

CO-DESIGN

Shared
perspectives
on authentic
co-design

CO-DESIGN

Putting consumers
and carers at the
centre of mental
health reform

AN OUTCOME OF THE CO-DESIGN INITIATIVE 2016

This report was commissioned by the Co-design Initiative, an independent voluntary project auspiced by Civil Society.



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The three artists: Heide, Peter and Phil were a welcome break in the proceedings and used music to remind us why we were there and who we were doing this for.

And lastly I would like to thank all the people who participated in the two forums and the many people who have signed up to the Co-Design initiative around Australia, I look forward to hearing from you as you become involved with your Public Health Networks and start to rebuild the mental health system in your local area.

Regards

Douglas J Holmes

Douglas Holmes

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Introduction

Co-Design

Shared perspectives

The Co-Design Shared Perspectives report provides a framework for the implementation of co-design projects in mental health. It provides an introduction to the principles and practices of co-design.

The report aims to help groups and organisations to adopt a co-design approach in all aspects of mental health service from the system level to service provision and daily practice. It is relevant to anyone who is interested in using authentic co-design practices to deliver improved mental health outcomes for all stakeholders.

The perspectives in this report represent the views of people from the many different stakeholder groups – consumer, carer, health professional, service provider, planner, evaluator and researcher – involved in mental health in Australia. They are an outcome of the **Co-design Initiative**; a voluntary consumer and carer led project which invited a broad cross section of stakeholders to participate in two co-design symposia in 2016.

Information in the report is based on presentations made to those symposia and contributions from over 200 participants in the Co-design Initiative. All information has been verified against the good practice literature on co-design and co-production.

The **Co-design Initiative** is a response to the planned review and reforms of the Australian mental health system, led by the creation of Primary Health Networks commencing in 2016. The project's goal is to ensure that consumers and carers are at the centre in mental health system design, development and delivery.

Using co-design methods has the potential to transform consumer participation into an integral driver for change.

Co-design involves working together

Looking beyond surface change, co-design identifies some of the partnership and collaborative practices that have the potential to transform the way in which mental health services are delivered. The key word is 'together' – moving away from a siloed 'them and us' approach to a collaborative approach in which every stakeholder has an important role to play.

These shared perspectives on co-design provide a starting place for this transformation.

Terms Used in this Report

Consumer and carer

In this report the words 'consumer', 'service user' and 'people with lived experience' are used interchangeably to refer to people who have a personal experience of mental illness. The words 'carer' and 'family member' are used to refer to people who are in a close relationship with someone who has personal experience of mental illness.

These words were chosen as the most commonly used and most readily understood descriptors of people whose personal lives have been affected in some way by mental illness. However, there was criticism of the term 'consumer' at the Co-design Initiative symposia as an inadequate and sometimes offensive label. One possible reason for this is discussed on page 41 of this report.

Co-design and co-production

Co-design is defined on page 9 of this report. The report draws on evidence for both co-design and co-production and uses these terms interchangeably to refer to collaborative work between consumers, carers and professionals at the 'doing with' end of the spectrum of participation. The differences between co-design, co-production and consumer participation are discussed on page 39.

Project

This report refers to 'co-design projects'. Project, in this context, means a time limited activity to achieve one or more specific objectives. An example would be the development of the National Framework for Recovery Oriented Mental Health Practice (2013).

The word project was selected as most co-design activities are short term and focussed on specific objectives. However, Section 2 of this report includes a discussion of the need for longer term approaches to co-design that are not project based (see pages 30 - 35).

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PRINCIPLES

CO-DESIGN

The characteristics of
authentic co-design

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Chapter 1 Principles of Co-design

'Nothing about us without us' is a fundamental human right, but research evidence shows that it is also a smart way to run big human systems like mental health services.

When services are better at wrapping around the person, rather than expecting the person to 'be compliant', we all win – consumers get more person-centred care that helps them fulfil their own unique potential, family member support for the consumer's recovery journey is recognised and valued, staff working in services experience more job satisfaction as they work with rather than on consumers, and the tax-payer gets better value-for-money as services improve their support for recovery and self-management. How can this transformation take place? Co-design is the best approach we have. Co-produced knowledge which blends lived experience and professional expertise is more ecologically valid, co-delivered training produces experiential learning (which is how adults change), and co-designed services address access inequities and reduce waste.

There is a need for fundamental transformation of mental health services and systems, and Australia has the potential to rise to be an international leader!

Mike Slade
Professor of Mental Health Recovery and Social Inclusion
University of Nottingham

This message from Professor Mike Slade opened the Co-design Initiative symposia in Melbourne and Sydney in 2016.

What is Co-design?

Co: together, mutually, in common

Design: to prepare the plans, form and structure for a work

The Co-design Initiative started from the New Economics Foundation (NEF) definition of co-production:

“Designing and delivering services and systems in an equal and reciprocal relationship between professionals, people using services, their families and their community.”

(Adapted from NEF, 2011)

Co-design can engage consumers and carers in all aspects of the design and development of health services, practices and systems. It involves partnering between all of the people who are most affected by decisions and services at every stage in decision making from problem identification to design, development, delivery and evaluation.

Any project or activity could be appropriate for co-design. Co-design is a way of making sure that the people who will be affected by a decision about health service provision are integral to the decision making process.

Co-design is a way of working together that emphasises:

- **Equal partnership** – consumers, carers, families and community members working in equal partnership with service planners and providers (Staley, 2009)
- **Shared decision making** – best practice involves consumers and carers from the beginning at the project development stage (Pinfold, et al., 2015) and at all stages of decision making. Service users and professionals fully share the task of planning, designing and delivering services (Bovaird, 2007). At all of these stages decisions are made – formally or informally – that change the original design therefore consumers and carers need to be integral to the whole chain of production and governance.
- **Innovation** – finding local solutions that are relevant and responsive to service users

“Co-design takes a ‘ground-up’ approach to finding solutions to social problems. It respects individuals as partners in an initiative for change and looks to create a system which is truly responsive to the people it intends to serve. Co-design begins with the people – their experiences, perspectives,

values, challenges and understandings.” (VCOSS 2015)

→ **Integration** – bringing all stakeholders together to provide an integrating mechanism (Bovaird, 2007) for otherwise fragmented service systems

In co-production we need to be equal partners, have collective ownership and have co-responsibility and there’s no one person who is the boss. Both professional and consumer input must be equally valued and included right from the beginning of the processes – no more excuses.

We must work by consensus and move away from the dictating authoritarian leadership styles – consumers, carers, families and community know what works best for them and their peers. We need health systems that are driven by the needs of the community (consumers, carers, families) and not by the needs of the service providers. Consumers must have an equal say and role in how services are designed and delivered.

Michael Burge
March 2016

“Co-design practice reflects more a way of thinking than it does a process. It can be done in a multitude of different ways, and therefore cannot be delineated in a concrete step-by-step process. This is because people, problems and contexts are always going to be variable; as will the organisations and practitioners who work with them.” (VCOSS 2015)

Co-design, co-production and co-delivery mean not only designing the services together from the ground up , but also fully developing, implementing and evaluating together. No longer just gestural or occasional consultation, but active participation at every stage. From conception to realisation and sustaining stages. It is participatory democracy in action. For an enduring service development must make sense to all who need it as well as all who work within it. Only being engaged or involved at the implementation or delivery phase will not generate genuine ownership or taking of real responsibility for the work plan.

Alan Rosen
April 2016

Co-design Principles

“We need national principles to underpin co-design” (Symposia feedback)

The following principles of co-design were identified by participants in the Co-design Initiative. These principles are also well documented in the literature on co-production (Pinfold et al., 2015).

The co-design principles start with equitable partnership. Without an agreement and commitment to work respectfully together as equals for mutual benefit a project cannot be described as authentic co-design.

“Co-production ... promotes equal partnership between service workers and those intended to benefit from their services – pooling different kinds of knowledge and skill, and working together....”

(New Economics Foundation, 2011)

“Equality is the central principle of co-production and the major goal to work towards. A team based on co-production principles requires equality of partners. How it allocates work is a vital part of a co-production project. Remunerating all contributions is also essential; it is a fundamental principle of user involvement and recognises the value of the contribution of all team members to the research” (Pinfold et al., 2015)

“We need genuine co-design done from the beginning – from this moment on – and do this within the broader process of capacity building” (Symposia feedback)

1. Equity

Co-design is collaborative promoting an equitable partnership between stakeholders

1.1 Equity in numbers

→ There is parity of representation for consumers and carers at all levels from the Board to practical implementation of services

1.2 Equity in responsibilities and remuneration

→ The roles and responsibilities of all stakeholders are clearly defined

→ Clear payment structures ensure that consumers and carers are paid for their contribution

1.3 Equity in decision making

→ There is commitment to consensus building

→ Processes and language are understood by all participants

→ Decision making is transparent and all participants are kept informed

Inclusion

Co-design is inclusive, supporting the involvement of all stakeholders

2.1 Co-design teams

- Consumers, carers, family members and professionals work together as the project team.
The project is integrative, bringing together all the different stakeholder groups involved in the subject of co-design
- The co-design team includes all the areas of knowledge and skill required to achieve the project objectives.

2.2 Outreach to include the ‘hidden voices’

- There is a commitment to include those who do not usually have representation in decision making e.g.
 - People with all experiences of illness, at all stages of recovery
 - People from all age groups and experiences of life including:
 - i. Culturally and linguistically diverse groups
 - ii. Younger children and older people
 - iii. People with diverse sexual orientation
 - iv. People with dual mental health and/or physical health diagnoses
 - v. Homeless people and people who do not access health care

2.3 Flexible and creative communication pathways to engage stakeholders

- Practices support multiple pathways for engagement, including strategies for people with different communication needs.
- Time is allowed in all projects for relationship building

3. Capacity Building

Co-design initiatives ensure skill development and capability building for all participants

Training and resources that assist professionals, consumers and carers to learn together to acquire the skills for working in partnership are an essential component of effective co-design and co-production.

3.1 Orientation, training and mentoring in collaboration and co-design are available for all participants

3.2 Participants have the opportunity to learn together as well as separately to establish shared understanding of co-design

3.3 Practices are trauma informed. Consumers, carers and family members are provided with support to assist them to articulate their stories and safely participate in co-design activities.

Recognising the potential imbalance of power between professionals, organisation representatives and other stakeholders, and the legacy of trauma, people with lived experience, their carers and families are provided with support to help them to contribute in ways that are safe and empowering.

4. Co-created

Participants commit to learning from each other

“Everyone on the same

4.1 Project principles and processes are co-designed

→ Locally agreed principles are developed as a first step in every co-design initiative including a shared definition of what co-design means in this context

4.2 Participants commit to sharing existing knowledge

→ Partnership requires a commitment from all participants to listen and learn from each other. To work together effectively, partners need to share existing knowledge and data

4.3 Shared learning and co-created knowledge are documented

→ An important part of co-design is learning together co-creating new knowledge about co-design as well as about the subject of the project.

Local Design - there is no one ‘correct’ way of doing co-production

Every partnership is different. Every region and health service or system is a little different. The principles of authentic co-design have been shown to be consistent across different types of project and in very different settings including health services, policy, research and commercial product development. The actual process of co-design needs to be developed for its specific context and the people who will participate.

5. Purposeful

Co-design works towards real outcomes that are meaningful to all participants

5.1 The goals and outcomes of the project are co-defined

→ Objectives and performance indicators reflect the interests and needs of consumers, carers and families as well as those of the health service or system

→ 5.2 Co-design is integral to the project

The goals of the project will impact on consumers, carers and families and their knowledge is important to the project

5.3 Co-design produces outcomes

→ Co-design is more than the provision of advice or information. The project has authority to make decisions and take actions.

5.4 All participants know how their contributions will be used

→ All participants receive feedback on the outcomes of the project. There is a clear connection between the work of consumers, carers and family members and the outcomes of the project.

6. Innovative

There are opportunities to explore and experiment with alternative solutions

Innovation is significant positive change that unlocks value in existing resources. More than having new ideas, innovation evolves from what we know to change the way we think about the world.

“At the heart of good design is a search for better solutions, practical innovations and making improvements that enhance people’s lives, address problems or open possibilities for better lives. Innovative ideas must translate into practices that create value. Innovation requires all partners to be open to experimentation, risk taking and change. It requires us to think outside the boundaries of how things work today to see a future that looks different.” (Cruickshank, Coupe & Hennessy)

“Creativity is inevitable when people from different backgrounds share their needs, learn to see things from a different single angle and work on solutions together” www.healthcodesign.org.nz

7. Sustained

There are opportunities to build on the co-design process for future initiatives

Co-design requires investment of time and resources to enable real participation that influences outcomes. Effective co-design projects make provision to capitalize on the

knowledge, networks and processes developed during the project in order to facilitate future co-design.

7.1 The project has adequate time and resources to achieve its purpose

7.2 Communication pathways, networks and processes are sustained for future use or shared with others for use in different projects

8. Evaluated

Evaluation is integral to all co-design projects

8.1 Impact and outcome evaluation is a part of every co-design project

8.2 Co-design experience and processes are evaluated

8.3 Evaluation strategies reflect the principles of co-design and are chosen to facilitate input from consumers, carers and family members

Evaluating co-design

Like any other activity, co-design should be able to demonstrate that it has an impact on the quality and effectiveness of project outcomes. Evaluation and continuous learning is a core principle of co-design.

We often think of wisdom as ‘having answers’, yet the value of the answer depends entirely on the validity of the question. What questions should be asked about co-design?

Changing perspectives on the measurement of good health service

Co-design must be purposeful, that is, it must be working towards achievement of clear objectives. Measurement of the achievement of those objectives is as important for co-design initiatives as for any other approach to design.

The outcome measures for many health services and for broader scale reform of health systems focus on the impact on the service or system. They are defined by health service providers and funding bodies to reflect their own areas of concern (Batalden et al., 2015).

A common goal in mental health is to reduce the number of people who require inpatient hospital care. Measuring the number of people who use hospital services demonstrates the impact of change on the system. It does not necessarily indicate improvement in mental health. It could as readily indicate that people are being refused hospital care or that hospital care has become so undesirable that people are refusing admission.

For consumers and carers the success of a service or health system reform is likely to be measured by improvements in quality of life (Bassman, R. 1997).

“Needs are defined by experience and not statistics” (Symposia feedback)

The focus of the consumer and carer movement – and therefore of co-design – is person centred practice that contributes positively to the experience of recovery. The goals of co-design therefore need to be holistic, person focussed and recovery oriented, developing services and systems that best meet the needs of people.

“Health service decisions are often made primarily based on the needs and interests of the service. Involving patients in decision making helps ensure balanced and effective improvements that offer mutual gains for both patients and service”

www.healthcodesign.org.nz

Service focussed measures such as numbers of service users are appropriate when they are balanced by measures that investigate the impact of change on people’s lives. Possible areas for investigation include:

- Service user satisfaction
- Personal development or change
- Reduction in stress or distress
- Quality of life

“Key findings from the UK Department of Health have found that patient involvement increases patient satisfaction and also promotes greater trust between patients and professionals” (Farrell, 2004).

Evaluating co-design processes

Co-design has its own value independent of the specific objectives of the project. The extent to which co-design was able to implement good practice principles and the impact of co-design on participants are also important areas for investigation.

There is a need to ensure that co-design is authentic and not just a name attached to a project.

There is always a risk that frameworks, standards and guidelines will be used to justify a ‘box ticking’ approach rather than as drivers of real change (Batalden et al., 2015).

Useful areas for evaluation of co-design processes include:

- The extent to which a project was able to implement the co-design principles and methods outlined in this shared perspective
- Participant satisfaction
- Participant self reported measures of personal development and learning as an outcome of co-design

- Evidence that consumer, carer and family expertise has influenced the outcomes of the project
- Documentation of co-created knowledge about co-design

Evaluating progress

While there are many examples of co-design in practice, this approach is still new for many people. Tracking the progress of implementation of co-design as a core approach to service and system development is an important area for investigation.

Useful areas for evaluation of progress in the uptake and implementation of co-design include:

- Co-design is embedded in policy as a requirement for all health system reviews, planning, service and system design, implementation and evaluation
- Co-design is a part of the process from the beginning
- Outcome measures and KPI reflect the importance of co-design
- There is a sufficient budget and timeframe to conduct the work of co-design

Evaluation methods

Some evaluation methods are more consistent with co-design and collaboration than others. Narrative enquiry and action evaluation cycles are both methods that lend themselves to co-design evaluation.

Co-design of evaluation is as important as co-design at other stages in the development of health care. Co-design participants are partners in deciding what gets measured and how data is interpreted.

2

PRACTICE

CO-DESIGN

Approaches and
tools to support co-
design

AN OUTCOME OF THE CO-DESIGN INITIATIVE 2016

Chapter 2 Practice of Co-design

Co-design - for me it means the coming together of consumers, carers, health professionals and policy makers (and any other relevant stakeholders really) to design a system of care and/or an approach to care that produces great outcomes for the consumer and for the community as a whole

Caroline Johnson
March 2016

“No design without co-design”
(Symposia feedback)

For any team to work and reach its desired goals, each member brings themselves to the project in a "co-production, co-design" manner. This is about partnerships, collaboration, equality. Each person's perspective, lived experience, knowledge, skills and attributes is ideally respected equally.

In mental health care, services and systems, as in any service industry, the customer, or the client is at the very heart of its existence. The "consumer" is the end user of the service and the system. Who better to tell and teach us what works and doesn't work in reality?

This perspective is critical in any "co-design" approach to enrich the outcomes for the beneficiary bringing their question or issue into focus. "Co-design is about relationships, trust, respect and equality, encouraging open honest dialogue of all members of the project, in discussions, idea development, creation and innovation of methodologies, delivery and evaluation strategies.

This process not only ensures that the intervention, service delivery, technique, tools or whatever is offered has meaning, relevance and a tangible benefit for the end user, but also enriches the experience and ideally engages the end user to take self-ownership and be self-determined for their own lives and wellness. Ultimately this is about all of us...

Jane Burns & Ingrid Ozols

Dialogue for Change

More than two hundred people contributed to this report. Many of them said that they were not sure what co-design was or that it was a confusing concept. Yet when they were asked to identify the essential elements of co-design they produced the same core principles as the evidence based literature on co-design and co-production.

The ideas in this report are not new. People understand co-design and people are doing co-design in mental health in Australia.

Is Co-design complicated?

Co-design involves hard work but the concept itself is not difficult. Co-design is a place to start an honest conversation between all the people involved in the mental health system, meeting as equals with a common interest.

Honest conversation about real issues is the beginning of co-design. Creative techniques can be used to help different groups of people get involved, and some of these approaches are described in the rest of this chapter, but at its heart, co-design is about dialogue and that can happen swiftly and in any context.

Reports (like this one) share knowledge in one direction, from the writers to their audience. When the audience already knows something about the subject, the words on the page are enough to make the connection. When the audience does not read, does not understand, or perhaps actively rejects the information, then the words on the page have little power to bring about change.

Something similar happens when we share stories of personal experience. More emotive and powerful than many reports, stories are still one-directional communication.

Bringing people together face to face to share knowledge – that is to meet for the sole purpose of hearing each other's stories and learning together – is a powerful tool for change.

Relational practice is essential for co-design (Dunston et al., 2009).

Unless we can join forces and recognize each other's humanity, how can we do business together, let alone make progress?

Daniel Lubetzky

Prioritize Listening

Most projects set out with objectives and timelines and try to move directly to concrete plans and finding solutions. Dialogue tends not to happen when the focus is on business process, agendas and outputs.

It is essential in co-design to allow time to build relationships; to allow for conversation to develop.

Having an opportunity to voice experience and be listened to, is the first and most important step in integrating diverse insights. Rather than moving immediately to problem solving, the first step in co-design is to enable people to have their say and to listen to each other.

The ability to know about another person's experience and relate to it requires engagement with what has happened to them through what they say, what they think and feel. It also requires an understanding of what they dream for the future. When we access feelings, dreams and imagination we start to find our shared ground of human experience (Sanders, 2002).

Potential outcomes of prioritizing listening include:

- The development of trust and an ability to move on to decision making
- Understanding of the context of knowledge in the experiences of everyday life
- Development of a shared language between participants

Mindset

The equal and inclusive partnership of co-design is a method to overcome the challenges of integrating the very different experiences of stakeholders in the mental health system.

Co-production will not work if services come with entrenched pre-determined ideas of what the solutions must be.

Michael Burge, March 2016

“More than a method, co-design is a mindset. It is the belief that all people have something to offer to the design process if they are given the right tools with which to express themselves”.

(Sanders, 2002)

Co-design is an admission that no one of us – regardless of our background – holds the whole story. No one holds all the answers. We can only find the answers together.

Co-design starts from acceptance that to find solutions we need to look to those who are not currently at the decision making table as well as those who are. This is a

challenge for all leaders, to “*remain inclusive of diversity and dynamism of community life*” (Warriner, 2009).

Co-design is a flexible and highly relational approach, very different from most business processes. Organisations that use co-design must be ready to experiment and adapt as relationships develop. This departure from existing practice requires support from the highest levels in the organisation.

Exploring Difference

Different perspectives and goals are not necessarily incongruent. They may simply be expressed in a different experience language. Honesty and transparency in communication can go a long way to bridging what we see as gaps between groups with different experiences.

Exploring meaning and finding the common ground – those things which everyone can agree on – is an important part of the work of co-design.

Focus on recovery

One way to achieve this is to focus on recovery. As Anthony has pointed out, “recovery is a unifying human experience” (Anthony, 1993); everyone experiences difficulties in life and must face at some point the challenges of recovery.

“Co-design means... It’s not anymore a matter of gathering and mixing expertises but of creating a collective vision that is generated by a new awareness, never experienced before: the sense of community and the making together.”

Giovanna Missoni, 2015)

Open Dialogue

The Open Dialogue therapeutic approach, which works to help those involved in a crisis situation to be together and to engage in dialogue as they work towards shared meaning, provides a useful model for approaches to co-design. The emphasis is on helping dialogue to happen rather than promoting change as the first objective. This helps to validate thoughts and feelings. From this emerges understanding of how all participants relate to other (Jane Hetherington).

Getting Started

“Don’t over think it” (Symposia feedback)

We can become paralysed by our perceived differences. We can become trapped in correct procedures. We can be so risk averse we dare not say anything. Or we can set in place some basic steps towards co-design:

- Start the conversation
- Work on something that is meaningful to all participants
- Listen to each other
- Document what you learn and then...
- Build on what you learn to improve practice and improve the outcomes of co-design

Embracing diversity

Conference Question: What makes an individual consumer 'qualified' to represent the breadth and diversity of the consumer experience?

Consumer and carer representatives are responsible for sharing insights from their own experience. Every person's experience is a little different. There are many different ways of perceiving and articulating what's needed and many different interests. Co-design engages the experience of all stakeholders. In co-design, diversity is an asset.

"The real challenge is to get as many people involved as possible in a capacity that enables them to make the most positive contribution."

(Cruickshank, Coupe & Hennessy, 2013)

A key aspect of co-production is its emphasis on merging very different viewpoints (Pinfold et al., 2015). The more people you can engage in co-design the better but then again the more people you engage the harder the whole thing becomes to manage towards project objectives. This section looks at some of the approaches that can help to integrate diverse voices into meaningful outcomes.

Engage peer networks

Finding the hidden voices involves finding one or two people who are able to link into their own peer networks and act as connectors.

Multiple pathways

For some people working with other stakeholders face to face around a meeting table will be a challenge. Their experience of distress, isolation and potentially trauma may make it difficult to trust other stakeholders enough to share knowledge.

Opportunities to share need to be culturally appropriate and reflect awareness of the lack of power and the trauma experienced by many people with mental illness. Some people are not comfortable sharing in a group setting. Others may not be comfortable submitting their knowledge in an extensive written form. Many are not comfortable directly challenging or questioning people in authority.

Interaction is important but so too is the flexibility to allow people to participate in different ways and through less intensive options than full team membership. Some people will not have the time, resources or inclination to immerse themselves in co-design. Every co-design strategy needs to leave room for broader participation through consultation strategies.

Creative use of technology, physical outreach especially to specific groups and more remote communities, and creative ways of contributing knowledge (e.g. through performance, visual art, poetry) are all desirable. Film has been used successfully in Experience Based Design projects to enable people to talk about their experience to larger audiences without having to be physically present at every forum.

When people do meet face to face, holding meetings in neutral community settings is important (Pinfold et al., 2015). Other ways to enable dialogue include using online platforms that allow participants to interact.

Find common ground

Everyone's story contains valuable knowledge that can – and should – contribute towards the development of an effective mental health system.

But simply sharing story is not enough to enable change to services or alter the way systems work. At some point, the story must inform the development of more formally expressed knowledge.

The goal of co-design is co-created knowledge. Co-design works towards consensus rather than compromise.

Compromise is defined as “an agreement or settlement of a dispute that is reached by each side making concessions” (Merriam-Webster). This tends to leave everyone feeling as if they have lost.

“To avoid ‘design by committee’ participants have to be able to change the way they think about problems and solutions. Individuals cannot just have an ideal position then compromise until the compromises overlap and agreement is reached but with everyone equally unhappy. This change in process demands a degree of reflection and willingness to take risks with new processes...”

(Cruickshank, Coupe & Hennessy, 2013)

Sometimes it is necessary to compromise, particularly where the best way forward is not supported by existing resources. When this is necessary, member-checking – making sure that each participant understands what is happening and why – can minimize the sense of loss in compromise.

Learn together

Learning together can be an equalizing experience that helps to put everyone ‘on the same page’. Capacity building for co-design can provide an opportunity to start the process of integrating voices.

The recovery college approach provides a useful model and processes to support co-design.

Mutual Benefit

People have a lot going on in their lives. They need to see the benefit to themselves in co-design activities. Be clear about the purpose of your co-design activity and let people know clearly what they are being asked to do and how their knowledge will be used.

Make sure that activities give something of value back to participants. This could include payment for participation; peer networking and support; opportunities for learning and personal development; and activities which are safe, comfortable and enjoyable. Regardless of the incentive to participate, participants should feel respected and heard.

What does equity look like in practice?

Stories from Experience – Project Background

The National Eating Disorders Collaboration (NEDC) works in partnership with three key interest groups – researchers, clinicians, and consumers and carers – to develop a picture of what is needed to address the complex issues of recovery from eating disorders in Australia. The contribution of people with eating disorders and their families and carers is critical to the development of NEDC resources and reports.

In 2014 the NEDC started work on the '*Stories from Experience*' project.

Stories from Experience is a learning resource designed to help adults who are in recovery from an eating disorder to reflect on their experience, make decisions about safely sharing that experience and construct purposeful accounts of their experience for specific contexts.

The content for the resource is the result of a constant iterative process between people with different types of expertise as ideas have been reviewed, trialled and adapted to best meet the needs of the intended users of the resource.

The NEDC consulted with people with personal experience of eating disorders to identify their interest in learning to share their personal story and their resource needs. An online survey was made available to all interested members. Individual semi-structured interviews were conducted by telephone with survey respondents who indicated that they were willing to provide more in-depth information and be part of the development of the resource.

Information from these consultations framed the scope and objectives for the project, and the first draft of a content map.

An iterative method was adopted in which review, evaluation and adaptation of the resource was an integral part of the development process. Two advisory groups

were formed, working separately but communicating with each other through NEDC staff:

- *Group A* was made up of six people with personal experience of eating disorders who had helped to shape the start of the project. This group acted as a sounding board, reviewing all of the work in progress, providing feedback and generating new ideas.
- *Group B* was made up of six people with the specific expertise needed to develop the resource. This group included: people with personal experience of eating disorders, consumer advocates from the mental health sector, teachers, writers, peer support leaders and eating disorder clinicians. Each person in the group represented more than one area of knowledge. This group was responsible for guiding the NEDC staff team as they created the resource and contributing content from their own areas of expertise.

Between October 2014 and March 2015 conversations went back and forth between these groups as ideas took shape on paper, content was tested and new ideas emerged. In this process both groups started to create art work and shared personal stories as well as putting the nuts and bolts of how to write and share stories

What we thought would happen at the beginning of the project didn't look like the end result. Everything took longer than expected. The resource is longer than expected. We thought we were writing a booklet, and then it grew to five modules and ended up with fourteen modules.

This has been a constant learning experience as ideas were tossed around. We had to learn as we went, looking for evidence across different fields and listening to people with personal experience to create something that matched their knowledge.

The end result is a truly coproduced resource. Everyone made a contribution that reflected something of their personal journey in life as well as their expert knowledge.

together.

While the resource is 'finished' it is still seen as a work in progress. It will continue to be used, reviewed and adapted to make sure that it provides people with experience of eating disorders with the tools they need to safely communicate their experience. The process of co-design is ongoing.

Equity in practice

- Equal numbers of consumers and professionals on the oversight group – this was a challenge in practice because all of the consumer representatives contributed significant technical skill and all of the professionals had considerable experience

in facilitating consumer voice. It was difficult to know 'who was who' but that degree of integration seems to represent co-design

- Separate reference group of consumers who helped to define the overall project and goals and actively monitored the project's progress towards those goals. In other words, the consumers had the final decision making power
- A large outreach survey that enabled many people to participate to a more limited extent to meet their own needs and preferences
- A staff team made up of one consumer who was also a professional editor; one writer who was also a carer; and one NEDC staff member

For more information on the NEDC and the *Stories from Experience* project visit www.nedc.com.au

The following exerts outline some of the work of the Young and Well Cooperative Research Centre and provide information to help others interested in engaging young people in co-design to get started.

The full blog and guideline report are available for download from www.youngandwellcrc.org.au

Why lived experience must be at the epicentre of real-world research

Exert from a blog from Associate Professor Jane Burns & Ingrid Ozols

Starting out in 2011, the Young and Well CRC prioritised three things in its mission to undertake real-world research that can be rapidly translated into policy and practice.

It established a Youth Brains Trust, a group of innovative and smart young people at the heart of the organisation, who are passionate about participatory design and its importance in creating great research that has real life relevance.

It committed to conducting a National Survey, combining the voice of young people, and large scale data collection to create compelling research which can be seen in the Game On report..

It also enshrined the tenets of participatory design in a set of guidelines to which all Young and Well CRC research complies.

Participatory Design and Participatory Action Research is an opportunity for collaboration, collective inquiry and doing, by, with and for the community. This process places the lived experience at the epicentre of the design process. In mental health service delivery this means that people with a lived experience are critical in shaping the design of new treatment and service options. Using the narrative of the lived experience, and understanding the social context, ensures that people are

engaged in a shared dialogue that gives people a voice with a focus on what works and what doesn't.

Evidence-based research is about building capacity through rigorous formal tools and resources, demonstrating effective outcomes. High quality research is fundamental to shaping good policy, but the best evidence is that created in an equal partnership with those who have used the system.

This "evidence" provides important persuasive information, which educates and demonstrates, statistical, economic, treatment and/or services options that influences government, service providers and community on many levels to provide people with appropriate support.

Young and Well CRC, along with its 75 partners in youth mental health, have a deep commitment to participatory design and action-based research that is driven by the voice of young people. This has demonstrated the powerful reality such research approaches yield and how outcomes can, very quickly, be used by policy, decision-makers and service providers

Participatory Design of evidence-based online youth mental health promotion, prevention, early intervention and treatment

(Hagen, Collin, Metcalf, Nicholas, Rahilly, & Swainston, 2012)

Exerts from Young and Well Cooperative Research Centre guidelines. Reproduced with permission.

The Young and Well Cooperative Research Centre works in partnership with young people, professionals, scholars, parents and community to address the complex challenge of young people's mental health difficulties. Collaboration and drawing on the perspectives, insights and expertise of a range of stakeholders are at the centre of our approach.

Of particular importance is the involvement of young people across the organisation and research projects - keeping their needs, experiences and knowledge at the centre of our activities. This collaborative and engaged research initiative takes a holistic approach to youth mental health and wellbeing. It aims to bring about new knowledge for the development of interventions that are effective, relevant and appealing, and which shape institutions and communities that foster safe, healthy and resilient young people.

One of the key challenges is how to research, design and develop interventions that are based on sound evidence *and* are engaging for young people. How can we conquer challenges of stigma and access to embed health interventions in the everyday experience of youth? Participatory Design is one strategy for exploring and integrating the views, experiences and creativity of the young people that such interventions seek to benefit.

Participatory Design research seeks to understand the 'lived experience' of users and make the often tacit experiences and specificities of everyday practice available as resources for design. Participatory Design goes beyond consultation and testing to seek active contribution of users as co-designers in the creation of design proposals and alternatives, throughout the design process. In Participatory Design, knowledge is generated by researchers and users through methods specifically designed to support a process of mutual learning, and create a 'shared language' between design researchers and users.

Pragmatically, a Participatory Design approach helps us to develop interventions that are engaging to young people and therefore are more likely to be used, increasing the overall reach and impact of the intervention. Ongoing involvement by young people throughout the design process increases the feasibility and acceptability of the proposed concepts and ideas and ensures that recommendations generated by young people, and then interpreted by researchers or designers into 'design

proposals', still effectively reflect young people's input. Continuous engagement also helps keep pace with the fast-changing uses of technology, mitigating some of the impacts of the inherent time lag of translating research and evaluation findings into practice.

The visual and playful nature of Participatory Design methods can also engage and motivate young people who otherwise might not see the intervention as interesting or relevant to them. This can help to facilitate research with groups who are traditionally considered 'hard to reach' or less likely to seek help when they need it (e.g. young men).

Participatory design methods

Methods and artefacts such as scenarios, prototypes, mock-ups, and collage and mapping are used to progress design, and make design decision making processes accessible to non-designers. Participatory Design is characterised by such generative, experiential and action-based methods that put emphasis on play, co-operative learning, creating visions of the future and design by-doing.

For example: a Young and Well CRC approach to Co-design workshops

Co-design Workshops help to immerse stakeholders and build a shared understanding about an issue based on personal perspectives and experience as well as previous research findings.

Participants then use this understanding as the basis to collaboratively generate, explore and evaluate new ideas or alternatives. Co-design Workshops make use of generative methods and tangible tools and techniques such as Inspiration Cards and storyboards to enable young people to actively participate in generating design ideas. Co-design Workshops can be used early to explore issues, generate concepts or prototype existing concepts and are tailored to suit particular project and creative objectives. They are best suited to evolving design proposals from one phase to the next.

Workshop activities include games like Snakes and Ladders; a playful way for young people to come up with a set of ideas and terms that, in their own words, described factors related to mental health and wellbeing. Snakes represented potential obstacles to overcoming challenges, ladders represented the good things that the participants perceived as helping young people to overcome challenges. The activity established a shared vocabulary and set of concepts that could be built upon throughout the day. Conducted as a competition, two teams raced to get as many words as possible... with the emphasis being on generating a lot of ideas, not on getting it 'right'.

Examples of Participatory Design Resources

- www.DesigningWithPeople.org
- www.peopleandparticipation.net
- www.MakeTools.com
- www.InnovationGames.com
- Participatory Design Conference proceedings available through www.dl.acm.org

Experience Based Knowledge

There is an extensive literature available on co-design, co-production and participatory design which can be used to support co-design projects, including a number of online toolkits, many based on the principles of Experience Based Co-Design (EBCD).

Experience-based co-design (EBCD) is a participatory action research method for collaboratively improving health care services.

The sequence of steps in an EBCD project include:

- Collecting experiences from service users, carers and staff either through interview or direct observation
- Identifying the critical moments where experience between service provider and service user intersect “touch points”
- Feeding back the analysis of “touch points” to project participants and involving them in reaching consensus on prioritizing these
- Co-design event(s) which enable small groups to contribute from their diverse experience to the develop improvements

(Larkin, Boden & Newton, 2015)

The following toolkits may be helpful as a starting place for co-design. The emphasis in these toolkits is on co-design for existing health services.

- **The King’s Fund EBCD toolkit** provides step by step guidance on how to use the EBCD process <http://www.kingsfund.org.uk/projects/ebcd>
- **User-Centred Healthcare Design (UCHD)** (www.uchd.org.uk) uses the EBCD process. UCHD developed the Better Services by Design website (www.bsbd.org.uk) which provides a description of their method and a number of design tools.
- **Health Service Co-Design guide** and toolkit were developed through healthcare improvement projects in cancer services at Waitemata District Health Board, New Zealand. www.healthcodesign.org.nz/
- **Co-production in social care**: What it is and how to do it, Social Care Institute for Excellence (SCIE) Guide 51 published online 2015.

<http://www.scie.org.uk/publications/guides/guide51/index.asp>

- The Mental Health Experience Co-Design (MH ECO) method implemented at the Darebin Community Mental Health Centre in Victoria, is based on EBCD (Fairhurst & Weavell, 2011; Ning, Weavell & Woodhouse, 2010)
<http://tandemcarers.org.au/index.php>

Strengthening Voice

“We need a place to share our stories” (Symposia feedback)

To meet the good practice principles of sustained and inclusive engagement of people with lived experience and their families in co-design, there needs to be mechanisms to connect and bring the very diverse people affected by mental illness together.

“It is hard for organisations to get the information from consumers because there is no funding and no mechanism to bring the voices of a sufficient diversity of consumers and carers together” (Symposia feedback).

In this context, the Co-design Initiative explored the concept of regional consumer and carer led hubs to act as connecting points for consumers and carers.

Locally designed hub models

A ‘hub’ is the centre of an activity. The Co-design Initiative symposia posed the question: What could a consumer and carer ‘hub’ look like in the context of PHN regions?

Participants highlighted the diversity of PHN regions and the diversity of communities within regions. There can be no ‘one size fits all’ approach in co-design and no single approach is likely to work to facilitate regional co-design.

Local solutions, co-designed by local people and services are essential to enable co-design to become embedded in mental health reform. However, the Co-design Initiative symposia identified two broad approaches to ‘hubs’ that could be used as starting places for local design. The first of these prioritizes bringing consumers and carers together as leaders in co-design.

Regional hubs could serve many different purposes to meet local needs. The purpose common to all regional hubs is to act as a connecting point for consumers, carers, service providers, professionals and community in order to enhance the review and reform of the mental health system.

Each regional hub must be an independent entity, run by local people for the benefit of local people. The focus of the regional hub is on local, regional issues and representation of local consumers, carers, family and community.

Information Hubs

In this model the hub acts as a connecting point and network to facilitate co-design and co-production in a region.

*“Providing network connections and leadership to the region to support all the services that are grappling with consumer and carer consultation processes”
(Symposia feedback)*

This approach to a co-design hub could provide:

- Support for relationship networks
- Proactive engagement, liaison and communication between potential co-design stakeholders
- Skill development and capability building in collaboration and co-design
- Peer to peer mentoring to build knowledge and capacity
- Leadership and coordination of local co-design activities
- Proactive identification of opportunities for co-design
- Creation and promotion of local knowledge

The purpose of the information hub is to facilitate co-design as a tool for transformation of the mental health system. It is not a service centre.

This approach lends itself to a ‘virtual’ environment, connecting as many people as possible through smart use of technology to facilitate co-design and co-production. Where face to face meeting is desirable, the hub should be located in an accessible and neutral community location (libraries were one suggestion) and not in a medical centre.

Some of the identified characteristics of an information hub include:

- Creating connections and building on what already exists
- Culture of continuity of shared knowledge and experience – enabling experience based wisdom to accumulate
- Providing ways for people with lived experience and families to connect and learn from each other formally and informally
- Acting as an information resource for everyone in the community
- Outreach activities engage with people who may be quite marginalized/separate
- Using and respecting the stories of a diverse range of people
- Coordinated and run by peers

Local partnerships

Co-design is a way of working together. It does not justify the creation of another organisation working in isolation to add to the existing fragmentation of the mental

health service system. Regional hubs are designed to bring people and organisations together and not to add another group to the existing mix of services.

A measure of success for this type of hub would be the extent to which it was able to add value to existing groups and services and bring all stakeholders together in authentic co-design activity.

If the information hub intends to seek funding, then each hub would need an auspicing agency i.e. an organisation already established in the region that is willing to take responsibility for legal transactions such as funding contracts and employment of staff. Possible auspicing arrangements include a local or state based consumer and carer organisation, or a consortium of local agencies.

Potential roles

Like any other co-design initiative, an information hub will require people with lived experience to take on responsibility for the work and they should be adequately remunerated for that work and the expertise they contribute.

Existing roles in other areas, such as peer navigators and community connectors may provide a model for staff roles.

A leadership model focused on competencies that promote equality and empowerment for peers is required; a 'power with' approach (O'Hagan, 2009).

Influential connections

Knowledge generated by consumers and carers must have an interested audience – influential groups or organisations that are engaged and ready to learn from and contribute to the knowledge.

“We need realistic channels for outcomes of hub to be fed back up the line to implement meaningful change” (Symposia feedback)

Building relationships with the PHN and with members of the PHN Community Advisory Committee is a desirable first step towards creating a regional information hub.

First Steps

Suggested steps to initiating regional consumer and carer information hubs included strengthening existing connections to start the conversation about co-design.

1. Establish Connections

- Appoint a local person(s) to be the central point for connection
- **Proactively invite stakeholders to engage in discussion about co-design and the reform of the mental health system**
 - **Your PHN**
 - **PHN Community Advisory Committee members**
 - **Existing consumer and carer groups and**
 - **Individuals**
- Set up a locally relevant information process (e.g. e-news: emails: online

2. Promote Co-Design Principles

- **Use and promote awareness of co-design principles**

3. Engage Diversity

- Map the different 'voices' that are already being heard and the ones that are missing from current decision making
- Co-design a needs survey *with* consumers and carers *for* local consumers and carers
- Start the conversation with existing and missing groups to identify the

4. Work towards a local Co-design hub

- **Identify an auspicing agency** (local organisation or a consortium of agencies)
- Agree terms of reference to co-design the hub
- Co-design the purpose, scope and governance of the hub
- **Engage the PHN and other bodies to work cooperatively with the hub**

Creating the Meeting Place

To meet the good practice principles of sustained and inclusive engagement of all the stakeholders involved in the mental health system there needs to be mechanisms to connect and bring people and their knowledge together.

“Integrate co-design work into mainstream and Aboriginal health services”

“Respect all people as one voice – recognise all experiences (consumer, carer, clinician etc) – take away the categories because people fit multiple categories”

“Be careful not to separate consumers and clinicians”

“Create a resource for the region to tap into - a hub leadership group that is inclusive”

(Symposia feedback)

Service hubs – an alternative approach

“Coordinated one stop shop for all health services, information and practical help”

“A hub is an integrated ‘one stop shop’ to meet people’s needs” (Symposia feedback)

Co-design Initiative contributors identified a ‘one stop shop’ approach as their preferred solution to mental health reform provided that the hub developed independently in each region to reflect local needs. This approach puts the hub itself at the centre of mental health reform.

This vision involves creation of a physical centre where people can engage with what they need when they need it, supported by their peers, reducing the adverse effects of trauma from using mental health services

- Functional integration of existing physical and mental health and community services and consumer groups
- Continuity of care across developmental lifespan
- A point of self referral
- Brokerage and commissioning of services
- Central source of information, support for system navigation and individual advocacy
- Peer mentoring and support
- A dedicated, physical and safe space
- Open outside business hours

Like information hubs, the purpose of the service hub is not to duplicate services but to enable services – those that exist and those that need to be developed – to function effectively together to provide person focussed care.

Club house, or therapeutic community processes may be appropriate as organising approaches to ensure that the hub maintains its service user focus.

More than medical services

A possible risk with this approach is that it becomes overly focussed on health service delivery.

There is a need for “*a shift away from ‘service’ thinking*” (Symposia feedback) towards a more person focussed and holistic approach to recovery.

As Anthony (1993) has noted “*recovery from mental illness involves much more than recovery from the illness itself... recovery is often a complex, time-consuming process*”.

In this hub approach peer and community support is central to the hub with medical, mental health and other services integrated into the mix on a needs basis.

The one stop shop is not a new idea but it is an idea with current relevance in health system reform in Australia. In recent months: the NSW Government has announced the creation of three "one-stop-shop" treatment centres for people with mental illness and their families (announced 2015); the Commonwealth Government has announced the creation of 'health homes' to coordinate healthcare for people with chronic illnesses which includes mental illness (announced 2016); and the Commonwealth Government has announced the implementation of a one-stop-shop digital gateway aimed at giving Australians easy access to high-quality mental health advice and resources when and where they need them (announced 2015)

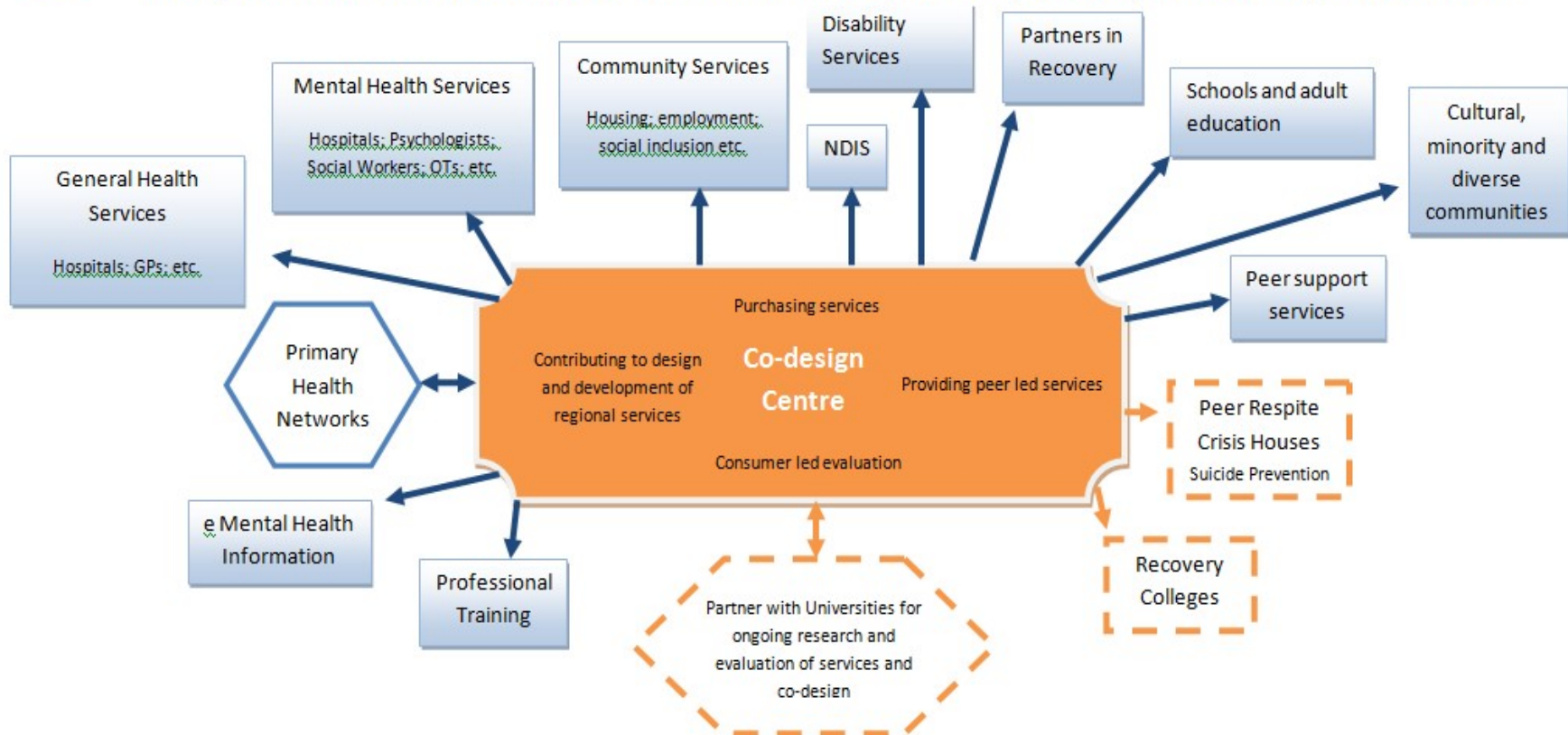
The risk is that the concept of the one stop shop is limited by the current boundaries of health service provision (Batalden et al., 2015) rather than expanding to include all the diverse sources of community support that can play a part in recovery.

One participant's vision for a 'one stop shop' appears on the following page.

An example of a Recovery Hub



Placing consumers and carers at the centre in mental health system design, development, delivery and evaluation



3

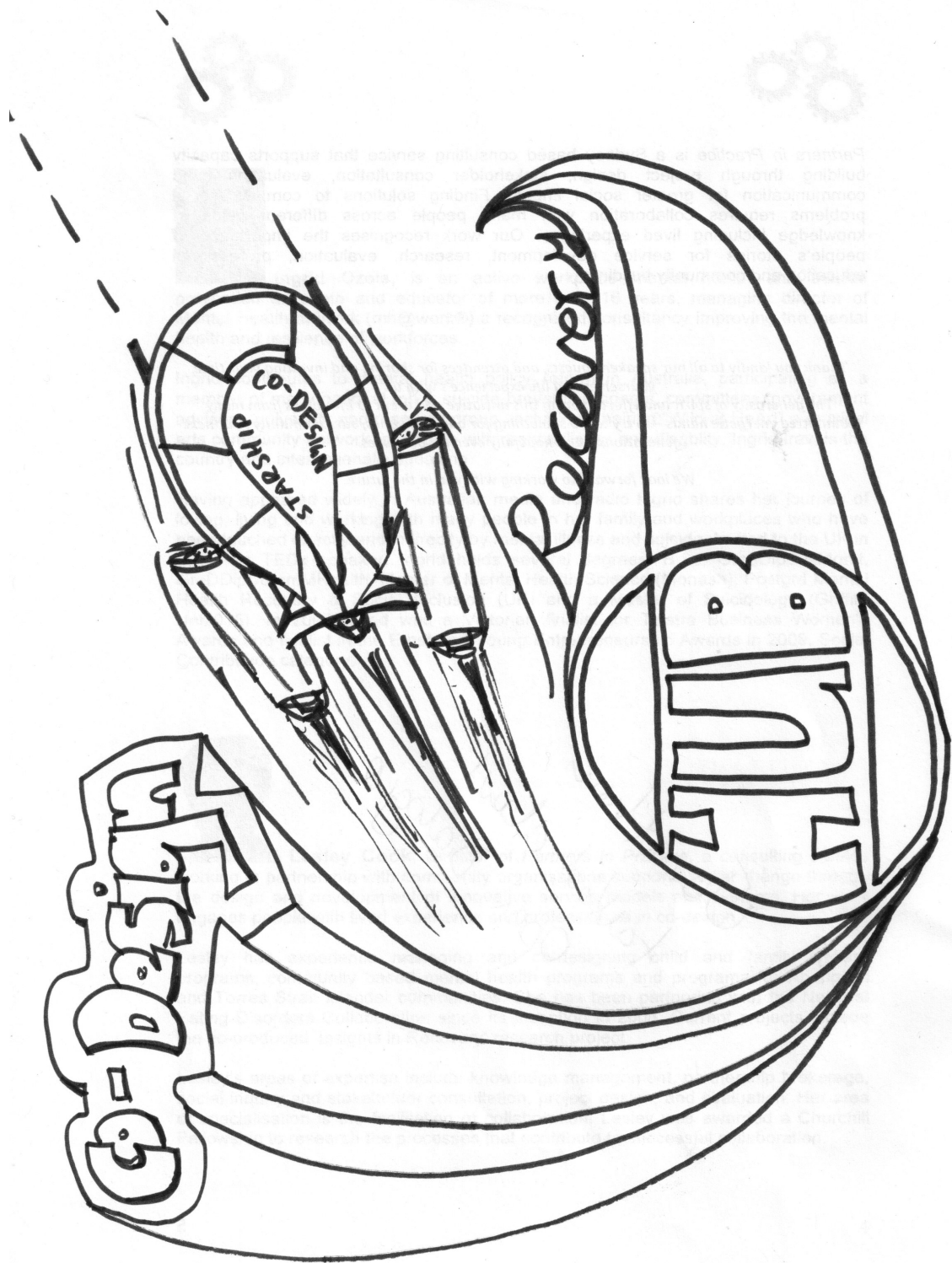
POTENTIAL

CO-DESIGN

An opportunity to
improve the
effectiveness of
mental health
services

AN OUTCOME OF THE CO-DESIGN INITIATIVE 2016

Chapter 3 Potential for Co-design



A vision from the Sydney Co-design Initiative Conference, 7 April 2016

An opportunity for change

The implementation of Primary Health Networks (PHN) responsible for reviewing the mental health service needs in their regions provides an immediate opportunity for service users – consumers, carers, families and community members – to have direct input into the development of mental health services in their own communities. The introduction of the National Disability Insurance Scheme (NDIS) also emphasises the need for shared decision making.

PHNs are required to achieve their objectives by developing a thorough understanding of the health care needs in their region, working with Community Advisory Committees (PHN Grant Programme Guidelines).

This opportunity sits firmly within the Australian policy and standards environment that promotes inclusion of service users in the collaborative development of mental health services e.g.

National Framework for Recovery Oriented Mental Health Services

Domain 5: Action on social inclusion

“The experience of mental health issues provides a person with significant additional knowledge, resilience, skills and resources that can enrich local communities.”

“As people with experience of mental health issues, local communities and mental health services have much to gain from each other, mental health services have a responsibility to assist to create opportunities for interaction and collaboration”

These policies and standards reflect a broad shift in perspective from designing services *for* people to collaboratively designing services *with* people (Sanders, 2002).

The shift has been gaining momentum slowly over decades and people with experience of mental illness have worked hard, contributing through many different advisory groups, to make ‘designing with’ a reality. For many this has been both rewarding and exhausting. Consumer and carer representatives have spent their personal energy, time and resources to achieve change, often without any personal benefit.

There comes a point at which participants must stop squandering their own energy in order to call attention to the processes that are not working and challenge the environment of the mental health system to change in response to experience based expertise.

“Consumer involvement makes mental health services more effective. There is now extensive evidence-based support for this position... It is contended that the paradigm shift from consumer

'participation' to consumer 'leadership' may be more fruitful in realizing the considerable benefits that result from effective consumer involvement in mental health services" (Gordon, 2005)

Design or Participation?

Are co-design and consumer participation the same?

When I first heard the term co-production, I thought here we go again another buzz word. I was curious why many are using this term so freely now and what is the difference between co-production and good old fashion genuine and meaningful consumer involvement, participation, engagement and influence at every level. Is this just a rebranding, relabeling, sexing up, etc or really something different? Is Co-production simply a new label for volunteering?

Michael Burge, March 2016

Consumer participation 'means any way in which people who use health services actively influence the healthcare system' (Kate Moore, 2006)

It has also been broadly defined as 'the process of involving health consumers in decision-making about health service planning, policy development, setting priorities and quality issues in the delivery of health services' (Commonwealth Department of Health and Aged Care, 1998).

Consumer participation has become an integral part of Australian mental health service standards (reference) and the National Mental Health Strategy (see doc HV-Oct2011). Broad scale community consultations and consumer advisory groups have become standard practice.

Participation involves a wide variety of activities occurring at different levels of commitment from educating and informing to full co-production. The International Association for Public Participation Australia (IAP2) identifies a *Collaboration* level of participation, focused on genuine commitment to partner robustly with the public in service decision-making (IAP2, 2014).

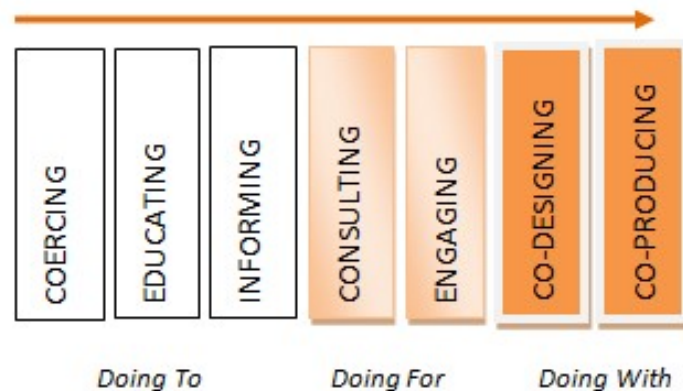


Figure 1: A Ladder of Participation

Slay, J. & Stephens, L. (2013)

There are limitations to the effectiveness of the lower levels of participation as defined in this ladder.

While there have been some excellent opportunities for consumer participation in Australia, policies and standards have yet to ensure consistent participation (O'Hagan, 2009), especially in relation to the bigger issues of policy and system reform (see doc HV-Oct2011). Design is a longer journey than consultation and a more extensive involvement than committee representation.

Some of the known barriers to participation include:

- Insufficient time and money to enable participation – many consumers and carers have limited resources and competing priorities in their lives including education, paid work and family responsibilities
- Past experience in consumer participation which has not been meaningful or of benefit to the participant
- Access to a suitable means of communication – this is particularly relevant for young people who may feel excluded by the processes of participation and by culturally and linguistically diverse communities. It is also relevant for people in rural and remote communities where distance and unreliable access to communication technology inhibit participation

These can be addressed through implementation of the principles of authentic co-design, by paying participants, by ensuring co-creation of meaningful project objectives, and by creating multiple approaches for people to engage with the project.

“For too long, “reform” of mental health services in Australia has been piecemeal and fragmentary, and largely imposed from above by different levels of government on consumers, their families and service providers. Consultation of all main stakeholders has been intermittent and erratic at best, and virtually missing at crucial points.”

Alan Rosen, April 2016

Participation by Invitation

To participate, people must be invited to join a consultation or group and the invitation is issued by the service provider or other organising body (O' Hagan, 2009). They may have to meet entry criteria or provide an application with curriculum vitae. The terms of engagement are determined by the organising body. There is a sense in which the consumer or carer comes in as an outsider providing information in to the service domain (Dunston et al., 2009).

This context puts the inequalities in relationships between service users and professionals in sharp focus and can perpetuate the inequalities experienced during treatment (Pinfold et al., 2015).

In co-design all participants are 'insiders' working together in co-created environment towards mutual goals (Dunston et al., 2009).

Committees and their recruitment processes which often resemble job recruitment have their place but are by their very nature excluding of many of the people who most need to be involved. Limited representation is not enough to engage all the different life experiences that are affected by the mental health system. Co-design is as inclusive as it can be within the project context.

Co-design offers a new and extended role for consumers and carers

"Consumers expect more than just participation in decisions about care and treatment. In a modern health system it is essential that consumers are involved in policy decisions as major stakeholders. Without this, the policies risk being one dimensional. Too often consumers are treated as targets rather than stakeholders and genuine contributors, despite the big ticket commitments to consumer participation". (see doc HV-Oct2011)

In co-design, the concept of consumer and carer leadership, engaging people with lived experience as equals in the development of an effective mental health system, replaces the more vulnerable concept of invitations to participate (O'Hagan, 2009). Beyond token representation and advisory groups, there is a need for a framework that enables people with lived experience to work alongside health professionals and policy makers (Dunston et al., 2009).

"Unlike participation, leadership assumes people with mental health problems have the power to set the agenda, make major decisions and control resources" (O' Hagan, 2009).

"Consumers tend to approach participation in one direction. In addition to approaching entities or applying for vacancies in the hope they can participate in a meaningful way, consumers should aim to initiate and start their own projects, then invite others to join in participation, co-production, co-design and other forms of partnership. In other words, reversing the approach."

Bè Aadams

Language matters

"The language used in co-design needs to be neutral and not a barrier to equality"
(Symposia feedback)

The words 'consumer' and 'carer' are the most common terms used when referring to people who contribute from their life experience and knowledge. This report uses

these terms as the best available and most readily understood descriptors of lived experience. Despite this common usage, many people are uncomfortable with these labels.

A consumer is a person who buys goods and services (Merriam Webster Dictionary). Using health services is only one small part of each person's journey through illness and recovery.

If we want to understand recovery we need to value more than service use. We need to value the complex knowledge of people who are navigating the recovery journey in different circumstances. There is something to be learned from every experience including the experience of those who do not choose to use health services to support their recovery (Anthony, 1993) and those who service providers might label as 'mild to moderately' unwell.

Personal development through the experience of mental distress needs to be ascribed significant value (O'Hagan, 2009).

"For us to be involved as a 'consumer perspective' we have already lost power as all others may identify as 'professionals'. As partners in co-design we need acknowledgement of our expertise." (Symposia feedback)

Recognising the value of experience based expertise and reflecting this in respectful terminology can be validating to those who share from their experience (Aadam, 2016) and can help to break down the barriers in professional-consumer partnerships.

Co-design potentially equalizes the balance of power by engaging all participants as equals at every stage of the process (Aadam, 2016).

"When someone sails solo around the world we give them celebrity status. The people who are called consumers and carers are navigators, explorers, experts by experience, surviving and often thriving in circumstances others can barely imagine".

What does Co-design, Co-production & Co-delivery mean to me?

An extract from Alan Rosen, (April 2016) presentation to the Melbourne Co-design Initiative Event

Combining Different Expertises

Co-design, Co-production and Co-delivery entail working together to develop services that work well, in terms of rigorous research evidence of good outcome, clinical experience, and especially in terms of acceptability to and desirability by individuals and families with lived experience of mental illnesses. We achieve this by mobilizing and marshalling different experts to work together. This confluence of expertise, like 3 streams forming a powerful river, combines and synergises academic, clinical and lived experience types of expertise. Alan Rosen April 2016

At the micro level, Co-design, Co-production and Co-delivery mean that clinical professionals, support workers, as well as consumer and carer, Aboriginal and transcultural peer professionals must be able to work together towards common purposes for and with particular individuals, families and groups.

Again, at the micro level all these service providers should be working together on personalised wellness and recovery plans, co-produced and reviewed with individual consumers, their families and support teams.

Simultaneously, at the macro level they should be designing and delivering highly integrated wholistic services, working to a single framework which represents the cooperative development of one unitary strategic mental health plan for that region, combining public, NGO and private fee-for-service interests.

Flattening the Working Hierarchy

A Co-design, Co-production and Co-delivery trifecta means not working at cross purposes, and not having some stakeholder groups (eg providers) dominating others (eg service-users and carers), effectively saying to all the others : “we know what’s best for you”. This is known as the presumption of “Vocational Ownership” of a stakeholder group (eg service users) by another more dominant stakeholder group (eg clinician providers). (Thornicroft G, pers comm.).

Co-design, Co- production and Co-delivery entail working in partnership. Partnerships work best when they are between parties who are equals. Equals in status, respect, and in power. We have a long way to go in these respects. But we are at least have turned the first corner and are on the road, near the beginning of a new long journey together.

Widening both the Social Inclusion and the Common Ground

Co-design, Co-production and Co-delivery means building together a shared vision, with a common mental map of our mental health service, that inspires and makes sense to all participants, forming an ever-evolving learning organization, learning in teams, and inclusive ongoing communities of practice with all service-users and providers. Co-design, Co-production and Co-delivery means finding and widening the most common ground we can stand on together at the same time (Senge P, 1990).

Modernising participatory practices with, by and for the community - all of us together

By Prof. Jane Burns & Ingrid Ozols

Enshrined at the centre of our National Mental Health Policy (1992), is the concept of consumer and carer participation in one's own treatment and recovery process, and beyond....

“Nothing about us without us.”

The interpretation of this has varied. For an individual it has meant self-responsibility and self-determination in an optimistic, hopeful and supported recovery framework. Increasingly, we are seeing this reflected in policy and the National Mental Health Commission has squarely positioned ‘person centred care’ as the cornerstone of National Mental Health Policy into the future. Although it sounds simplistic, critical to this policy and fundamental to driving person centred care is the basic tenet of treating consumers, families and carers as people. They must be recognised as active advocates and hard-working partners - alongside all stakeholders – in the fight to change and improve mental health, services, interventions, research, systems and policy at every level and point of process.

We (Ingrid and I) met in 2000, I had been charged with driving the youth and public health agenda at beyondblue: the national depression initiative and Ing was in charge of establishing, BlueVoices, the beyondblue Consumer network. Back then, 16 years ago, it seemed obvious to us that if you were going to design campaigns and services, conduct research and development and inform policy that it was logical to involve people with a lived experience in that partnership. Recently, there is buzz about the dawning of a new era, the “CO” family; co-creation, co-design, co-production, and the like, as if this was a new way of being and doing. For us, participatory design is the only way to move forward. There is now a swathe of evidence to support this approach.

“Collective wisdom driving collective change and impact.”

Yet while this concept seems logical, it is not common practice. Not in the design of services, not in our research institutes and not in the shaping of policy. Most

disturbingly, it is not common practice in the provision of care or support in our communities and for many it is desperately desired, wanted and needed.

Meaningful, relevant beneficial outcomes can really only come about through a team effort of stakeholders where the “user of the system” is the linchpin of any true transformational change to health care. How can personalised care packages be developed and delivered in collaboration without the person who must be driven to engage, own, commit, live with and DO the work of recovery? How can others with their lived experiences not be part of the bigger strategic approach when they have first-hand knowledge of what has and hasn’t worked, the barriers and challenges they can see from a different lens?

We have both tried, with various degrees of ad hoc success, to move this philosophical DNA into being a natural way of “working and doing” with our mental health services and system changes. We are not yet there.

As community members, modernising our thinking, actions, change management processes, communication and language is critical if we wish to see our vision of better mental and physical wellness, and reduced suicide rates, live and breathe.

Critically, we need to “acknowledge and accept” that we are all people, humans first. In very different ways, we are all consumers and carers of the health care system at some point in our lives. We each bring life experiences and different knowledge and expertise. No one person is greater or better than any other. Each of us deserves to be respected and embraced. This leads to building trusting and solid working relationships.

Through the efforts of all of us, giving of ourselves, “change is possible – if we just have the nerve”

(J.K. Rowling).

The opportunity to be brave is here today - we have the support of the Prime Minister and the Minister for Health. As Prime Minister Turnbull so eloquently put it, our single greatest asset is not coal in the ground or our mining industry. Our single biggest asset is what is in our head, our mind. He argued, and indeed the research shows, that mental health will determine the mental wealth of this great nation that we have the privilege of calling home. And yet, to be brave requires determination and the drive to overcome all types of challenges within such frameworks – having grit is, at times, exhausting. Some days it is easier to take the path that is known, the one that doesn’t break your heart with the disappointments, the criticisms and the challenges that come when you attempt to disrupt a system that is fundamentally flawed.

Brene Brown, a vulnerability storytelling researcher and enormous TEDx success, talks about the fact that “sharing vulnerabilities builds compassion and empathy. The courage it takes to show this side of ourselves drives creativity and innovation. If we

can do this in our working teams, in whatever space we occupy, in our case mental health reform - it is doable.

We have a mandate to disrupt the status quo. We are at a critical juncture in Australia's history – major mental health reform running in parallel with the National Disability Insurance Scheme. But to achieve the seismic change we require and realise our vision, we must be brave and we must recognise that consumers and carers are equal partners on this journey. Only then will we truly achieve 'person centred care'.

"I can do things you cannot,

You can do things I cannot,

But we can all do small things with great love &

Together we do something wonderful"

- Mother Teresa

Conclusion

The outcomes of the Co-design initiative confirm the literature on co-design and co-production. The same principles are documented across the literature on collaboration and the literature on supporting cultural diversity in the commercial world.

The principles are in a way the ‘basic rules of engagement’ for any venture that needs to bring people from very diverse backgrounds together to find solutions to complex issues.

Co-design is not a panacea (Bovaird, 2007). It is however the only way to work to create services and systems that reflect the needs of real people rather than statistics.

Co-design needs to be well resourced. It will take time, coordination, and potentially creative use of technology, to sustain the long term relationships needed for real change.

There is a need for commitment from all stakeholders - from policy makers and planners, from researchers, from health service providers, from consumers, carers and families – to set aside assumptions, competition and reluctance to change in order to make the best we can of our limited resources.

“Great opportunity – let’s make it count. Now is the time to move from consulting and engaging, from ‘advisory committees’, to actually working together to create the change in mental health services that we all want to see” (Symposia feedback)

The immediate opportunity represented in each PHN region may be to collaboratively engage in mapping what we have, what works and what does not and who is slipping through the cracks.

Co-design for both Commissioning & De-Commissioning

“To begin with this means co-operative mapping of what works, what are the gaps, and scanning both research and experiential narrative accounts for the evidence for what additional or alternative services that we need.”

Alan Rosen April 2016

Effective participation needs to be well resourced

“Creating the conditions for participation takes time and resources, however the payoff is significant and it is cheaper in the long run. Schedule the time to plan the activities and protocols and build relationships” (Hagan et al., 2012)

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Appendix 1: The Co-Design Initiative

The Co-Design Initiative is a voluntary project led by consumers and carers and auspiced by Civil Society Australia. It is a response to planned review and reforms for the mental health system, led by the creation of Primary Health Networks.

Our goal... is to ensure that consumers and carers are at the centre in mental health system design, development and delivery.

Co-design Events

In March and April 2016, the Co-design Initiative organised two co-design events, one in Sydney and one in Melbourne. Referred to as 'conferences' and as 'symposia' these were actually interactive workshops that enabled a large number of people to share their knowledge, experience and ideas about co-design.

The core question considered at these events was: how can we make sure that consumers and carers are integral to and leading the reform of the mental health system in each PHN?

Two interactive workshops explored the questions:

Workshop 1: Common Ground – what are the essential elements of authentic co-design?

Workshop 2: Co-creation – what could a consumer and carer 'hub' look like in the context of a PHN?

More than two hundred people participated in the events. The written and verbal feedback from the events has formed the basis of the Co-design: Shared perspectives on authentic co-design report.

Appendix 2: Melbourne 22nd March, 2016 Speakers



Shol Blustein is the General Manager, Service Innovation at the South Eastern Melbourne PHN. In this role, Shol leads the organisation's commissioning and service design functions. Prior to this, Shol was the Strategy Lead at Pinnacle Group Australia, a boutique management consultancy firm that works with not-for-profit, government and community sector organisations across the health, mental health, disability and broader social sectors. Shol holds a

PhD from Queensland University of Technology (Law & Policy).



Michael Burge OAM, a retired Army Warrant Officer of 20 years service, is a mh advocate has for consumers and carers with Veterans' Affairs and Qld Mental Health and has represented consumers and carers on numerous local, state and national committees. Michael is an accredited Master MHFA Instructor and widely published in Mental Health Magazines.

Michael has a long list of committee and advisory board memberships; Consumer Co-Chair National Mental Health Consumer Carer Forum (NMHCCF), National Mental Health Workforce Advisory Council, National Register of Consumers and Carers, National Recovery Working Group, Fourth National Mental Health Plan Flagship 1 Steering Committee (Social Inclusion), Expert Reference Group for development of Certificate IV Mental Health Peer Support, and National Advisory Council on Mental Health, amongst many other mental health related activities.



Professor Jane Burns, is the founder and CEO of the Young and Well Cooperative Research Centre, an organisation that unites young people with researchers, practitioners and innovators to explore the role of technology in improving mental health and wellbeing for young people aged 12 to 25.

Jane holds a Principal Research Fellowship at Orygen, The National Centre of Excellence in Youth Mental Health and an Honorary Fellowship at the Brain & Mind Centre. She has led the youth agenda for *beyondblue*, was a Commonwealth Fund Harkness Fellow at the University of California, San Francisco, and was Director of International Partnerships at Inspire Foundation. Jane held a VicHealth fellowship from 2006-2013, an NHMRC fellowship from 1997-2000 and an NHMRC scholarship from 1994-1996. She holds a PhD in Medicine from the Faculty of Medicine (Public Health and Epidemiology) University of Adelaide.

Jane was recently announced a winner in the category of Social Enterprise and Not-for-profit for 2015's Australian Financial Review and Westpac Group 100 Women of Influence, and was a Victorian Finalist in the 2012 Telstra Business Women's Awards. Jane is a Graduate of the Australian Institute of Company Directors.

By Josie Hayden



Heidi Everett is a mental health system recovery advocate; singer/songwriter; autobiographical performer; creative workshop & Mi/h project facilitator; illustrator, writer, filmmaker. Heidi is the Director of 'Schizy Week Jam'; Mimosa Arts Festival; Psych Ward Support social media project, as well as facilitator songwriting workshops with Wild at Heart Community Arts music network for

mental health.

She has appeared on Andrew Denton's production 'Angels and Demons' (2008); SBS 7:30 Report about misuse of anti-psychotics (2013); ABC & local radio. Heidi's latest advocacy project; campaigned against the widespread rollout of Drug Detector Dogs and Handlers in psychiatric wards. Heidi uses original music to help raise positive and hopeful profile of mental illness & recovery story through solo performance, duo and band.



Phil Heuzenroeder, founding Artistic and Executive Director of one of Australia's leading Community Arts organisations, Wild at Heart, this unique network embraces people with disabilities and mental illness, expressing their life's journey through music, song-writing, singing, film-making, dance, event management

workshops and performance events.

Phil has led the Bipolar Bears rock band since 2000 and appeared in a 3 part documentary series on SBS1 TV in 2010. Working extensively as a musician, video artist, event manager and facilitator over the past 16 years, he leads many workshops in singing, song writing and music, film and music video clip making, event management and technical production. He also consults with local government and non-government disability organisations on strategies to create more inclusive arts, cultural practice and participation.

Phil directs the 80 voice Melbourne Mass Gospel Choir with performances at the Falls and Port Fairy Festivals, The Famous Speigeltent, Vodafone Arena, Federation Square and many festivals and leads gospel singing workshops, trains soloists and singing leaders across Victoria.



Douglas Holmes, a long-term mh consumer advocate, is the Consumer Participation Officer, St Vincent’s Health, NSW. In 2014 Doug was awarded “TheMHS Exceptional Contribution Award,” which recognises an individual who has made an outstanding contribution to mental health service delivery and acknowledges a remarkable accomplishment in the unfolding story of Mental Health Service delivery in Australia and New Zealand. Doug is also the Chairperson of “hearing voices network – NSW. A Director of Neami National since 2007. TheMHS Conference Committee Manager since 1997. Doug holds a Diploma in Training and Assessment Systems; Cert IV in Workplace Training (Category 2).



Vern Hughes is Director of *Civil Society Australia*, and has been Director of the *Centre for Civil Society* since 2007. He has been an advocate for civil society in Australia since 1988. Vern has been a writer, practitioner and networker in community, church, social enterprise and cooperative movements. He is a former CEO of *South Kingsville Health Cooperative* (Australia's only consumer-owned primary health care centre); Director of *Hotham Mission* in the Uniting Church; Founder of the *Social Entrepreneurs Network (Australia and New Zealand)*; and Director of the *Cooperative Federation of Victoria*. He is an Adjunct Fellow in the Faculty of Business and Entrepreneurship at *Swinburne University*. He is also a historian and researcher on civil society, social policy and political reform issues.



Dr Caroline Johnson is a general practitioner in Melbourne and a passionate advocate for mental health reform. She loves working with consumers and carers to achieve a shared vision of improved mental health care. Caroline has extensive experience from undergraduate through to postgraduate training of doctors in mental health skills and recently completed a PhD exploring the way people experiencing depression are monitored in the primary care setting. She is the clinical lead in mental health on the RACGP Expert Committee in Quality Care and a board member of Mental Health Australia



Professor Alan Rosen, AO, inaugural Deputy Commissioner of the Mental Health Commission of NSW, is an eminent psychiatrist and researcher. A professorial Fellow, Illawarra Institute of Mental Health, University of Wollongong, Clinical Associate Professor, Brain & Mind Centre, amongst other institutes, including University of Wisconsin and visiting senior fellow in medical anthropology and social medicine at Harvard University. Alan, for more than 30 years, was formerly director and clinical director of Royal North Shore Hospital & Community MH Services, Sydney.

Alan’s experiences and expertise is extensive. Authoring, co-authoring more than 140 published and journal articles, chapters on 24 hr community based alternatives to acute and long-term inpatient care, rehabilitation, recovery facilities and teams, assertive community

treatment and support, and integrated mental health service systems; early intervention in psychosis; stigma; dual disorders, deinstitutionalization, consumer, family and peer participation in and contributions to services, family interventions, Aboriginal and remote area mental health, cultural influences on mental health service systems, qualitative and quantitative outcome measures, research and evaluation in mental health, service standards, mental health services for impaired clinicians, worldwide mental health commissions, the National Mental Health Strategy, international community psychiatry, Human Rights of individuals with severe and persistent mental illnesses, Activity Based Funding for mental health services, Art and Psychiatry, and the history of Australian Psychiatry.

Alan, the founding steering group member of The Mental Health Services (TheMHS) Conference of Australia & New Zealand, recently celebrated its 25th anniversary. Recently he co-edited a “The Early Intervention of Nearly Everything for better Mental Health Services”.



Ingrid Ozols, is an active workplace mental health and suicide prevention advocate and educator of more than 16 years, founder and managing director of Mental Health at Work (mh@work®) a national & internationally recognised consultancy aimed at improving the mental health, resilience and productivity of organisations and their people.

She contributes to mental health policy reform in Australia, participating as a member of many national mh & suicide prevention boards, committees, government advisory, university and research groups. Ingrid travels the country and internationally speaking (and chairing) many conferences & workshops. Currently, Ingrid is Acting Chair of Wild at Heart.

Having appeared widely in Australian media and radio Ingrid shares her journey of loving, living and working with many people in her family and workplaces who have been touched directly and indirectly by mental illness and suicide. Invited to the UK in 2015, as TEDx speaker, Ingrid holds several degrees: B.Sc, GradDipBusMgmt, GraDDipCommMHealth, Master of Mental Health Science (Monash), Postgrd Mental Health Recovery & Social Inclusion (UK) and a Master of Suicidology (Griffith Uni2015). In 2007 Ingrid was a Victorian finalist for Telstra Business Women’s Awards and finalist in the Ernst and Young Entrepreneurship Awards in 2009, Social Contribution category.



Lesley Cook, Director of *Partners in Practice*, a consulting service working in partnership with community organisations supports social change through the design and development of innovative service models and systems. Her work engages people with lived experience and professionals in co-design.

Lesley has experience managing and co-designing child and family welfare programs, community based mental health programs and programs for Aboriginal and Torres Strait Islander communities. She has been partnering with the National Eating Disorders Collaboration since its inception in 2008. Current projects include the co-produced 'Insights in Recovery' research project.

Lesley's areas of expertise include knowledge management, partnership brokerage, social inquiry and stakeholder consultation, project design, and evaluation. Her area of specialisation is the facilitation of collaboration. Lesley was awarded a Churchill Fellowship to research the processes that contribute to successful collaboration.

Partners in Practice is a Sydney based consulting service that supports capacity building through project design, stakeholder consultation, evaluation, and communication for greater social impact. Finding solutions to complex social problems requires collaboration with many people across different fields of knowledge including lived experience. Our work recognises the importance of people's stories for service development, research, evaluation, professional education and community building.

Thank you kindly to all our speakers, guests, and attendees for sharing and investing your time, yourselves and life experience's with us.

The generosity of spirit and effort to bring this initiative and event to life comes from many committed energetic hands – to try to DO something for our loved ones, our community , our next generations – and hopefully even for ourselves.

We look forward to working with you in the future.

Appendix 3: Sydney 7th April, 2016 Speakers



Be Adam - I once filled out a questionnaire to see what values I held. What came out on top was that I really dislike injustice. The value of wanting a just society explains to me why I have always been drawn to social and political activism. Because I have lived experience and was

introduced to the mental health consumer/survivor movement several years ago, I am currently focusing my energies in the mental health sector.

If I was to call myself anything, it would be an advocate. Through my research work, workshop facilitation, partnerships with organisations, consulting work and being part of boards, committees and other working groups, I am actively advocating and working towards a just, fair and equitable system for all in the mental health sector – and by extension, for all people in society.



Michael Burge OAM, a retired Army Warrant Officer of 20 years service, is a mh advocate has for consumers and carers with Veterans' Affairs and Qld Mental Health and has represented consumers and carers on numerous local, state and national committees. Michael is an accredited Master MHFA Instructor and widely published in Mental

Health Magazines.

Michael has a long list of committee and advisory board memberships; Consumer Co-Chair National Mental Health Consumer Carer Forum (NMHCCF), National Mental Health Workforce Advisory Council, National Register of Consumers and Carers, National Recovery Working Group, Fourth National Mental Health Plan Flagship 1 Steering Committee (Social Inclusion), Expert Reference Group for development of Certificate IV Mental Health Peer Support, and National Advisory Council on Mental Health, amongst many other mental health related activities.



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International Partnerships at Inspire Foundation. Jane held a VicHealth fellowship from 2006-2013, an NHMRC fellowship from 1997-2000 and an NHMRC scholarship from 1994-1996. She holds a PhD in Medicine from the Faculty of Medicine (Public Health and Epidemiology) University of Adelaide.

Jane was recently announced a winner in the category of Social Enterprise and Not-for-profit for 2015's Australian Financial Review and Westpac Group 100 Women of Influence, and was a Victorian Finalist in the 2012 Telstra Business Women's Awards. Jane is a Graduate of the Australian Institute of Company Directors.



Peter Duffy is a singer songwriter and has been involved in the “*No Suppression*” group. For the last 5 years worked as a Consumer Worker for over 20 years in the Eastern Suburbs at the Prince of Wales Hospital Kiloh unit.

<https://www.facebook.com/No-Supression-320064311447646/>

Peter has worked with **Lynda Hennessy** to support the development of the MAD Pride concerts in Sydney since 2002

<http://www.mindfreedom.org/campaign/madpride/introduction>



Douglas Holmes, a long-term mh consumer advocate, is the Consumer Participation Officer, St Vincent's Health, NSW. In 2014 Doug was awarded “TheMHS Exceptional Contribution Award,” which recognises an individual who has made an outstanding contribution to mental health service delivery and acknowledges a remarkable accomplishment in the unfolding story of Mental Health Service delivery in Australia and New Zealand. Doug is also the Chairperson of “hearing voices network – NSW. A Director of Neami National since 2007. TheMHS Conference Committee Manager since 1997. Doug holds a Diploma in Training and Assessment Systems; Cert IV in Workplace Training (Category 2).



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Robyn Kruk AM has been Chief Executive of a number of national and state agencies including the New South Wales Department of Premier and Cabinet, New South Wales Health, and National Parks and Wildlife. At the national level she was the Secretary of the Environment portfolio, and established and was the inaugural CEO of the National Mental Health Commission. Recently becoming a board member of Mental Health Australia (formerly the Mental Health Council of Australia). She has also worked in child protection and as a volunteer in crisis counselling.



Ingrid Ozols, is an active workplace mental health and suicide prevention advocate and educator of more than 16 years, managing director of Mental Health at Work (mh@work®) a recognised consultancy improving the mental health and resilience of workforces.

Ingrid contributes to mental health policy reform in Australia, participating as a member of many national mh & suicide prevention boards, committees, government advisory, university and research group, including Chairing “Wild at HeArt” a musical arts community network for people with mental illness and disability. Ingrid travels the country and internationally speaking.

Having appeared widely in Australian media and radio Ingrid shares her journey of loving, living and working with many people in her family and workplaces who have been touched directly and indirectly by mental illness and suicide. Invited to the UK in 2015, as TEDx speaker, Ingrid holds several degrees: B.Sc, GradDipBusMgmt, GraDDipCommMHealth, Master of Mental Health Science (Monash), Postgrad Mental Health Recovery & Social Inclusion (UK) and a Master of Suicidology (Griffith Uni2015). In 2007 Ingrid was a Victorian finalist for Telstra Business Women’s Awards and finalist in the Ernst and Young Entrepreneurship Awards in 2009, Social Contribution category.



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Partners in Practice is a Sydney based consulting service that supports capacity building through project design, stakeholder consultation, evaluation, and communication for greater social impact. Finding solutions to complex social problems requires collaboration with many people across different fields of knowledge including lived experience. Our work recognises the importance of people’s stories for service development, research, evaluation, professional education and community building.

Thank you kindly to all our speakers, guests, and attendees for sharing and investing your time, yourselves and life experience’s with us.

The generosity of spirit and effort to bring this initiative and event to life comes from many committed energetic hands – to try to DO something for our loved ones, our community , our next generations – and hopefully even for ourselves.

We look forward to working with you in the future.

Appendix 4: Next Steps

Consumer and Carer Hubs – Getting Started

Mental health services are changing. The Australian Government announced in November 2015 its intention to move towards a person-centred whole-of-care approach to mental health based on localised decision-making. It has re-directed \$365m in 2016/2017 away from the hospital sector and \$200m from the drug and alcohol sector to pilot personalized models of care in regions, to be commissioned through, but not delivered by, 31 Primary Health Networks (PHNs).

The **Consumer and Carer Co-Design Initiative** is a national voluntary project led by consumers and carers. Its goal is to enable large numbers of consumers and carers to co-design and co-produce personalized and community-based mental health services with PHNs, service providers and practitioners.

How it Works

1. In each of the 31 PHNs around Australia, a **regional hub of consumers and carers** is being established. You can join the hub in your region by filling in the form at this link <http://www.partnerships.org.au/MHCo-DesignRegistration.htm>

A map locator for each PHN is available at <http://www.health.gov.au/internet/main/publishing.nsf/Content/phn-locator>

2. Each hub is a consumer and carer-governed group of at least 20 people. Each hub will be supported in developing its capacity to co-design, drawing on internal peer-based resources and external experience and expertise as required.
3. Each hub will appoint a Convenor or Convenor(s) and devise its own governance, leadership and communication arrangements as it sees fit. Convenors will be networked nationally for sharing of strategic information and experiences.
4. Each hub will also appoint a Team Leader or Team Leaders(s) to coordinate particular aspects of the work of the hub.
5. In each hub, the Convenor(s) and Team Leader(s) will constitute a Leadership Group, and will meet and/or liaise as they see fit.
6. Each hub has four functions:
 - a. contribute to design and development of regional services;
 - b. purchase services;
 - c. provide peer-led services;
 - d. conduct consumer-led evaluation.
7. Hubs may partner with organisations as they see fit in undertaking these

functions.

8. The establishment of hubs in the 31 Primary Health Network regions does not mean that the hubs relate only to the Primary Health Networks. The PHN regions simply constitute regional boundaries for workable regional hub activity – the hubs will relate to service providers, practitioners, state government mental health bodies, and networks in their respective regions, as well as PHNs.

You can register to participate in your region by filling in the form at this link <http://www.partnerships.org.au/MHCo-DesignRegistration.htm>

Governance Arrangements

1. The Initiative is overseen by the [National Campaign for Consumer-Centred Health Care](#), a project of Civil Society Australia.
2. The Steering Group of the Campaign will appoint Convenors and Team Leaders, and link them in advisory and mutually supportive networks. The Steering Group may also remove the appointment of Convenors and Team Leaders, should this be required to ensure effective operation of the hubs.
3. The Steering Group will monitor, advise and provide strategic guidance and support for the operation of the hubs.
4. The Convenor of the Steering Group is responsible for the effective operation of the Steering Group and its support for the operation for the hubs. The Convenor of the Steering Group is Vern Hughes vern@civilsociety.org.au

Getting Started

1. Any consumer and carer who wishes to participate in a hub should first express their interest using by filling in the form at this link <http://www.partnerships.org.au/MHCo-DesignRegistration.htm>
2. A participant who wishes to contribute as a Convenor or Team Leader should express their interest by by filling in the form at this link <http://www.partnerships.org.au/MHCo-DesignRegistration.htm> or by contacting the Convenor of the Steering Group (Vern Hughes).
3. In each hub, the Convenor(s) will make contact with participants to initiative activity, beginning with a face-to-face or online meeting or participants. This meeting will make organizational arrangements that suit the group.
4. Contact: Convenor Steering Group Vern Hughes vern@civilsociety.org.au

Appendix 5: NDIS Starship Enterprise Parable

In Australia we are all eagerly waiting on the NDIS Starship Enterprise mothership to finish implementing the NDIS across Australia.

The NDIS has been a long time coming some say light years - as it kept running into unknown senate-aroids and unpredictable oppositional alien forces from other planets. It has a huge arsenal of innovative treatment and care. It will go where no mental health care system has ever gone before – taking a flexible whole of life approach with participants, their families and carers, offering real hope for the future, genuine and meaningful choices, and recovery focused self-directed care.

Now imagine – it's coming soon to a town near you - this crazy big thing called the NDIS filled with recovery focused self-directed care & armed with a smorgasbord of innovative care & choices like you have never seen before in this beautiful sunburnt country.

It won't just change what we call things but what we do *remember*:

"a wombat dressed in different clothes is still a wombat".

Remember real reform means changing NOT just what we call things.



Michael Burge CONGO Canberra 2012

No longer are consumers just coming along for the ride – consumers are at the helm of this ship. On board is a peer workforce the likes of which you have never seen before, instilling hope, coaching wellness and genuinely connecting with other human beings to help them overcome distress.

The mission of the NDIS is to help reform a dysfunctional, broken system of care that sometimes looks like a patchwork quilt full of holes and gaps that is not adequately meeting the needs of people with a psychosocial disability.

The NDIS enterprise has some of the most advanced technology that has ever been developed – to everyone's surprise it has been developed in collaboration with consumers, carers, their families and the community utilising co-design, co-production and innovation.

In co-production we need to be equal partners, have collective ownership and have co-responsibility and there's no one person who is the boss. Both professional and

consumer input must be equally valued and included right from the beginning of the processes - no more excuses.

“Nothing about us without us”

As long as we all hold onto hope the ship will never run out of fuel. By the way the ship is fuelled with an endless supply of hope. It makes us all feel so warm and fuzzy inside like you want to hug everyone & live happily ever after – doesn't it.

All I can say is beam me up Scotty - now - I can't wait.

Talk about a Hollywood movie in the making.

Let's all hope it is a blockbuster like we have never seen before.

“It's not about what is, it's about what it can become” – Dr Seuss

Let's all hope it is full of real & meaningful choices and not just programs that promise much and deliver little. Let's hope that being stuck in the same service for years will be a thing of the past.

Let's hope we do not have any more of the lucky dip type service delivery.

Be careful if you are a service provider and don't meet the needs of the consumer, they will find someone else who does. If you want consumers to utilise your services, then you need to meet their needs otherwise you will find yourself supporting less & less people.

It will not be as hard as getting a divorce for a consumer to free themselves from a service provider that is not meeting their needs – it will happen as soon as the consumer wants it to happen.

We have had enough of the condescending, patronising, tokenistic, intimidating, discriminating, institutionalised, dismissive attitudes. Michael Burge TheMHS 2009

It's not good enough anymore, to not listen to what consumers are saying about what really makes a difference in their lives – no more excuses – consumers are the experts in what works for them, not service providers.

The NDIS will eventually phase out and vaporise the lucky dip type service delivery, the lack of continuity of care, the fact that some consumers have too many care plans from different service providers; having your care plan, type of treatment, place of treatment, care plan, doctor, clinician, changed numerous times will be a thing of the past. No more dart board type funding where consumers have to close their eyes and hope for the best.

From 'them' and 'us' to 'we' From 'yes, but...to 'yes, how...'

It will help consumers thrive and not just survive, lead contributing lives, have something meaningful to do and look forward to and not be stuck in the same service for years and years.

It will ensure consumers are in the driver's seat and will have the right supports at the right time, consumers will no longer be unwilling passengers with limited choices.

Remember that saying from "Martin Luther King"

History will have to record that the greatest tragedy of this period of social transition, was not the strident clamour of the bad people, but the appalling silence of the good people.

Thank-you

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FROM THE MADHOUSE TO CODESIGN

PLACING CONSUMERS AND
CARERS AT THE CENTRE IN
MENTAL HEALTH SYSTEM
DESIGN, DEVELOPMENT
AND DELIVERY

BRINGING ALL THE
PARTS TOGETHER

RECOVERY
COLLEGES

SUICIDE
PREVENTION

E-MENTAL
HEALTH
INFORMATION

COMMUNITY
BASED
SERVICES

PRIMARY
HEALTH
NETWORKS

INTRODUCING THE
CONSUMER AND
CARER CO-DESIGN
INITIATIVE AS A
DRIVING FORCE

ADDRESSING KEY PRIORITIES FOR
MENTAL HEALTH SYSTEM
DEVELOPMENT:

CO-DESIGN OF SERVICES

CO-DELIVERY OF SUPPORT

CO-EVALUATION OF IMPACT