BEYOND STICK! NOTES

Co-design for real: mindsets, methods and movements

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What to expect

This book will help you to do co-design better. It's not a simple how-to but a collection of principles and patterns that you can adapt to different contexts, with different people.

Be gentle with yourself – you won't develop all of the required mindsets, skills and practices overnight. A client once told me that learning and doing co-design is like walking in a dark cave with a dim torch. While going into the cave alone can be scary, taking a guide, connecting with other practitioners and working in a team can help to light your way and give you direction.

This book refers to academic sources, but it's not academic writing. It comes from my lived experience of social systems, as a designer and co-design practitioner. I thank Ingrid Burkett, Penny Hagen, Simon Harger-Forde, Elizabeth Sanders and Pieter Jan Stappers for laying much of the groundwork. I also thank Kataraina Davis for her contribution to this book.

Given that I am a social designer, this book focuses mostly on health and social care in government and not-for-profit contexts. It focuses on enabling the meaningful participation of marginalised people and families. *Beyond Sticky Notes* draws on many sectors, practices and frameworks as well as the principles of social justice, traumainformed practice and recovery-oriented practice.

Like all books and models, it's biased and incomplete. I wrote this book because I see big gaps in how we think about and practise co-design, and enormous interest in understanding how we can move from designing for people, *to designing with them*. While I didn't invent co-design, I've failed and learned a great deal over the past decade. I hope that learning is valuable.

This book is organised into three parts, as outlined below.

Part One: Foundations for Co-design is about the bedrock of designing with people. It defines co-design and outlines the shifts in culture that are required to enable more co-design to happen (I call these social movements). Part One then goes on to briefly explore the role of power, privilege and equity in co-design, and to address several commonly held misconceptions about co-design.

Part Two: Six Mindsets for Co-design is about your attitude during co-design. It includes six mindsets that are essential for all co-design practitioners: *elevating lived experience*, *being in the grey*, *valuing many perspectives*, *curiosity*, *hospitality* and *learning through doing*. As you deepen your co-design practice and teach others, return to the mindsets to see if they're alive. Despite our best intentions, we often regress to old ways of being and doing when we feel isolated, vulnerable or uncertain.

Part Three: Methods for Co-design is about delivering co-design. It's structured around the co-design process (page 16) beginning with assessing the need for co-design and building the conditions for meaningful participation (I call this the *Model of Care for Co-design*). It includes information about creating co-design teams, including principles that set co-design apart from other facilitation, improvement, design or community development approaches. Before skipping to a specific phase, ensure you have read the *Model of Care for Co-design* (page 90) as it should underpin everything you do. Part Three is very detailed, take your time.

It will be tempting to cherry-pick new tools and techniques. That isn't a good idea, for the reasons explained in Parts One and Two. Before starting co-design, know that it's more than delivering workshops. It involves working with power and practising the mindsets.

Introduction

Beyond Sticky Notes is born from frustration and hope – frustration that decision-making in systems happens *about* people and families but seldom *with* them, and hope that we can use the mindsets and methods of co-design to change that. While co-design isn't a panacea for all of our troubles, it can and does contribute to better programs, services, policies and systems (Burkett, 2012; Lam et al., 2018). I know – I've seen it firsthand many times.

When we make decisions on behalf of other people, we assume we understand their dreams, needs, experiences and capacities, or lack thereof. In doing that, we overlook their knowledge and their skills.

I believe that in order to improve systems and services we need to build the capability of people and communities. Co-design is one way to do that.

Currently, many systems and organisations fail to listen to people with lived experience, or to see and build their capability to design, deliver and evaluate change. This leads to policy gaps, where professionals' understanding of what people want and need is vastly different to people's lived realities (Percy-Smith, 2007). One in four Australians feel lonely and have a poorer quality of life as a result (Australian Psychological Society, 2018). Intergenerational disadvantage continues (Cobb-Clark, 2019), and there are low levels of trust in our democracy (Stoker, Evans & Halpuka, 2018). Establishing more services, programs and inquiries just won't cut it.

Many of our health and social care systems are bursting at the seams through increasing demand and clinical complexity. While this is happening, those systems remain increasingly dependent on professionals to come up with and implement ideas to improve those same organisations and services they are overwhelmed within.

Given our policy gaps, how well is that working for us? Could we tap into the contributions that people with lived experience can make?

While professionals try to do more with less and less – many wise, passionate and eager people with lived experience are left on the bench. What if instead of asking too much from people with lived experience, we're asking too little?

We don't need to throw away professional expertise to embrace co-design, but we do need a greater diversity of perspectives and partners. Yes, professionals must share their knowledge, but they must also listen, learn and, in some cases, get out of the way.

We don't have a lack of resources to transform our systems; we're looking in the wrong places.

The value of small circles

Experience tells me that *small circles* – such as shared meals, quiet conversations and co-design teams – are some of the few reliable places where we can care for each other and create change. I believe that small circles of trust are influential in creating much bigger circles of trust and positive social impact. What I know to be true is:

- There is a significant need for co-design where power imbalances are weighty, historic and enduring for example, in mental health, policing, justice and child protection.
- Encouraging new ways of working in those contexts is an important task that requires specialist skills, as well as changes in values and norms within organisations.
- We can't bluntly apply tools from commercial design to social design that are not sensitive to power or trauma.
- As people with lived experience, telling our stories isn't enough. Many times, we also want a seat at the tables where

decisions are made for and about us. To do that, organisations must make more seats available for lived experience.

- If we want our systems to produce better outcomes for the people they serve, we need different relationships between professionals and communities – relationships that are radically non-paternalistic and are instead grounded in mutual learning, love, curiosity and dignity.
- Love and co-design go hand in hand. We can't elevate the voices and contributions of people with lived experience if we don't see and champion their wisdom and resilience.
 We can't partner with anyone we don't think highly of.
- We must slow down and be more interested in each other, especially when we feel there is 'no time' and when we think we already know the answers to our unasked questions.
- Co-design changes us, and we must let it.

In the introduction I've explained how I think organisations are overlooking the contributions that people with lived experience can make to reimagine and transform our broken and straining systems. Moving on, Part One of this book establishes the foundations for co-design, including the key principles, overall process, necessary social movements and the importance of sharing power.

Part One: Foundations for Co-design

Definition and principles of co-design

Co-design is an approach to designing with, not for, people. While co-design is helpful in many areas, it typically works best where people with lived experience, communities and professionals work together to improve something that they all care about.

Overall, the primary role of co-design is elevating the voices and contributions of people with lived experience. Beyond writing on sticky notes, co-design is about how we are being (our mindsets), what we are doing (our methods) and how our systems embrace the participation of people with lived experience (social movements).

Here are four key principles for co-design:

Share power

When differences in power are unacknowledged and unaddressed, the people with the most power have the most influence over decisions, regardless of the quality of their knowledge or ideas. To change that, we must share power in research, decision-making, design, delivery and evaluation. Without this, there is no co-design.

Prioritise relationships

Co-design isn't possible without relationships, social connection and trust among co-designers, funders and organisers of co-design. Trust paves the way for conversations where we confront the metaphorical elephant in the room (or a stampede of them, in some cases). You can't buy trust; it can only be earned – the better the social connection, the better the process and outputs of co-design.

Use participatory means

Co-design provides many ways for people to take part and express themselves, for example, through visual, kinaesthetic and oral approaches, instead of relying solely on writing, slideshows and long reports. Participatory approaches aren't about relaying information or giving presentations; they're about facilitating self-discovery and moving people from participants to active partners.

Build capability

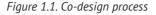
Many people require support and encouragement to adopt new ways of being and doing, learn from others, and have their voices heard. To support that, designers can move from 'expert' to coach. In codesign, everyone has something to teach and something to learn.

You can use the principles to build a shared understanding of codesign in your team or organisation, as well as to assess how different tools and methods could be adapted to work within a co-design process. If you get stuck, ask yourself questions such as: *Will this share power? Does it build capability? Are we prioritising relationships?*

Process for co-design

Co-design is a design-led process that uses creative participatory methods. There is no one-size-fits-all approach nor a set of check-lists to follow. Instead, there are a series of patterns and principles that can be applied in different ways with different people. Co-designers make decisions, not just suggestions (Burkett, 2012).

Figure 1.1 describes the phases of co-design, beginning with the need to *Build the conditions* for the genuine and safe involvement of people with lived experience.





The co-design process isn't linear and could change course based on your context. Part Three of this book provides detail about each phase within Figure 1.1, with a focus on how to prepare diverse groups of people to share power, create safety and work together.

#Tip: There is no co-designing without co-deciding.

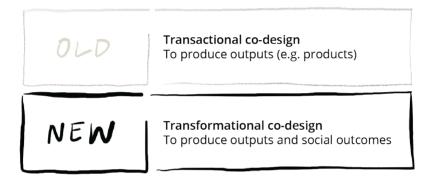
While Part Three of this book makes suggestions about how you can use the co-design process for real, it is a pattern, not a prescription.

Transformational 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.

Figure 1.2 describes the difference between transactional and transformational co-design. 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 output). This book focuses on transformational co-design.

Figure 1.2. Transactional versus transformational co-design



As Burkett (2012) notes: 'Co-design happens over time and across structures – it requires a different kind of relationship between people which incorporates trust, open and active communication and mutual learning. Co-design is a process not an event.' (p. 8) 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.

#Tip: It's not co-design if there's only ever a homogenous group of people (e.g. teachers without students) – that's a workshop or an interagency meeting.

Co-design is successful if the process and outputs (for example, a policy or a service) create value for the people they are intended to benefit. We can assess that through involving people with lived experience in monitoring and evaluation as partners.

Social movements for co-design

To make co-design a reality, we need systems, organisations and communities to embrace the leadership and contributions of people with lived experience. Doing that requires different ways of thinking and being, which are missing from many teams, organisations and systems. Table 1.1 describes several social movements that are necessary to make co-design a reality and a norm. They are based on my work over the past decade across many organisations and systems.

From	То
Making decisions for people with	Making decisions with people with
lived experience	lived experience
Valuing professional expertise	Valuing professional and lived
above all	experience equally
Seeing marginalised people as	Seeing marginalised people as
a burden	resilient, creative and capable
Colonising, heteronormative and	Compassionate systems that see and
ableist systems	respond to dimensions of difference
Believing that resources are scarce	Seeing an abundance of experience,
to make change	ideas and energy for change
Focusing on 'consumer' councils	Embedding participation in
and committees	everyday practice
Rushing to solutions	Slowing down to listen, connect
	and learn

Table 1.1. Social movements for co-design

In many health and social care systems, decision-makers don't have to live with the felt consequences of their decisions. Often, feedback mechanisms in organisations are so delayed (if they exist at all) that the messages that something isn't working fail to make their way through the hum of operational, regulatory and financial priorities. What if the goal of our social care systems was to learn continuously from and with the people we support? How would that change things?

As a social movement, co-design is about challenging where there is an imbalance of power within select groups of individuals who make important decisions about others' lives, livelihoods and bodies. These decisions are often made with little to no meaningful involvement of the people who will be most impacted by them.

#Tip: Enable people with lived experience to be a part of your decision-making, don't add more advisory groups that keep people separate.

To change how decisions are made, we need to redefine who the 'right' people are to make decisions and better tap into the contributions that people with lived experience can make – your lived experience and mine. Making that a reality will require significant shifts in how we think, listen and work. *Want to be a part of this change?* Here are some ways that you can be part of this movement.

- develop and practice mindsets for co-design (page 44)
- help your family, team or organisation to listen to people with lived experience
- create meaningful roles for people with lived experience within systems change, design, delivery and evaluation
- talk positively about people with lived experience, focusing on strengths and what they can contribute

- refer to people with lived experience as people, rather than labels that replicate power differences such as 'users' (Binder, Brandt & Gregory, 2009) 'clients' or 'beneficiaries'
- create the conditions for the genuine participation of people with lived experience. Some ways of doing that are explored in the **Model of Care** for Co-design (page 90).

If you're a senior leader or commissioner, you'll focus on allocating ample time and budget to co-design and act as a strong sponsor for co-design initiatives (including removing roadblocks for the co-design team). You'll build the authorising conditions for co-design more broadly (for example, through new governance models that share power). If you lead an organisation, you might use policy imperatives to encourage a shift in practice from the systems described in the left of Table 1.1 to the systems described on the right.

While this book focuses on design-led mindsets and methods, it would be remiss not to acknowledge the existence of and possible overlap with other approaches. These include, for example, the Public Participation Spectrum from the International Association for Public Participation¹, human-centred design, co-production (a sibling of co-design), deliberative democracy, varying kinds of community and international development, jams and hackathons, and whatever else makes you think, 'But what about this approach?'

While different approaches can support co-design, they don't necessarily involve a design-led process, share power, prioritise relationships, or involve creative methods (Blomkamp, 2018, p. 735). In co-design, we move beyond discussing and making recommendations about what should or could happen, into creatively testing and implementing new approaches to create better outcomes.

¹ www.iap2.org.au/resources/spectrum