks with less capital than you to step up. Are you an organisation that gets money thrown at you? Consider partnering with a lesser known community organisation who have exceptional practice you need to learn from.

I see a lot of ‘recreating the wheel’ and folks not honouring the work and vision of the giants in our field due to people being in competition with each other. If we’re truly dedicated to the work of social and systems change, we need movement building. We need to face and make visible obstacles like market competition – a product of our economic models – and remember what we’re here to do. We’re here to [do justice](#) (nod to [Vikki Reynolds](#)). We’re here to dismantle what’s not working and create more dignifying experiences for people. That’s never going to happen if people are climbing on top of and over each other to be the ‘first’. We need to make ego-driven activity visible – we need to talk about the elephants in the room or they will keep controlling the narrative, our intentions and decisions.

**What do we stand to gain as a community by finding and building meaningful ways to listen and genuinely hear what’s happening at that grassroots level, to seek to understand that rich diversity of experience and voices and to harness the power, potential and wisdom that only this kind of work and engagement can unearth and contribute?**

History tells us that we gain everything. When the most marginalised win, we all win. Do you want to keep walking down the street and seeing folks sleeping rough? Do you want to keep hearing about Aboriginal deaths in custody? Do you want to hear about folks locked up in detention for wanting a better life for themselves and their families? I don’t because it hurts my heart and it’s fucking cruel.

As I said earlier, allowing this stuff to keep happening are choices we’re all making due to widespread apathy and ignorance. If you need to justify humanity from an ‘economic standpoint’, it’s this – invest in people and we all win. Punish people and we all lose. Investing in seeing communities thrive means the survival of all of us – it’s harm reduction.

Listening to – and working with – community means we get to learn from one another, we get to engage in conflict, we learn how to heal, we learn how to come back to ourselves. Community isn’t something to idealise and romanticize or the ‘key’ to everything – I would remind people that unchecked and uncritical beliefs around ‘community’ can turn into groupthink or cult dynamics, but what I do believe is that we need to learn how to be together. Not to ‘be one’ – but to fight for the world we want to make manifest.



Illustrator: Chadai Chamoun: <http://chadai.pb.gallery/>

 @oxidised.c on Instagram

### **What's your favourite co-design or co-production project that you've ever worked on and why?**

What I'm doing now with Y-Change. Something that the team didn't even consider to be co-design or co-production because they didn't speak that language. They saw it as a platform, as meaningful engagement and participation. That language made sense and so it was about translating what is already happening inside of this context and drawing patterns to the systems change and design community – not erasing the brilliant work that's already been done or trying to make it fit into more colonised/conventional concepts.

It feels like everything I've been through and learnt has led me up to this point. I watched Y-Change for years and circled around them as we used to bump into each other a lot with the work we were each doing. I had so much respect for what they were building and the ways they were going about it. I never imagined ending up at the heart of it like I have but now that I'm here, it makes so much sense.

I get to be part of a body of work that has stretched across 13 plus years. I get to honour the vision of the original founders and embody the fierceness in which Y-Change was birthed inside of. Y-Change was imagined out of fury for the harm that was being done and continues to be done, and out of courage and love for the young people who survived and became circuit breakers. Being able to carry on this legacy feels like the honour of a lifetime, truly. I don't ever want to live in a world without Y-Change in it.

We get to reject the limitations placed on us by society as people with a lived experience being somehow 'lesser' and in need of 'empowerment.' We get to place justice at the heart of our work and move towards healing, together. We get to make sense of what we've been through in the hope that the stream we are widening means that those who come after us don't have to fight the same fights.

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**Folks who have been working tirelessly in community building real impact are often overlooked because they won't play to the mainstream. They don't have marketing teams or business development staff. They have community, guts, and unique maps they've drawn as a by-product of surviving. Why isn't that enough?**

Morgan Cataldo

### **None of us are perfect. What has been your biggest stuff up, and what did it teach you?**

Thinking I was somehow here to change the world or ‘burn the system down’. How much unchecked white privilege I held and how that influenced how I saw folks of colour and their struggles. Moving into spaces with a predetermined idea of what I thought needed to happen without putting my senses to the ground. I can think of times I worked alongside folks to support them in telling their stories and I wonder; did that do harm? Was that the right way to go about encouraging them to speak their truth?

My practice, worldview and identity has evolved so much and at every stage of that evolution, it’s been critical for me to reflect on what drives me and my intention. Is it to be the hero of someone else’s story? Is it to be liked? Is it to be a pioneer? Or is it to do the work that feels like the right work to do, regardless of recognition (nod to [Margaret Wheatley](#)). I continue to strive for the latter.

### **If you could offer advice to other awesome humans starting out in your field of work, what would that be?**

You’re not here to save anyone. Focus on partnership and do your work. Reflect on and study the giants of those who have come before you. Your inner work will never end, let that be a source of joy and the roots you dig deep into. Learn about the ways you show up as the oppressor, learn about intersectionality and white supremacy. Invest in people and relationships. Remain humble. Stay curious. Ask lots of questions all the time, try not to land on answers just focus on building context (nod to [Nora Bateson](#)). Trust your instincts but don’t let your hunches go unchecked for too long. Learn to trust people. Be trustworthy. Trust the process, let things be and get messy. Come alongside, always.

### **What gives you hope for the future of this way of working?**

Revolution in how we think about and approach care and support in the service sector. [Desupremifying](#) our practices and processes. Seeing folks who were once othered become our guides and teachers. Being witness to marginalised folks thriving, full of joy – enjoying their lives.

**We spoke recently about a shift of focus to changing what we can change, to using our energy to build the new and how staying in our lanes, working with like-minded souls and focusing on the things that matter has made such a difference. What has that looked like for you, and what do you most love about the people you've met since you made that decision? / has anything shifted?**

Everything shifts. I stop focusing on comparison and what I don't have and instead lean into the joy, needs and desires of my relationships and communities. My energy shifts to focus on imagining otherwise. My actions readjust to what I can do in this moment, right now.

I think of these two quotes from [Alok](#):

1. *"Comparison is creativity's curse. Genius is the ability to orbit elsewhere, imagine otherwise."*
2. *"Find immensity in what they call insignificant."*

This one from [Buckminster Fuller](#):

*"You never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete."*

You can get in touch with Morgan here:



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**For those of us who identify as the bridge-builders, this work is tough.**

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**Morgan Cataldo**

# The story of LGBTI Connect...

**We recently spoke to Robyn Lierton (Community Engagement and Diversity Manager at ECH ) who led the co-design process used to research, create and run LGBTI Connect - to find out more about what this fantastic project looked like in real life.**

As a leading not-for-profit service provider; the goal of ECH (Enabling Confidence at Home) is to promote self-determination and enable people to have the best possible life as they age, and we're proud of our strong commitment to inclusion.

In October to December 2016, I ran interviews with 13 older lesbians, gay men and transwomen, asking, "if you could wave a magic wand, what would the perfect aged care service look like to you"?

These interviews were driven by the ECH strategic plan (2015-2021), where our objective was the development of a tailored service for the Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) community.



Image provided by ECH (Enabling Confidence at Home)



We know that the most effective way to design a service is to co-design it with the people that will use the service, in this case LGBTI people aged over 55. Through interviews, we explored with participants what is important to them as individuals and members of the LGBTI community - their hopes and fears about ageing and their experiences accessing a range of services.

The participants reported that they are more likely to engage with a service provider that has

been recommended by someone they know; they would prefer to speak with another member of the LGBTI community in order to reduce fears of discrimination or their needs not being understood, and they would like to connect socially with others from the LGBTI community in order to reduce social isolation.

Drawing on these findings from the interviews, the participants later took part in a service design workshop, to create a unique service that meets the needs of LGBTI people aged over 55.

LGBTI Connect was the service idea that emerged from the workshop, with the team developing its four core functions:

**Access:** Provide a non-discriminatory access point, through the delivery of a peer-to-peer service, with five LGBTI older people supporting other LGBTI older people

**Navigation:** Guide people through the process of accessing aged care services, including the My Aged Care referral process

**Advocacy:** Attend the first appointment with the ECH care coordinators, if required, and provide an ongoing touchpoint for LGBTI clients

**Connection:** Facilitate social connections through the delivery of monthly social events called the Rainbow Social Program, and an individual visiting program for people unable to attend group activities



Image provided by ECH (Enabling Confidence at Home)

We understand that the people who are going to be using the service are the experts in the area and they would be able to guide us about what was likely to improve the wellbeing of LGBTI people aged over 55. Thus we ensured that the voices of LGBTI people were central to the design, development and roll-out of the service through continuously going back to the co-design participants to seek advice and direction.

The co-design participants all identified as lesbian, gay or transgender, and were chosen across a number of spectrums, including age (55–78 years), physical abilities (frail-fit), social connectedness (isolated-connected), and services used at home (none–5+). Each participant was heavily involved across the life-span of the project, including: the functions of the service, designing the profile of the LGBTI Connect role, participating in role-plays to identify issues or areas that required additional thought and participating as clients in the initial six-month trial period. Two of the original co-design participants were even employed as LGBTI Connectors and continue to work in these roles three years after the role out of LGBTI Connect.

There have been many, many highlights throughout the life of LGBTI Connect. The first being the development of this fantastic service that is very unique in Australia. Before the development of LGBTI Connect, ECH was struggling to find and connect with older LGBTI people, as many same-sex attracted and gender diverse people are fearful of reaching out to service providers due to a fear of discrimination.

ECH understands that LGBTI people are more likely to be socially isolated as they age as they are less likely to have biological family members to provide support. Additionally, LGBTI people are more likely to live with chronic health conditions but are less likely to seek assistance. With this in mind, we wanted to support LGBTI people as they age, but we really wanted to understand exactly the type of support people from the LGBTI community were seeking.

Three years down the track, we contact over 150 LGBTI older people every month through our range of social and service navigation programs, helping people stay connected with each other and providing timely support in the home when they need it. During our recent Rainbow Tick re-accreditation, one of our clients stated that they “have never felt happier or healthier since contacting LGBTI Connect”.

There have been many fantastic stories of the ways that LGBTI Connect has improved the lives of older LGBTI people in South Australia. About six months after LGBTI Connect had been established as an ongoing ECH service, an 80 year old Independent Living resident contacted the LGBTI Connect team, wanting to meet other same-sex attracted and gender diverse people through the Rainbow Social Program. She said that, although she has known since she was a teenager that she was

same-sex attracted, she has never openly identified lesbian. It was only now, as an 80 woman, that she feels safe and supported enough to openly identify as a member of the LGBTI community.

This is only one of many happy stories of people feeling safe, welcomed and supported by members of 'their tribe'. In 2018, the LGBTI Connect service was recognised by the Australian Aged Care Quality Agency as providing outstanding services to the LGBTI community in South Australia, by being awarded the Best Practice Commendation Award.

ECH and the LGBTI Connect team are very proud of LGBTI Connect and were very pleased to be recognised by the aged care quality agency in this way. One of LGBTI Connect's greatest strengths is the team's ability to listen and respond to the needs of older LGBTI people in our community. This year the team plans on reaching out to LGBTI people in regional areas of South Australia to provide support, as this was raised as a significant gap by LGBTI people in these areas.



Image provided by ECH (Enabling Confidence at Home)

*You can read more about LGBTI Connect here:*

 <https://lgbticonnect.ech.asn.au/>

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# Co-design + working with is not new

We all know that co-design + **working with** people who are experts by experience is not new.

In the spirit of us all learning and growing together, here are some key resources, some people to know and to watch out for, according to our key contributors.

## Rockstars

### Shining stars of influence + inspiration

*Adrienne Maree Brown*

*Sloan Leo from FLOX Studios*

*Lesley-Ann Noel*

*Morgan Lee Cataldo*

*Antionette Carroll*

*Ingrid Burkett*

*Penny Hagen*

*Gael Surgenor*

*Kataraina Davis*

*Sacha Costanza-Chock*

*Sarah Fathallah*

*John McKnight and the Careless Society*

*Adrienne Maree Brown,*

*Kelly Ann McKercher,*

*Kylie Long,*

*Lauren Oliver,*

*Jackie Crowe*

*Professor Pat Dudgeon*

*Leilani Darwin*





# Holy Grails

## **Holy grails of resources (frameworks, guides, courses, books, podcasts)**

*The Value of Lived Experience in Social Change*  
by Baljeet Sandhu,

*A Delicate Activism* by Allan Kaplan and Sue Davidoff,

*Justice-Doing at the Intersections of Power*  
by Vikki Reynolds,

*Intentional Peer Support* by Shery Mead

*Trauma Informed Facilitation workshops* by Liz Scarfe

*Designers critical alphabet cards*

*Co-design Bootcamp* by Emma Blomkamp

*Beyond sticky notes co-design for real*  
by Kelly Ann Mckercher

*Design Justice* by Sascha Costanza-Chock

## **Pioneers and wavemakers (activists, artist, philosophers and organisers)**

Angela Davis, Audre Lorde, Grace Lee Boggs, James Baldwin, Lilla Watson and Vikki Reynolds.

## **Organisations who deserve a high five for giving all things working with lived experience a red hot go!**

*Launch Housing, Mind Australia, SHARC and  
The Constellation Project*

*ECH LGBTI Connect*

Artwork by Nina Sepahpour

 [ninasepahpour.com](http://ninasepahpour.com)  [@ninasepahpour](https://www.instagram.com/ninasepahpour)

# Talking cultural safety

**Leilani Darwin**

Leilani is a proud, strong Aboriginal woman who has been touched on a personal level many times by suicide and mental illness. She is a Quandamooka woman, whose ancestral home is Stradbroke Island. Through her own lived experience and work within the sector, Leilani is a powerful advocate for Aboriginal and Torres Strait Islander led, culturally informed practices within mainstream services.

Leilani's passion, tenacity, and unwavering willingness to speak the truth even when her voice is shaking, her leadership and the difference she's made in this space is nothing short of awe inspiring. She took some time out of her busy schedule to talk to us about her work and why it matters...



### **Can you share a little about the work that you do now and what led you to this point?**

I find myself in a unique and privileged position to advocate and champion the rights and expertise of Aboriginal and Torres Strait Islander people in suicide prevention and mental health initiatives. I'm the Head of the Aboriginal and Torres Strait Islander lived experience centre. This opportunity has come through a wide range of work and in partnership with the Centre of Best Practice in Aboriginal and Torres Strait Islander Suicide Prevention under the leadership of Professor Pat Dudgeon. As a young person who experienced grief, loss trauma and survived several suicide attempts I never contemplated that I would be doing the work that I am. I genuinely believe that I am ancestrally led in my journey and as the doors open I choose to walk through them even when I feel that there are so many more who could do better.

### **What have been your greatest barriers and enablers?**

As I walk through this journey it often feels like groundhog day. You are having to fight the same battles and truly try to shift others' understanding and capacity to engage with and work in genuine collaboration with me and my community. I rely on Pat Dudgeon and others as role models and mentors, reflecting that if they can continue so can I. We don't always win our battles, though in my experience I prefer to be a truth teller in a respectful way with hope that along the way we make changes. That we empower Indigenous led responses, leadership and governance.

People with open minds and hearts who are willing to learn and have genuine collaboration are key if we want things to change.

### **Like co-design, the word 'cultural safety' is thrown around a lot. What should it look like in real life... what does it look like done properly?**

It's very important to understand who you are wanting to work with, be it a partner or collaborator. We don't consider diversity enough, it's often after the fact and not at all stages. When you work with people to consider cultural safety, specifically people from those cultural groups you will ensure that any potential to be unsafe with regards to cultural practices, protocols and processes will be reduced. Seems to be common sense however what we see is often well intentioned people who just forget or don't consider that something they think will work might not be safe.

**In regards to the cultural safety of working with projects, what do organisations need to appreciate and understand before they even attempt to start?**

Know your area, who are the traditional owners, are there any governance groups that should be consulted in the first instance. They should also seek to understand and consider what are some of the things that are happening in the local area, are different groups not getting along? What would you need to do to engage everyone?

**Who is a person in this field who inspires you?**

Professor Patricia Dudgeon, she has been such a trailblazer and for all this time has persevered through processes and decisions that can be so frustrating, so I enjoy seeking her advice and mentoring.

**“People with open minds and hearts who are willing to learn and have genuine collaboration are key if we want things to change.”**

*In addition to her current role as Director Aboriginal and Torres Strait Islander Strategy at Black Dog Institute, Leilani also sits on several working committees and advisory boards at the National and State level where she advocates for greater inclusion of those with lived experience alongside the need for cultural leadership, self-determination and culturally safe services and policy reform for Aboriginal and Torres Strait Islander people. You can find out more about Leilani’s work here:*

 [linkedin.com/in/leilani-darwin-87927b136/](https://www.linkedin.com/in/leilani-darwin-87927b136/)





Stradbroke island image via Upsplash

# Measuring what matters

**Jo Farmer**

Meet the awesome Jo Farmer. Jo is a policymaker and evaluator, working to improve the lives of people living with mental illness and trauma. Jo has lived with mental health conditions for as long as she can remember, and this lived experience is integral to her work.

Jo took some time out from her busy (+ blossoming) consulting schedule, to share her thoughts + perspective on the value and importance of evaluating in partnership with people with a lived experience.



## **Tell us about the work that you do, and how you came to be here doing it?**

In my early career, I worked in the health policy sector, conducting research and designing policy on a range of issues, but mostly health workforce. Like most evaluators, I fell into it: I got a job with an evaluation consulting company without any experience with evaluation. I realised I loved this way of looking at the world – using data and stories to improve what and how we implement policies and programs. At the same time, I've lived with mental illness since I was young and outside of work, I was finding ways to put my lived experience to use, volunteering with organisations and contributing to advocacy. In 2017, something clicked – I could combine this lived and professional experience to help build a better mental health system. My favourite projects are those that put people with lived experience front and centre, co-designing and evaluating in partnership.

## **Why evaluate in partnership with lived experience?**

People with lived experience have so much to add at every stage of the evaluation process. In designing evaluations, they identify evaluation questions that service designers might never think of. Consumers and carers provide insights that might never be captured if we just evaluate using program administrative data and staff experiences. In analysis and reporting, people with lived experience bring their own lens to the data, to interrogate it and make connections that others might not make.

Currently, I think people with lived experience are largely confined to a role as research 'subjects' in evaluation. I'd love to see more lived experience co-evaluators play an active role throughout the evaluation design and analysis processes.

I love seeing commissioners of evaluations that recognise the value that people with lived experience bring to a project. It's great that there's a growing acceptance that evaluation in partnership with lived experience is vital

Jo Farmer

## **When you get a request to be part of a project, what are the things that make you fist pump, and what are the red flags?**

Often they're the same thing! I love seeing commissioners of evaluations that recognise the value that people with lived experience bring to a project. It's great that there's a growing acceptance that evaluation in partnership with lived experience is vital. But it also means there's a risk that 'lived experience' and 'co-design' are thrown in as buzzwords to a request for quote, without genuine recognition of what this means for a project. Meaningful partnership takes time, capability and resources. Commissioners have to be willing to commit to that if they really want to commit to co-design and co-evaluation.

### **What are the challenges with measuring in the mental health sector?**

One of the hardest things about measuring what matters in the mental health sector is that so many of the concepts we're measuring are not visible. What does increased mental wellbeing look like? Increased confidence? Increased happiness? Compounding this, many of these concepts are understood differently, and impacted by so many factors like culture, family and previous experiences.

That's why it's so important to work with consumers to understand what these concepts mean to them so we're not imposing artificial, overly clinical measures on the complexity of the human condition. Do the concepts we're currently collecting data on even matter to consumers?

I'd love the health system to be more welcoming of qualitative data that allows the space for these complex concepts to be explored – this is where co-evaluation with lived experience flourishes.

### **What are the barriers to co-evaluating?**

I mentioned before that one of the biggest challenges is having enough time and resources to complete a project. I've worked on many projects where commissioners expect we can design evaluation frameworks in two weeks. That might be possible, but not if you want to get a sense of what concepts matter to those with lived experience, how you might define them, and then refine a measurement and research approach that has been co-designed with consumers. Partnership with people with lived experience is not a once-off interaction. You have to build in time and mechanisms to go back-and-forth, to wrestle with some of the difficult ideas.

Partnership requires evaluators to cede some of their power back to people with lived experience. This is not something all researchers and evaluators are comfortable with – many of our research 'structures' are set up to perpetuate the status quo. For example, we use existing 'validated' measures because there is reverence for comparison across studies, even when the measure that gets used isn't quite fit-for-purpose. Or we rely on ethics approval processes that can be quite paternalistic and focused on 'protecting' people with lived experience rather than enabling participation. I've worked on more than one project where we've had to scale back to scope of engaging with consumers because the consent processes we have to use restrict people's willingness or ability to participate. As a discipline, I think researchers and evaluators have a long way to go in striking a better balance between genuinely protecting people from research exploitation and empowering people to have a voice.

## **What should funders and commissioners expect from organisations who say they're doing co-design, and how can they measure it?**

There's some simple clues that funders can pick up on about whether co-design is genuine – how long did the process take, who led it, how many people with lived experience were involved. It is not co-design if you have one consumer rep on a steering committee of many clinicians and policy people! It's not even co-design if you have more representation, but that group never gets to meaningfully grapple with evaluation design and analysis challenges.

Issues of power and values are implicit in all things evaluation. If these things aren't made explicit, evaluators run the real risk of perpetuating the power imbalances inherent in a mental health system that has not been designed with and for people with lived experience. I'd love to see more funders and commissioners embracing these challenges, rather than shying away when things get too hard.

Meaningful partnership  
takes time, capability  
and resources.  
Commissioners have  
to be willing to commit  
to that if they really want  
to commit to co-design  
and co-evaluation.

Jo Farmer



*You can find out more about Jo's wonderful work, including her lived experience writing, at [www.jofarmer.com](http://www.jofarmer.com).*

# The working with Pub Test

A product, a resource and a contemporary practice that pass the *working with pub* test...



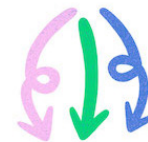
The Model of Care for Co-design describes how to support people during co-design – in two parts:

**Part One: Before togetherness**

**Part Two: Together and beyond**

Creating safety requires more care and hospitality from people who design and run co-design initiatives. People with lived experience do not have to change to suit us professionals.

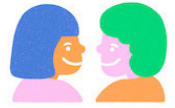
*Slow down to create safety*



Before togetherness

**ASSESS THE FIT**

Determine if the work you want to do is needed, if it will add value to the lives of people with lived experience, and if you should lead it.



Together and beyond

**SEEK ON-GOING FEEDBACK**

Inexperienced facilitators often take silence as agreement and move ahead when there is unfinished business, confusion or contempt.



Before togetherness

**RECRUIT WISELY**

Carefully select professionals to work alongside people with lived experience.



## 1. Co-design mindset prompt cards

Fresh from Beyond Sticky Notes are these simple, practical yet glorious prompt cards. The cards break down each aspect of the Model of Care for Co-design into simple prompts for individual practitioners and teams to use while planning and doing co-design. They draw on a range of literature, particularly trauma-informed and strengths-based practice. You can get your own set [here](#).

## 2. Recognising the real deal co-design

This must see video of a presentation by designer, researcher and co-design advocate Jo Szczepanska definitely passes the working with pub test. [video link](#)

## 3. Paid Participation

When it comes to working with people with lived experience- ditching words (+ outdated expectations) like voluntary or vouchers, and instead building equitable paid participation into project budgets - most definitely passes the **working with** pub test.

## **Thanks for joining us for Issue 1 of *with us*.**

Hope that you found some inspiration and hope in it's 'ziney' e-pages, and that collectively we can take this energy forward to inform our own working with adventures.

### **Coming up next time**

Nothing about us without us. Join us for Issue# 2 as we talk with and about the rock stars of the lived experience movement and choirs of heartfelt voices singing collectively for change.

*Subscribe here* to be first to know when Issue 2 lands.





Made with love and hope for the future of *working with.*

**Subscribe here**  
[www.bettertogethercollective.com](http://www.bettertogethercollective.com)