

**Royal Commission** into Victoria's Mental Health System

### WITNESS STATEMENT OF CATH ROPER

I, Cath Roper, Consumer Academic, of Centre for Psychiatric Nursing, University of Melbourne, Level 6, 161 Barry Street, Parkville in the state of Victoria, say as follows:

### Background

- I hold a Bachelor of Arts, Diploma of Education and Masters in Social Health. I used mental health services, involuntarily and annually over a period of 13 years up until 1998. In one of my hospitalisations I had the fortune of meeting a research team headed by Yoland Wadsworth, called the Understanding and Involvement project. This project aimed to identify strategies for embedding consumer participation at the then Royal Park hospital site. I subsequently became one of the first four Staff-Consumer Consultants in Victoria. In November 1999 I was appointed Consumer Academic at the Centre for Psychiatric Nursing (CPN), a pioneering role for a mental health consumer on-staff in an academic setting, a post I still hold today.
- In my role as Senior Consumer Academic, I provide support to a small team of Consumer Academics at the CPN. I contribute to policy development, engage in activities to support the consumer workforce, co-develop and facilitate training with mental health nurses, and provide this training to staff in mental health services. I teach a core consumer perspective subject to mental health nurses enrolled in the Graduate Diploma in Nursing Practice (Mental Health) at the University of Melbourne. I also write publications, give presentations, provide supervision to students and members of the consumer workforce and engage in research from a consumer perspective. Areas of interest are:
  - (a) ending seclusion and restraint;
  - (b) implementing supported decision-making where people are on Treatment Orders or involved with public mental health services;
  - (c) co-production;
  - (d) consumer-run alternatives to traditional mental health services;
  - (e) ethics and human rights in relation to mental health legislation and mental health services;
  - (f) growing communities that embrace diversity neuro, physical, psychological and emotional; and
  - (g) supporting the consumer workforce.

Please note that the information presented in this witness statement responds to matters requested by the Royal Commission.

- 3 Since April 2019 I have acted as a Consumer Advisor to the Chief Executive Officer of this Royal Commission. As part of this role, I provide independent advice on the Commission's policy and engagement activities.
- 4 Attached to this statement and marked "CR-1" is a copy of my curriculum vitae.

### Lived experience in governance and co-production

5 Marginalised groups are by definition locked out of decision-making and spheres of influence. When some of us started advocating for co-production, it was to shift people's thinking away from the twenty-year history in Victoria of consumers "participating" or "being involved" in projects where the agenda was already set by others. We wanted government to move away from more passive constructions of 'involvement' in the development delivery, review of mental health services, to: consumers working alongside government and services in commissioning, designing and delivering services. If coproduction was going to be successful, there needed to be much greater investment in consumer leadership. Increased investment in the Victorian consumer workforce has only just started to happen over the last five years or so and while this has contributed to a growth in capacity and numbers, positions of influence for consumers in Victoria are lacking.

### The concept of "co-production"

- 6 Co-production is a process; a way of doing work together that pays close and constant attention to power disparities and uses deliberate strategies to both unveil and address them (Roper, Grey and Cadogan, 2018).<sup>1</sup> What distinguishes co-production from other collaborative approaches is that whoever is closest to the problem being considered (in this case, consumers) must be involved from the outset, either in the agenda setting phase, or in the early stages of planning and thinking through the scope of and rationale for a project. Co-production includes all phases of work from co-planning, co-designing, co-delivering through to co-evaluating.
- Attached to this statement and marked "CR-2" is a copy of the visual representation of co-production phases taken from the co-production guide (Roper, Grey and Cadogan, 2018).
- 8 At its best, the process creates both practical and relational outcomes where the capacity of all participants is enhanced. Co-production in the mental health system can't be achieved without investment in three things: first, consumer leadership, second, the

<sup>&</sup>lt;sup>11</sup> See Roper, C., Grey, F. & Cadogan, E. (2018). Co-production: Putting Principles into Practice in Mental Health Contexts. Retrieved from: https://recoverylibrary.unimelb.edu.au/data/assets/pdf\_file/0010/2659969/Coproduction\_puttingprinciples-

https://recoverylibrary.unimelb.edu.au/data/assets/pdf\_file/0010/2659969/Coproduction\_puttingprinciple into-practice.pdf.

development of actual opportunities and positions for consumer leadership can be enacted and flourish and third, government and organisational literacy around the purpose, scope, benefits and range of consumer roles and perspectives.

- 9 In my view, given the power disparities that exist in mental health, co-production requires the involvement and leadership of consumers from the outset; that is, consumers need to be involved in setting the agenda, or in the early stages of planning and thinking through the scope of and rationale for a project.
- 10 The core principles which underpin co-production partnerships with consumers are:
  - (a) consumers are partners from the outset;
  - (b) power differentials are acknowledged, explored and addressed; and
  - (c) consumer leadership and capacity is developed.

Projects without these features are *not* co-production.

- 11 To illustrate the point, the project that I describe at paragraphs 18 to 28 below is an example of co-production. The agenda came from the consumer workforce; the project team comprised a majority of consumers, the leadership capacity of the consumer team members was enhanced and the non-consumer members of the partnership were continually open to learning from consumer perspective. In the example, a consumer academic from the CPN and an independent consumer researcher approached government with an identified consumer workforce need for discipline specific supervision. From the outset, we had an opportunity to set the agenda and articulate workforce needs. Throughout the life of the project, the process has been underpinned by the core principles for co-production partnerships with consumers; we worked together with government, attended to power and built the capacity of consumers and consumer leadership.
- 12 From the outset, it is important to offer this critique: to achieve co-production we must move away from "old thinking" (which involves the participation of consumers within a structure that already exists) and consider creative actions that can be invested in that will unleash consumer leadership and innovation.

### Distinguishing "co-production" from related concepts

### Co-production as distinct from co-design

13 In my view, there is a distinction between co-production and co-design. One difference is that in co-production, whoever is closest to the problem is actively involved in setting the agenda, or in the early stages of planning and thinking through the scope of and rationale for a project from the outset. In the context of mental health, the people who are closest to the problem are the consumers. Another difference is that in co-production, all phases are co-planning, co-designing, co-delivering through to co-evaluating.

- 14 In co-design, consumers are not always involved from the outset. An analogy would be having a product, and then working with the end-users about whether and how that product is useful. For example, a general hospital wants to devise a strategy to decrease anxiety in people waiting to see a doctor. So, it develops a strategy to understand and solve the problem through working with service users. By this time, however, the problem and scope have been already identified. Co-production in the planning stages may have identified that this is not the most pressing problem to investigate from the service users' perspective. Or they may have identified that anxiety is not the problem.
- 15 The Australian Centre for Social Innovation (TACSI) has adopted the language of codesign that is conceptually quite close to how I conceive of co-production and their resources reflect this. They adopt a co-design process with the 'people closest to the problem' to identify the issues and solutions and use capacity building strategies among communities. The Department of Health and Human Services (DHHS) in Victoria engaged TACSI to develop, using co-designed processes, a series of local, fit for purpose co-design resources for mental health services, located on the TACSI website here: https://www.tacsi.org.au/workshops-dhhs-resources/.
- 16 TACSI has developed a particularly useful co-design readiness tool where organisations can self-rate capabilities for co-design mindsets, skill sets and project resources in preparation for adopting co-design methods (see the attachment marked "CR-3").

### Co-production cannot occur without investment in consumer leadership

17 At individual project level and at the state-wide level, co-production cannot occur without investment in consumer leadership. At the project level, this means consumers are in lead roles as thinkers, creators and advisors, with genuine influence and authority and they are properly remunerated, well supported, including through accessing consumer networks. By now, at the State level, consumer leadership in mental health should have been reflected across many settings and contexts. After 25 years of policy stating that consumers should be involved at all levels of service development, delivery and review, Victoria has few to no consumer leadership roles in service governance or executive level, the consumer workforce is still riddled with part-time roles, there are few to no consumer leadership roles in government with genuine influence, none within statutory bodies, no policy leaders and no roles in service monitoring. The few roles that do exist tend to be advisory only or specific to engaging other consumers. Yet there are examples of consumers in leading roles in other jurisdictions. Against this backdrop, co-production methods are susceptible to tokenism and being poorly understood. There remains a lack of literacy around the difference between participation and co-production; representation and leadership.

### The contribution of lived experience to the development of policy, practice and research

- 18 There are a couple of things I'd like to say about this. First I need to qualify my thinking about the language of "lived experience" and explain why I believe it to be unhelpful. The language of "lived experience" conflates consumers' experiences with family or carer experiences. It also conflates service use with the experience of psychological or emotional distress. In Victoria, we have historically used the language "consumer", which makes clear we are talking about first-hand experience of refusing, using or being unable to access mental health services. We are a consumer of something (a service). In most contexts, "consumer" also refers to a person with first-hand experience" does not inherently signify service use. The obfuscation enabled by the term "lived experience" may be expedient when consulting with consumers and carers; however, the acontextual nature of the language fails to keep perspectives distinctive. Additionally, people talk about "lived experience" but do not distinguish this from "consumer perspective", which I will define below. So this language is problematic and needs changing.
- 19 Consumer (or service user) perspective refers to a way of seeing and a body of firstperson knowledge and analyses derived from experiences of using mental health services (Russo & Beresford, 2015; Roper et al, 2018). A consumer perspective comes from a self-identified position that simultaneously signifies being part of a wider historical, and socio-political global collective or movement (Epstein, n.d), itself historically located in civil rights movements of the 1960s (Chamberlin, 1998).
- 20 When we talk about consumers making 'a contribution' the language betrays how we are not talking about co-production; it signifies that consumers have not set the agenda or are not leading thinking from the outset (lower rungs than co-production on Arnstein's ladder, which I refer to below at paragraph 35).
- Putting these concerns aside, consumer perspective in policy and research are not well developed areas in Victoria and need investment. There is also a need for consumer led research, for example, which prioritises the research areas of interest to consumers (thinking of the upper two rungs on Arnstein's ladder). The Victorian Mental Illness Awareness Council (VMIAC) has already conducted consultations with consumers and their research priorities are compiled here: <a href="https://www.vmiac.org.au/policy-campaigns/policy-issues/">https://www.vmiac.org.au/policy-campaigns/policy-issues/</a>. However, there is no allocated funding for these priorities to be pursued.

### 22 For more information, see:

- (a) Epstein, M (n.d.) What do we mean by consumer perspective? Our Consumer
  Place, <u>www.ourconsumerplace.com.au/consumer/helpsheet?id=4755;</u>
- (b) Russo, J., & Beresford, P. (2015). Between exclusion and colonisation: seeking a place for mad people's knowledge in academia. *Disability & Society*, *1*, 153; and
- (c) Chamberlin, J., (1998), *Citizenship rights and psychiatric disability*. Psychiatric Rehabilitation Journal, Vol 21(4), Spr 1998, 405-408.
- I have only one example where co-production was successful in the context of development of policy, practice and research. It was a partnership between the CPN, VMIAC, an independent scholar and the Workforce Division of the DHHS. Two consumers approached the Victorian Government with an issue that was significant for the consumer workforce, which was around consumer perspective supervision. The scale of the need for discipline specific supervisors—that is, people who were able to provide consumer perspective supervision to peer workers had been identified at the VMIAC workforce conference. We knew that the lack of consumer perspective supervision was a huge unmet need for the consumer workforce. We already had good relationships with government, and we knew that they were likely to be receptive to the idea. Plus, there were many new workers coming on board with the Victorian Government's introduction of post-discharge peer roles, so it was timely.
- A key project group was established in 2016 by the Victorian Government, the CPN, VMIAC and an independent scholar. The partnership within that key project group has continued, even though the people in the roles have changed.
- 25 The state government then funded the consumer perspective supervision project, allowing for the employment of a project worker and conduct of consultations across the consumer workforce in Victoria including rural consultations, to identify support needs and develop underpinning values and principles for supervisor practices. A base-camp egroup was established to develop a community around the project of interested people and a number of skill building workshops were held for people interested in or providing supervision, and to establish ongoing networks. In line with capacity-building approaches, the consumer partners of the project team were also brought into a Government workshop where we learned about budgeting processes and funding pitches. It was not a situation of government doing everything behind closed doors and us having a very limited role. Our expertise was able to lead the project.

- 26 In this project, there was also an investment in consumer leadership. There was an understanding that it would take time to build capacity, and that the issue of power would need to be attended to throughout the entire process.
- 27 The project has comprised several phases. In the first phase, we developed a peer supervision framework with the constant involvement of consumer leaders in the workforce: <a href="https://cmhl.org.au/sites/default/files/resources-pdfs/FINAL%20CPS%20framework%2018.pdf">https://cmhl.org.au/sites/default/files/resources-pdfs/FINAL%20CPS%20framework%2018.pdf</a>. The project team employed the company Inside Out & Associates from New South Wales to host capacity building workshops for consumer perspective supervisors and develop a training and curricula framework and resources that would become a package that will be used to help train new consumer perspective supervisors.
- 28 The final phases of the project will be establishing an online database resource that will enable supervisees to find supervisors and developing strategies for consumer perspective supervisors themselves to be able to access regular consumer perspective supervision.
- 29 I appreciate that it is risky for governments to work using co-production principles because perhaps it will not be clear at the beginning what the linear steps will be, and it may take longer and be more expensive. But if you do not take those risks, then you will miss out on the true rewards of co-production. These include fostering genuine relationships between marginalised groups and government that are transparent and trusting, the building of capacity of a marginalised group and improved conditions that are founded on the wisdom of those who use services.
- 30 The new Victorian Collaborative Centre for Mental Health and Wellbeing (**Collaborative Centre**) can champion the co-production of research and training in mental health by ensuring there is a critical mass of consumer leaders undertaking that research and training. While there is already good consumer researcher capacity in Victoria, the Collaborative Centre should also foster the capacity of consumer researchers through scholarships and support and develop opportunities for consumers to lead research as well as coproduce research.
- 31 We are missing some kind of collaborative or collective of consumers who have a handle on issues of human rights and social justice who can bring these concerns into research and training and policy development settings. These concerns are imperative in a context where there are a significant category of people living in Victoria - just under 5,000 individuals using 2016 data who are on community treatment orders and whose legal right to refuse treatment is breached (Light, E., 2019. Rates of use of community treatment orders in Australia, International Journal of Law and Psychiatry, 64 pp.83-87). Regardless of whether individual consumers or clinicians think that these breaches are necessary or

justified, still, the breaches must be acknowledged and ameliorated, and people need pathways that lead them out of being subject to mental health legislation and back to enjoying citizenship status on an equal basis with others. Because we categorise along diagnostic or epidemiological illness lines, the category of people who are subject to mental health legislation is an invisible category. This means we have no information about their health and wellbeing specifically, and we do not investigate the impacts of the human rights breaches at statistical or experiential levels. Although perhaps challenging for some clinician researchers, adopting human rights perspectives in mental health research is imperative. This agenda tends to matter most to consumers who have the least control over research agendas. This needs to change and I would hope that the Collaborative Centre would lead this change.

### Importance of consumer leadership in co-producing research and innovation

- 32 Innovation is about building our capacity for co-production. You cannot have co-production without consumer leadership, and consumer leadership is a missing piece in our current mental health system. How does the proposed Collaborative Centre make up for the historic lack of consumer leadership? How does it redress the fact that the consumer voice is so thin and easy to marginalise? The consumer perspective is one that some people will find hard and challenging to hear. How do we hold that perspective in co-production activities in a way that is educative for non-consumers? We cannot continue having only psychiatrists in leading roles. This will inadvertently or otherwise continue the promulgation of deficit-based illness models rather than rights-based well-being orientations.
- I was so crestfallen when I heard that the Royal Commission would not have a consumer Commissioner. I was again crestfallen when I heard there would not be a consumer in an executive position in Mental Health Reform Victoria, the new Victorian Government administrative office which has been created to implement the Royal Commission's recommendations. I feel this way because this lack of driving change through consumer leadership goes on and on, decade after decade.
- 34 There are two things we can do to champion the co-production of research and innovation in mental health. First, we can open up leadership roles for consumers which means that at times, psychiatrists and others will need to step back into support roles; and secondly, we can start elevating consumer leaders as thinkers and innovators. I am not saying that consumers should be doing this by themselves; but I do think there is a need for investment in collective consumer leadership. For more on investment in consumer leadership, see below at paragraphs 38 to 40.

### Ensuring authentic co-production with people with lived experience

### The need for alternative thinking

- 35 It is helpful to refer to Arnstein's Ladder of Participation (Arnstein's Ladder), which conceptualises various levels of community participation in decision-making as rungs on a ladder. Arnstein's Ladder has eight rungs, with community control at the top, and rungs of non-participation at the bottom, like tokenism. Co-production is not at the top. It is third from the top, behind "delegated power" and "citizen control". For more information on Arnstein's Ladder, see S R Arnstein, "A Ladder of Citizen Participation" (1969) 35(4) *Journal of the American Institute of Planners* 216.
- A project cannot be called a co-production if it is unable to achieve a level of consumer participation that sits at a higher rung on Arnstein's Ladder. We are trying to get further up the ladder all the time. But we need to be honest about the level of consumer participation we are achieving: if you're consulting with consumers, then call it consultation, not co-production. There is nothing worse than calling something coproduction when actually the parameters have already been set and there is no genuine possibility for moving further up the decision-making ladder Maybe in a particular situation consultation is the best you can do and maybe it suits the task, if there is no possibility of a greenfield project. But in terms of co-design principles, we must have a model of taking the wisdom from service users, because someone who has used that service knows what it feels like.
- 37 In one way, consumer leadership in mental health services as they exist now would always be problematic in terms of Arnstein's Ladder, because it means working within a hierarchical medical framework, structured by mental health legislation, at odds with the values and principles underpinning the consumer workforce.. However, increased consumer workforce numbers, more systemic and policy influence and making up for the lack of historic leadership investment would enable the consumer workforce to be more effective and less endangered.

### Lack of consumers at executive level in current system

- 38 In Victoria, we do not have any consumers at executive level in organisations making decisions. It would be good to have consumers in those executive positions. As far as I know, there has only ever been one person in a mental health service in Victoria who was in a substantial governance role, but that service ceased funding the role.
- 39 Lack of consumer representation at governance level is problematic. If the consumer perspective is not present at the top level, then it will keep getting lost everywhere else and a critical mass needed to change culture will not occur. It is not possible to make your concerns heard if you are not in a position of being able to engage with how decisions

are getting made. There are many different roles that consumers can play. For example, consumers can be educators, advocates, researchers, service leaders, policy makers, systemic consultants, peer support providers or service auditors. It would be useful for Victoria to invest in consumer leadership in all of those roles and not just in peer support and consumer consultancy.

40 Although it would be good to have more consumers involved in the governance of existing services, there is still an incredible need for investments in alternative thinking and alternative services. Starting from scratch, Victoria could commission innovative service alternatives, outside of mainstream services, that invite consumers from the outset, to design and operate them.

### Examples of consumer leadership in other jurisdictions

- There are examples from other jurisdictions where people have taken the risk of investing in consumer leadership. More than ten years ago, Mary O'Hagan was a Commissioner in the New Zealand Mental Health Commission which had policy development responsibilities for the mental health sector. More recently, Mary O'Hagan was involved in developing the Wellbeing Manifesto. The Wellbeing Manifesto was prepared as a submission to the New Zealand Government Inquiry into Mental Health and Addiction. Its key theme is a journey from "Big Pharma" to "Big Community". The Wellbeing Manifesto is intuitive and understandable, and nourishes the idea of alternative thinking. For example, it is helpful to think about ourselves as a community, and not as a group of healthy people and a group of sick people.
- 42 Interstate, there are examples of consumers occupying positions of authority in different ways. For example, the NSW Mental Health Commission has a consumer Commissioner. I love that in Victoria we have consumer academics, but there has not been a growth in these roles in Victoria in other universities, other than at the CPN at the University of Melbourne. These roles are key influencers of mental health workforce practices and policies and can achieve so much more if further embedded in other academic settings.
- 43 There are some examples of consumers in leadership roles, but those examples have not come about as a result of systemic change. We need to embed in the existing system structural expectations about consumers taking leadership roles. Unless we do that, nothing much will change, and those few existing leadership roles will remain vulnerable.

### Services governed and delivered by people with lived experience

### Models of services delivered by people with lived experience as alternatives to treatment in hospital settings

- 44 There is no one model for what a service delivered by people with lived experience should look like. There are many different models, such as crisis alternatives; places that are for day visits that do not have beds; respite services; and advocacy groups. There are both informal groups and formal organisations. There is a huge variety of peer-developed and peer-run programs. There are voice hearing groups, community development groups, state-supported user groups, independent activist groups, peer workforces in hospitals and other mental health settings as well as independently run peer services, and these types of services are found across low, middle and high-income countries. For specific examples, see Gooding et al, (2018) and Grey and O'Hagan, (2015).
- 45 One interesting example is the Swedish Personal Ombudsman (PO) service. There they have an advocacy role whereby the person in that role does whatever the consumer needs. The role is helpful for working with people who are hard to reach, such as people experiencing homelessness. The role is played by peer workers, and people feel safe working with them because there is no threat of too much intervention or a sense of potential coercion. Information about this model is here: <a href="http://www.right-to-decide.eu/2014/08/swedish-personal-ombudsman-service-po-for-people-with-mental-health-problems/">http://www.right-to-decide.eu/2014/08/swedish-personal-ombudsman-service-po-for-people-with-mental-health-problems/</a>.
- 46 One reason why alternative services are so important is that they do not engage in coercion. They instead rely on the development of connections among people who mutually share helpful techniques and support. The absence of coercive treatment engenders an extraordinary sense of trust. Often people who have been through traditional public mental health services have encountered coercive treatment. One of the benefits of having an alternative is that coercion does not happen. That means that there is a feeling of trust around people having walked similar paths. Relationships are prized. Alternative services are relational: things are negotiated and force is not present, and the research shows that they can be highly effective as well as decreasing use of mainstream mental health services (Grey & O'Hagan, 2015). For example, alternatives to traditional in-patient service user satisfaction and less negative experiences (Gooding et al, 2018).
- 47 In peer run services, underpinning philosophies and practices tend to vary greatly from traditional mental health services. For example, strategies used include: counselling, art, meditation, physical work, massage, skills training and meditation (Gooding et al.).

- 48 Help is conceptualised as a mutual learning relationship: one person is not "helping" the other. The focus is on non-hierarchical relationships, on mutual negotiation and honesty (Mead & Filson, 2017). They are alternatives also because they foster relationships that prize individual meaning making and choice and are not about "surveilling each other" for signs of "relapse".
- 49 For information on the effectiveness of peer run services, see:
  - (a) PP 68 81 in: Gooding, P., McSherry, B., Roper, C., Grey, F., (2018) Alternatives to Coercion in Mental Health Settings: A Literature Review Commissioned by the United Nations Office at Geneva to inform the report of the United Nations Special Rapporteur on the Rights of Persons with Disabilities. Available at: <u>https://socialequity.unimelb.edu.au/\_data/assets/pdf\_file/0012/2898525/Altern</u> atives-to-Coercion-Literature-Review-Melbourne-Social-Equity-Institute.pdf;
  - (b) Grey F and O'Hagan M. The effectiveness of services led or run by consumers in mental health: rapid review of evidence for recovery-oriented outcomes: an Evidence Check rapid review brokered by the Sax Institute (www.saxinstitute.org.au) for the Mental Health Commission of New South Wales;
  - (c) Mead, S., & Filson, B., (2017). Mutuality and shared power as an alternative to coercion and force. Mental Health and Social Inclusion. 21. 10.1108/MHSI-03-2017-0011; and
  - (d) Peer Respites, Action and Evaluation <u>www.peerrespite.net/research</u>.
- 50 Alternative services might measure things differently from traditional services. For example, they might be measuring self-agency, hope or social support (Grey and O'Hagan, 2015). These are things that traditional services do not count. Victorians should have access to Services that foster and provide these experiences.
- 51 The Interim Report has recommended that there be a consumer-operated service. It will be interesting to see how the governance of such a service is negotiated and how the ethic of non-coercion, characteristic of a peer-run service, will be preserved. I think there is going to be a lot of carefully negotiated thinking around how this recommendation plays out, which is not a bad thing. But there is also a need for services that are not connected to traditional services.
- 52 There are people with lived experience in Victoria who have expertise in the various alternatives to hospital care. It would be good if we had a collective of consumer thinkers, leaders and people with expertise around alternative forms of care. The government should bite the bullet and fund services that are governed and delivered by consumers.

Accountability and outcome measures should be negotiated as part of funding arrangements rather than being pre-set and contingent.

### Lived experience workforce

53 The lived experience workforce is important because there is a wisdom that comes from having used services. There is no other way for services to reflect that expertise and that wisdom other than by drawing on the experiences of people who have been through those systems or who have experienced distress. There is no substitute for that, and no other workforce is in a position to do that. The user of the service has unique insights into what that service should be like.

### Supporting the expansion of lived experience workforces

- 54 Before we can expand the consumer workforce, there is a huge amount of work that needs to go into organisational readiness. Some work has been done in this area. See, for example:
  - Self Help Addiction Resource Centre (SHARC) organisational readiness training <u>https://www.sharc.org.au/sharc-news/sharcs-organisational-readiness-training-</u> <u>december-2019-peer-workforce-development/</u>; and
  - (b) <u>http://peerworkhub.com.au/wp-content/uploads/2016/05/Toolkit.pdf</u>.
- 55 There is still a huge ignorance out there amongst some organisations. For example, many do not know that the consumer workforce comprises different roles that have different functions (eg consumer consultants, peer support workers). Organisations need to develop literacy around the consumer workforce, and of course consumers are best placed to provide that literacy.
- 56 That kind of educative work is currently not resourced. This means that consumers are in the ridiculous situation of having to educate services about what they do as part of their job, which does not leave them much time to actually do their job. That must change. This has been going on for decades. Organisations have not had to come to terms with the different principles that underpin the consumer workforce, and then to make the necessary adjustments to their practices and policies. Once this practical work is done, we can start talking about what staff can do, how leadership can be built, and what supports are needed.

### Current resources available to organisations

57 We already have three documents that outline in great detail the needs of the lived experience workforces in three areas: alcohol and other drugs (**AOD**) workforce, carer workforce, and consumer workforce. These documents have been developed collectively over the course of several years, by many different consumers, carers and people who work in the AOD sector. Each document sets out the vision and objectives for the workforce, action plans, the principles and enablers, work force development needs and models of success. These documents are publicly available on the website of the Centre for Mental Health Learning (CMHL), *Peer Inside* <cmhl.org.au/peer-inside>.

58 The three groups (ie the consumer workforce, the carer workforce, and the AOD workforce) have come together to form a stewardship group facilitated by CMHL. The work of the stewardship group is to promote the Strategies, contribute to their implementation wherever possible, ensure that the necessary changes are happening, and continue to advocate for the needs of these workforces.

### Professional behaviours and practices underpinning recovery-oriented approaches

- 59 The *Framework for Recovery-oriented Practice* document identifies the principles, capabilities, practices and leadership that must underpin recovery-oriented approaches. It was produced in 2011, but it is still relevant. However, any articulation of recovery within public mental health services is constrained and to some extent dissonant. This is because the tenets of self-determination, choice and living a meaningful life with or without 'symptoms' underpinning the concept of recovery, are in jeopardy when mental health legislation can mandate treatment or require hospitalisation. See DHHS, Victoria, *Framework for Recovery-oriented Practice* (2011) <www2.health.vic.gov.au/about/publications/>. Attached to this statement and marked "CR-4" is a copy of this document.
- 60 The *Framework for Recovery-oriented Practice* is structured into nine "domains" that reflect the main areas of recovery-oriented practice. The nine domains are:
  - (a) promoting a culture of hope;
  - (b) promoting autonomy and self-determination;
  - (c) collaborative partnerships and meaningful engagement;
  - (d) focus on strengths;
  - (e) holistic and personalised care;
  - (f) family, carers, support people and significant others;
  - (g) community participation and citizenship;
  - (h) responsiveness to diversity; and
  - (i) reflection and learning.

- 61 In relation to each domain, the *Framework for Recovery-oriented Practice* identifies what the core principles are, what the key capabilities are, what constitutes good practice, and what constitutes good leadership.
- For example, within the domain of promoting a culture of hope, one of the core principles identified by the *Framework for Recovery-oriented Practice* is that "[t]he physical, social and cultural service environment inspires hope, optimism and humanistic practices for all who participate in service provision." One of the key capabilities is the behaviour of "actively uphold[ing] a culture of hope by using optimistic language, supporting people, their significant others and colleagues, and celebrating people's recovery efforts." Something that constitutes good practice in this domain is that individuals "[s]ustain hope for people's recovery, especially when people feel unable to carry hope themselves." Someone who is a good leader in this domain will "[c]elebrate rights of passage and achievements."

### Frameworks for reform and human rights

### Importance of frameworks for mental health reform

- 63 Social justice and human rights frameworks are critical for mental health reform, though I fear they are not as central to the Royal Commission's work as I would like them to be. Issues of human rights arise whenever we take away someone's right to refuse treatment. In particular, our conversation about compulsory treatment needs to be reframed in terms of breaches of human rights. There is a lot of work to do for people to get that point.
- 64 There is a widespread idea that sometimes people do not know what is in their own best interests, and that in those cases the state has to take over decision-making. That idea is a huge obstacle to be overcome for us to start framing compulsory treatment in a different way.
- 65 The legislation does not promote human rights—it actually tells us where it is legal to breach them. That legislative approval papers over the reality of those breaches, because it declares that the treatment is necessary.
- 66 I would like to us engage honestly with how the Mental Health Act 2014 (Vic) (Mental Health Act) endorses lawful violence. In my own experience, unwanted compulsory treatment was always administered with violence (Roper, 2019) https://jemh.ca/issues/v9/documents/JEMH%20Inclusion%20vi.pdf. We need to embark on a project of understanding how human rights are a distinctive feature of public mental health service delivery unlike healthcare services for physical health where, other than in exceptional circumstances, one may refuse medical treatment. The shift towards supported decision-making, which I discuss below, would be a lever for starting that project.

### Limitations of using a health paradigm to conceptualise mental health

- 67 In my view, mental health is not actually a health issue, and the use of the health paradigm for mental health is not helpful. One of the things that is limiting about it is how it leads us to think about discrimination in a particular way. De-stigmatisation campaigns have for decades relied upon likening "mental illness" with other chronic physical illnesses such as diabetes or asthma. Therefore, so the logic goes, people diagnosed with "mental illnesses" should not be discriminated against just as we would not discriminate against people with physical health conditions.
- 68 However, research tells us that a health model itself can be the cause of discrimination and a biogenetic explanatory frame that sees human distress as an illness can cause desire for social distance in others (Angermeyer et al., 2011): Angermeyer M, Holzinger A, Carta MG, Schomerus G. (2011), Biogenetic explanations and public acceptance of mental illness: systematic review of population studies. Br J Psychiatry. 199(5):367-72. doi: 10.1192/bjp.bp.110.085563.
- 69 In some ways a disability paradigm is much more useful than a health paradigm. Disability activism has been founded on equality before the law and the enjoyment of human rights by people with disabilities on an equal basis with others. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) enshrines these ideas and signatory countries such as Australia, must comply with them. The UNCRPD uses the language of "people with psycho-social disabilities" to signal its inclusion of people experiencing psychological or emotional distress within the concept of disability. The UNCRPD is clear that people with disabilities should be able to make their own decisions and have them respected by others. Additionally, they should be protected from interference by others. If they require support and resources in order to make and carry out their decisions, it is incumbent upon states and organisations to provide that decisional support. An illness model locates pathology within the individual, whereas a disability model centres on the interaction between the person, the "impairment", and society. Aspects of society can be enabling or disabling of a person achieving self-determined choices and a full life. Under this model, for instance, it could be argued that mental health legislation is disabling as it is both discriminatory-it applies only to a certain category of people-those diagnosed with "mental illness" and also breaches human rights (to make self-determined choices and refuse treatment like others can).

### Compulsory treatment

### Potential for coercion is incompatible with recovery-oriented care

- 70 In most cases, a person can refuse treatment in relation to their physical health. However, in public mental health services people are often not able to refuse treatment.
- 71 The presence of mental health legislation will always structure the relationships occurring in public mental health services. There is no doubt that a good therapeutic relationship is a good thing. However, the presence of coercion, or even just the potential for coercion, will always structure that therapeutic relationship. Coercion is always there whether in the foreground or in the background. This is why I would prefer that clinicians see themselves as decision-supporters. To me that is a far more helpful way for clinicians to conceptualise their practice than therapy in a relationship where the client is not a free agent.
- 72 For example, you cannot use recovery principles to seclude someone. Seclusion and recovery-oriented principles do not go together. Naturally, if a person does not want treatment, and you have told them that they have to have it, then the treatment will have to be administered with violence.
- 73 We talk about notions of recovery and the therapeutic relationship, but the existence of the *Mental Health Act* potentially structures everything that goes on within its ambit.
- 74 In the violent and forcible administration of that treatment, you can imagine what that might feel like for the consumer. But it is also a negative experience for the staff member. Many staff members are in this job because it is a calling; they want to help people who are having trouble. In no policy or training document do I see reference made to the realities of compulsory treatment for the staff members who are required to administer it.
- 1 think that there is a tendency for clinicians to jump straight to justifications for compulsory treatment, which means they do not have opportunities to understand and sit with these dehumanising aspects of their work. This is understandable: when we have to do something unpleasant, we need to hold onto a rationale that will sustain us. But the violence of involuntary treatment and its administration is real regardless of justification and has an impact on consumers and clinicians. These consequences must be noted and regretted rather than papered over and clinicians need to be supported so that they can hold these truths. It is a great pity, I think, that there are not opportunities on wards, for example, where staff can be led safely through ethical dialogues by consumer experts.

#### Supported decision-making

76 The *Mental Health Act* does not support the decision-making model that we should be engaged in. The decision-making model in it should be founded on *legal* capacity, and

not *mental* capacity. Clinicians involved in a person's treatment should be facilitating that person to make their own decisions. They can do this by finding out what the person's preferences are, working out what resources the person might need, and then helping the person access those resources. That kind of mindset could form the substance of the relationships between consumers and clinicians.

- 77 That mindset moves us away from a conversation about risk and fear. We are not talking about abandoning or neglecting consumers. We are talking about working together to find out what a person wants, and supporting that.
- The underpinning principles of supported decision-making are not well understood and Victoria was lacking in its implementation following the enactment of the *Mental Health Act* in 2014. Added to this, the implementation of supported decision-making is hampered by an approach to decision-making incorporated in the *Mental Health Act* that is based on a mental capacity test. A mental capacity test checks if a person can weigh up information and use it to make a decision. It is a pass or fail test and comes from a health model. Supported decision-making however comes from a disability paradigm and is based on a legal capacity model which asks: what resources does this person need in order to retain decision-making? This approach is based on human rights, dignity and equality. There are many problems with the mental capacity approach to decision-making such as that it does not take into account emotional aspects of decision-making, nor power imbalances where a disagreement might be more likely to be construed as a product of "mental illness" in an assessment.
- 79 The concept of capacity within the *Mental Health Act* is a pass-or-fail concept. We need to move from that into ideas of *legal* capacity. That change in focus will be an anchor for practitioners as they move towards a model of supported decision-making.
- 80 Currently, there is no incentive for people to do the work of supported decision-making. This work requires organisations that can support their staff to undertake initiatives that may push the boundaries, and that will support staff to sit with discomfort of negotiating risks with consumers rather than using treatment orders to force consumers into treatment. We cannot keep putting people on treatment orders because we're scared that they might do something in the future.

### Factors influencing the take-up of safeguards by consumers

81 In relation to Compulsory Treatment Orders (**CTOs**), the issue of power has an influence on whether people take up safeguards. For example, where the psychiatrist is mandating treatment, it can be difficult for the person to get their will and preferences heard. It is particularly difficult if their preferences differ from what the psychiatrist is saying.

- Two cases that ended up in Victoria's Supreme Court serve as examples. These cases were about unwanted treatment. The appeal first went to the Victorian Civil and Administrative Tribunal (VCAT) where it was ruled that the treatment in both cases should go ahead. When the cases were brought to the Supreme Court, Justice Bell determined that VCAT had misinterpreted and misapplied the capacity test in section 68 of the *Mental Health Act* in ways that undermined human rights to self-determination, freedom from non-consensual medical treatment and rights to personal inviolability which are protected by the Victorian *Charter of Human Rights and Responsibilities Act 2006* (Vic) (*Charter*). The lengths to which these two people and their families had to go, in order to preserve their basic human rights, demonstrates the lack of transparency and failures of accountability in the provisions as outlined in the Act as well as in the functions of VCAT.
- Another issue is that people may not know about their rights to access safeguards, such as their right to obtain a second opinion, have a nominated person who can communicate the person's wishes and preferences, access an advocate or complain about any aspect of care or treatment. Although they are a mechanism setting out treatment preferences, Advance statements have not been taken up widely. A VMIAC study found that more than 60% of consumers surveyed agreed it was difficult to find information, and only 8–15% of consumers reported that mental health services routinely provide information about advance statements and nominated persons, (VMIAC, 2018 p.8) https://www.vmiac.org.au/wp-content/uploads/VMIAC -Advancestatements-Nominated-Persons Consumer-Survey 2018.pdf.

### Abolition of compulsory treatment in Victoria's future mental health system

- 84 I am an abolitionist; I believe that compulsory treatment has no place in any mental health system. But that position can only be an ideal unless our sense of community evolves. In New Zealand, Mary O'Hagan's Wellbeing Manifesto provides a vision of moving from Big Pharma to Big Community that would be instructive for Victoria: https://www.wellbeingmanifesto.nz/. Taking that position, we need to be thinking about the kind of community we want to live in, and the supports all people need. How can we move ourselves into a position where there is openness towards the way people experience things? How can we nurture a sense of curiosity around the diversity of ways in which people think and act? Some people hear voices, some people believe they are sorcerers; as a community, we need to harbour more curiosity and take more interest in that.
- 85 I will continue to advocate for the abolition of compulsory treatment. In the meantime, we should reduce the rate at which compulsory treatment is used by enacting a framework for supported decision-making. Victorian clinicians need training and organisational support so that staff can re-orient practice away from 'therapy' towards discovering people's preferences and providing resources people need to retain or resume holding

the reins of their life, decreasing the likelihood of being embroiled in breaches of peoples' human rights.

### **Families and carers**

### Listening to consumers' voices rather than "balancing interests"

- In my view, the mental health system and provision of care should not be about seeking to create a "balance" between the interests of consumers and those of families and carers. Autonomy and the protection of others are two values that often cannot be reconciled. Instead of forcing them together, it would be fruitful for us to give consumers the freedom to elaborate their feelings and what is going on for them. We should not be asking them to try to reconcile their feelings and views with those of their families or carers.
- 87 I think spaces are needed for consumers, families and carers to be able to openly speak about their fears, face the risks involved, and think up ways these can be mitigated together. Of course, these ideas only have relevance where the consumer wants it to happen.
- 88 There is a whole different way of thinking about the interests of consumers and carers that is not a balancing act; it is actually an exercise in hearing each other. I am currently studying the practice of Open Dialogue: Von Peter, S. Aderhold, V., Cubellis, L., Bergström, T., Stastny, P., Seikkula, J., and Puras, D., (2019), Open Dialogue as a Human **Rights-Aligned** Approach, Front. Psychiatry, 31 May 2019. https://doi.org/10.3389/fpsyt.2019.00387. Open Dialogue is about hearing each other's voices and finding common ways to speak with and understand each other and drawing on the resources present in the social network.
- 89 I think these sorts of practices are critical, because otherwise conversations turn into competitions, and in those the consumer will always lose. The consumer loses because it is considered that their testimony cannot be trusted; that they do not have insight into their condition or know what is good for them. In contrast, I think it is critical that consumers have real, proper space to articulate their feelings and be supported by others to take up the reins of their own life.
- 90 Mental health services should invest in alternative approaches like family conferencing (Ellen Meijer, Gert Schout & Tineke Abma (2019) Family Group Conferencing in Coercive Psychiatry: On Forming Partnership Between the Client, Social Networks and Professionals, Issues in Mental Health Nursing, 40:6, 459-465, DOI: 10.1080/01612840.2018.1563254) and Open Dialogue so that they are available if people want them. We need approaches in which we deliberately and proactively try to

understand issues around power. We need to think consciously about whose voice might be the thinnest or the hardest to hear (and that approach will usually help the consumer).

91 Another example is an approach called Circles of Support. In 2018 the Mental Health Coordinating Council produced a feasibility study for circles of support (see http://www.mhcc.org.au/wp-content/uploads/2018/05/mhcc cos lit review.pdf). In the circle of support, the person with the disability is in the driving seat. The person picks who they want to support their decision-making, drawing on the expertise they need at that point. Family members might be involved, so might teachers, or friends, or financial, housing or other experts—and they work on the issues of decision-making together but the process is driven by the person themselves. In this way, the consumer's choices and self-determination are supported.

### Accountability

### Performance-monitoring arrangements that capture the outcomes and experiences meaningful to consumers, families and carers

- 92 As I said above at paragraph 50, the things that are important to consumers are not always measured. There's such a difference if you did measure things like how a person's sense of agency, or their sense of hope was affected by their use of a service. There are recovery-oriented measures that have been developed by consumers such as Patricia Ridgway in the United States. I also refer to the journal article at Attachment "CR-5" about measuring mental health in the clinical setting.
- 93 While services could then use that information for the purpose of providing services that are more in line with what consumers want and need, there will still be some problems that no amount of "service improvement" is going to fix. This relates back to the inbuilt presence of coercion in the context of public mental health services, due to mental health legislation and therefore the need to acknowledge the role of human rights and social justice. This provides us with another potent reason as to why non-coercive alternatives to traditional mental health services need to be funded.
- 94 Although surveys can be helpful for improving services, we should be mindful that merely running surveys is not an accountability strategy. That is for two reasons. First, surveys are sometimes conducted for cosmetic purposes. I have been aware of situations in the past where free hand survey responses were literally shredded. Sometimes no-one takes responsibility for checking whether surveys have improved anything. Governments should take responsibility for that rather than individual services. There needs to be an expectation that every single time you ask a consumer a question, there will be some kind of oversight and responsibility to act for change.

95 Secondly, the questions that are asked in surveys are not always devised by service users, which means that the questions do not necessarily pick up on the issues that are important to the service users.

### **Physical infrastructure**

### Features that consumers value in physical environments of mental health services

- 96 Adopting co-production as a way of informing design of physical environments is a good way to ensure that physical spaces are both locally contextualised and have the features that consumers value. A Victorian report looking at international examples of mental health ward designs 2016) (Scalzo, can be accessed here: https://www.churchilltrust.com.au/media/fellows/Scalzo S 2015 Design for Mental H ealth towards an Australian approach.pdf. The principles of good design in the report include plenty of natural light, ceiling height, homelike atmosphere, control for people over aspects of their own space (ie their own locks), a good mix of communal and private spaces and accessible garden areas. There should be plenty of activities and service users should have access to arts and music or headphones. One service had a labyrinth.
- 97 If we take the view that mental health issues are not health problems, as I say we should, then we are more likely to emphasise home-like features of the physical environment.
- 98 We should acknowledge that when people are receiving compulsory treatment, and are not permitted to leave a service, then the quality of the physical infrastructure becomes even more important. When people are being held involuntarily, and are not allowed to leave the ward, they need a sense of space; that they are not piled in on top of someone else, and that the ceiling is not so low that they feel like they are in a box. Any design feature that emphasises the agency of the consumer should be prioritised. The ability to lock your own door, and the sense of safety which that brings, is especially important for people who have been sexually assaulted.

### The role of consumers in ensuring that physical environments are healing, restorative, respectful and safe

99 On this point, it would be good to build new physical environments through co-production; but, as I said above, co-production is not at the top of Arnstein's Ladder. We should also be supporting initiatives that are consumer-led. We should be resourcing those initiatives and making the decision to take a risk on them. We should ask those consumers who are leading the initiatives what expertise they need access to. For example, within a consumer-led group working on an infrastructure initiative, there would not be an obvious need for a psychiatrist. Forming teams around a piece of work or a project is not based on representation; it is about expertise needed. So, you would want maybe engineers, architects, artists in the group. Many consumer run crisis alternatives are small houses with four or five bedrooms such as those in New York's Parachute programs (see <a href="https://www.nyaprs.org/e-news-bulletins/2015/parachute-nyc-highlights-success-of-peer-crisis-model-impact-of-community-access">https://www.nyaprs.org/e-news-bulletins/2015/parachute-nyc-highlights-success-of-peer-crisis-model-impact-of-community-access</a>).

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print name Cath Roper

Date 2 June 2020





**Royal Commission** into Victoria's Mental Health System

### **ATTACHMENT CR-1**

This is the attachment marked "CR-1" referred to in the witness statement of Cath Roper dated 2 June 2020.

### CATH ROPER CURRICULUM VITAE

Address:	Centre for Psychiatric Nursing (CPN) School of Health Sciences University of Melbourne Level 6/161 Barry Street Carlton 3010
Telephone:	+61 (03) 8344 9455
Email:	<u>croper@unimelb.edu.au</u>

### Academic Qualifications:

Masters in Social Health	Melbourne University	2012
Diploma in Education	Melbourne University	1989
Bachelor of Arts	La Trobe University	1984

### **Current Appointment:**

Employer:	Centre for Psychiatric Nursing & Department of Nursing, School of Health Sciences, University of Melbourne
Position:	Consumer Academic
Duration:	November 1999 – present

\*\*CV documents activities undertaken over the past five years, from 2014

### AWARDS

In 2019, the Centre for Psychiatric Nursing was publicly recognised for its Consumer Academic Program (CAP), achieving a Mental Health Service of Australia and New Zealand Award in the category of Education, Training or Workforce Development for the achievement of excellence, innovation and best practice in mental health services. Recognised by my peers, I was presented with the inaugural Victorian Mental Illness Awareness Council (VMIAC) - Victoria's peak mental health consumer organisation, Life-time Achievement Award in 2016.

### EDUCATION AND TRAINING

I coordinate the core subject, *Consumer Perspective Theory & Practice,* in the Diploma in Nursing Practice, Mental Health Stream, University of Melbourne which has been taught in the course for 20 years. Student evaluations have been consistently favourable. In response to Victoria's mental health reform agenda, I developed content for three highly successful industry-based workshops: *Supported decision-making, Every Moment Counts and Coproduction*. Subsequently these became coproduced workshops, delivered across a range

of mental health services, programs, and disciplines receiving excellent feedback from participants.

### **RESEARCH HIGHLIGHTS**

- 1. Consumer researcher, (2018/2019), Understanding the Role of Allies in Systemic Consumer empowerment, with Scholz, B., Juntanamalaga P., & Happell, B.
- Consumer researcher, (2018/2019), Investigating non-consumer researcher perspectives on collaborating with consumers in mental health research with Scholz, B., Gordon, S., Bocking, J., Liggins, J., Ellis, P., Platania-Phung, C. and Happell, B.
- 3. Consumer perspective consultant to the project: The United Nations Special Rapporteur report on alternatives to seclusion and restraint

### [available at:

https://socialequity.unimelb.edu.au/ data/assets/pdf\_file/0012/2898525/Alternatives-to-Coercion-Literature-Review-Melbourne-Social-Equity-Institute.pdf]

### Impact:

Despite only being released in October 2018, the report has already been promoted by the Disability Advocacy Resource Unit (Australia), the Disability and Human Rights Observatory (Portugal), the Sante Mentale ('mental health') Journal (France), Asylum Magazine (UK), the International Disability Alliance (IDA; IDA is the global umbrella organisation for disabled peoples organisations), the Mental Health in Higher Education Hub website (UK), and the VMIAC. Given this added dissemination, the report is likely to have wide reach and high impact, translating knowledge into practice.

4. Consumer researcher in the project: Gooding, P., McSherry, B., Roper, C., Grey, F., (2018) Alternatives to Coercion in Mental Health Settings: A Literature Review Commissioned by the United Nations Office at Geneva to inform the report of the United Nations Special Rapporteur on the Rights of Persons with Disabilities. Available at:

https://socialequity.unimelb.edu.au/ data/assets/pdf file/0012/2898525/Alternatives-to-Coercion-Literature-Review-Melbourne-Social-Equity-Institute.pdf

### Impact:

The Parliamentary Assembly of the Council of Europe passed a resolution, titled: Ending coercion in mental health: the need for a human rights-based approach. and the Assembly relied on a report of the Committee on Social Affairs, Health and Sustainable Development, rapporteur: Ms Reina de Bruijn-Wezeman (see Doc. 14895), which referred to this work.

- Principal researcher, (2017 ongoing) Generating knowledge through conversation: analysing expert perspectives of consumer workers, clinicians and academics in mental health. This innovative project focuses on knowledge development in the context of transdisciplinary conversations placing consumer perspective at the centre.
- Disability Storyteller, (with Dr Piers Gooding, respondent) <u>Voices of Individuals:</u> <u>Collectively Exploring Self-Determination</u> project (2015-2017). This ground-breaking, two-year European Research Council funded initiative, entitled the 'Voices of

Individuals: Collectively Exploring Self-Determination' [at: <u>https://ercvoices.com</u>] led by the University of Ireland, Galway centred on law reform in legal capacity to consent in the context of the lives of people with disabilities, and involved public workshopping and presenting of stories about legal capacity from 16 pairs of storytellers (with disabilities) and respondents. A book of the work was published and launched in 2018: *Global Perspectives On Legal Capacity Reform: Our Voices, Our Stories,* Routledge

Consumer researcher, *Reducing and eliminating restrictive interventions* (2014-2016). I wasa consumer researcher in a national research initiative to identify effective ways to reduce and prevent seclusion and restraint with Professor Bernadette McSherry, Professor Lisa Brophy, Dr Piers Gooding and others [report available at:

https://www.mentalhealthcommission.gov.au/media/123598/1408%20Seclusion%20 and%20Restraint Uni%20Melb final%20Report%205%20Sep%202014%20(D15-333268).PDF

This material contributed to the Mental Health Commission's position paper and widely distributed declaration on seclusion and restraint, which has been signed by dozens of services and professionals, and the research overall has likely contributed to falling national rates of seclusion and restraint in recent years.

- 8. Research supervisor, *The Safewards model, intervention and Victorian trial,* Department of Health and Human Services (2015 ongoing)
- Consumer Researcher, (2015 16), Development of a Program Logic and Evaluation Framework for the Victorian Independent Mental Health Advocacy (IMHA) Service, Department of Health and Human Services
- 10. Consumer Researcher, (2015), *Evaluation of Mind Australia's Peer Recovery Community (PRC) Services Implementation,* MIND
- 11. Consumer Researcher, (2014 15) *Reducing & Eliminating Seclusion and Restraint in mental health services*, National Mental Health Commission, Social Equity Institute, University of Melbourne
- 12. Consumer researcher, (2014 15), Consumer Perspective Group Supervision *Project,* Monash Mental Health Program
- 13. Consumer researcher, (2014), National Mental Health Commission, *National Contributing Life Project,* Craze Solutions

### Media

2017

Involuntary treatment, Australian law & real lives: a public conversation In an interview with ABC Radio National *Life Matters* program <u>https://abcmedia.akamaized.net/rn/podcast/2017/11/lms\_20171128\_0906.mp3</u> Cath Roper speaks to the issue from the perspective of her own experiences of involuntary admission and treatment, and makes the case that, "as a society, we have to take some responsibility ... for thinking: what message [does] that send a person seeking help, when that help is delivered with violence?". She highlights the tendency for involuntarily treatment to be framed as 'necessary', and calls for debate on what 'necessary' means when "we don't have good alternatives ...[which] would mean that we could look to something else and actually have some choices".

### One in 5 Podcast: Supported Decision-Making – no one size fits all

https://disability.unimelb.edu.au/media/one-in-five/episode-4-theres-no-one-size-fits-all-part-1

We hear about the move from substituted to supported decision making under the Mental Health Act 2014, how this affects health professionals, their legal obligations and how in practice, appropriate support for people with disabilities assists them to make informed medical and legal decisions.

### LEADERSHIP AND SERVICE

### Journal article Reviewer for:

- Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and PracticeJournal of Mental Health
- International Journal of Mental Health Nursing
- Journal of Psychiatric and Mental Health Nursing
- Medical Law International

### Supervision to Higher Degree students

- Provision of supervision to psychology PhD candidate at the University of Melbourne
- Advisory Committee Chair, consumer PhD candidate at the University of Melbourne
- Advisory group member to PhD candidate at the University of Melbourne

### Supervision to consumer workforce

 Provision of monthly consumer perspective supervision to four individuals and one consumer team

### Committees

I hold consumer roles on government committees relevant to state-wide training, innovation in the mental health sector, mental health workforce issues, sexual safety in Inpatient environments and the implementation of supported decision-making in mental health contexts.

### Consultancies

I am currently providing advice to the Director, Community Engagement of the Royal Commission into Victoria's Mental Health Services and to the policy and design team (2019/2020). I have previously provided consumer leadership and perspectives informing the Mental Health Organisational Capability Framework for the Department of Health and Human Services, Victoria, 2017 – 2018). I have co-facilitated training with TACSI (2017-18) *https://www.tacsi.org.au/* aimed at developing a process to co-design Victorian mental health services. I have provided a one day consultancy for a rural service on co-production with the CPN Director.

### **Keynote Addresses**

I have been invited to keynote at several international, national and local conferences. I have been an invited speaker on more than 20 occasions since 2014 and presented on my work at conferences on more than 16 occasions.

### PUBLICATIONS

Books

Happell, B., Cowin, L., Roper, C., Lakeman, R., Cox, L., (2013) Introducing Mental Health Nursing, a service user-oriented approach, 2<sup>nd</sup> edition, Allen & Unwin, Crows Nest, NSW

Roper, C (ed), (2003), *Sight Unseen,* Centre for Psychiatric Nursing Research and Practice, Melbourne Australia

### **Book Chapters**

Kemp, H., Bellingham, B., Gill, K., McCloughen, A., **Roper, C.,** Buus, N., River, J., (2020). Peer support and open dialogue: Possibilities for Transformation and Resistance in Mental Health Services. In: Rhodes P. (Ed.) Beyond the Psychology Industry. Springer, Cham DOI <u>https://doi.org/10.1007/978-3-030-33762-9\_6</u>

**Roper, C**., and Gooding, P. (2018). This is Not a Story: From Ethical Loneliness to Respect for Diverse Ways of Knowing, Thinking and Being, *Global Perspectives On Legal Capacity Reform: Our Voices, Our Stories,* Routledge pp154-164

**Roper, C**.,(2018). Capacity does not reside in me, In (Eds) C. Spivakovsky, K., Seear and A., Carter, *Critical Perspectives on Coercive Interventions: Law, Medicine and Society*. Routledge pp 85-97

**Roper, C** (2016) Is partnership a dirty word? In Russo and Sweeney (Eds), Searching for a Rose Garden, Challenging Psychiatry, Fostering Mad Studies, PCCS Books, Monmouth, UK <u>https://www.pccs-books.co.uk/products/searching-for-a-rose-garden-1</u>

### **Refereed Journals**

Gooding, P., McSherry, B. and **Roper, C**. (2020), Preventing and Reducing "Coercion" in Mental Health Services: An International Scoping Review of English-Language Studies. Acta Psychiatr Scand. doi:<u>10.1111/acps.13152</u>

Brophy, L & **Roper, C** & Grant, K. (2019). Risk factors for involuntary psychiatric hospitalisation. The lancet. Psychiatry. 6. 974-975. 10.1016/S2215-0366(19)30442-0.

**Roper, C.,** (2019). [Review of the book *Health and safety for spirit seers, telepaths and visionaries, by A.C.* Beyer]. Psychosis, 11:4, 379380, DOI: <u>10.1080/17522439.2019.1652844</u>

Daya, I., Hamilton, B.E., **Roper C.** (2019). Authentic engagement: A conceptual model for welcoming diverse and challenging consumer and survivor views in mental health research, policy and practice. International Journal of Mental Health Nursing doi: 10.1111/inm.12653.

Scholz, B., Platania-Phung, C., Gordon., S, Ellis, P., **Roper, C**., Bocking, J., Happell, B., (2019). Very useful, but do carefully: Mental health researcher views on establishing a Mental Health Expert Consumer Researcher Group pp. 1-10. J Psychiatr Ment Health Nurs.

**Roper, C**., (2019), Ethical peril, violence and "dirty hands" – ethical consequences of mental health laws, Special issue, Disordering Social Inclusion, Ethics, Critiques, Collaborations, Futurities, Journal of Ethics in Mental Health

Kennedy, H., **Roper, C.**, Randall, R., Pintado, D., Buchanan-Hagen, S., Fletcher, J. and Hamilton, B. (2019), Consumer recommendations for enhancing the Safewards model and interventions. Int J Mental Health Nurs, 28: 616-626. doi:<u>10.1111/inm.12570</u>

Juntanamalaga, P., Scholz, B., **Roper, C**. and Happell, B. (2019), 'They can't empower us': The role of allies in the consumer movement. Int J Mental Health Nurs. doi:<u>10.1111/inm.12585</u>

Happell, B., Gordon, S., Bocking, J., Ellis, P., Roper, C., Liggins, J. & Platania-Phung, C. (2019). "Chipping away": non-consumer researcher perspectives on barriers to collaborating with consumers in mental health research. Journal of Mental Health, 28(1), 49. doi: 10.1080/09638237.2018.1466051

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**Royal Commission** into Victoria's Mental Health System

### ATTACHMENT CR-2

This is the attachment marked "CR-2" referred to in the witness statement of Cath Roper dated 2 June 2020.

### CO-PLANNING

What are we looking to solve? Who should be involved? What approach should we use? Timeframes? Funding? Governance arrangements?

CO-DESIGN Define the problem. Develop solutions together. test solutions.

# CO-PRODUCTION

CO-EVALUATION What should we measure? Who should we ask? How will we get the information? CO-DELIVERY Delivering the solution -Who will do what?





**Royal Commission** into Victoria's Mental Health System

### **ATTACHMENT CR-3**

This is the attachment marked "CR-3" referred to in the witness statement of Cath Roper dated 2 June 2020.

## Individual mindsets for co-design None of Some of All team and the team the team decision makers We believe success is better outcomes for people. Tick the column that you think best describes your organisation. We believe in curiosity, we are continually looking to understand what would work and what would be better. We believe that people are the experts in their own lives and decisions about supporting them are best made with them. We believe that being in the grey is a necessary part of a codesign process. We believe that learning through doing is the best way to work through complexity. Even if things don't go right. We believe in honest and transparent communication throughout the process to keep all stakeholders aligned and aware of how their contributions are being used.

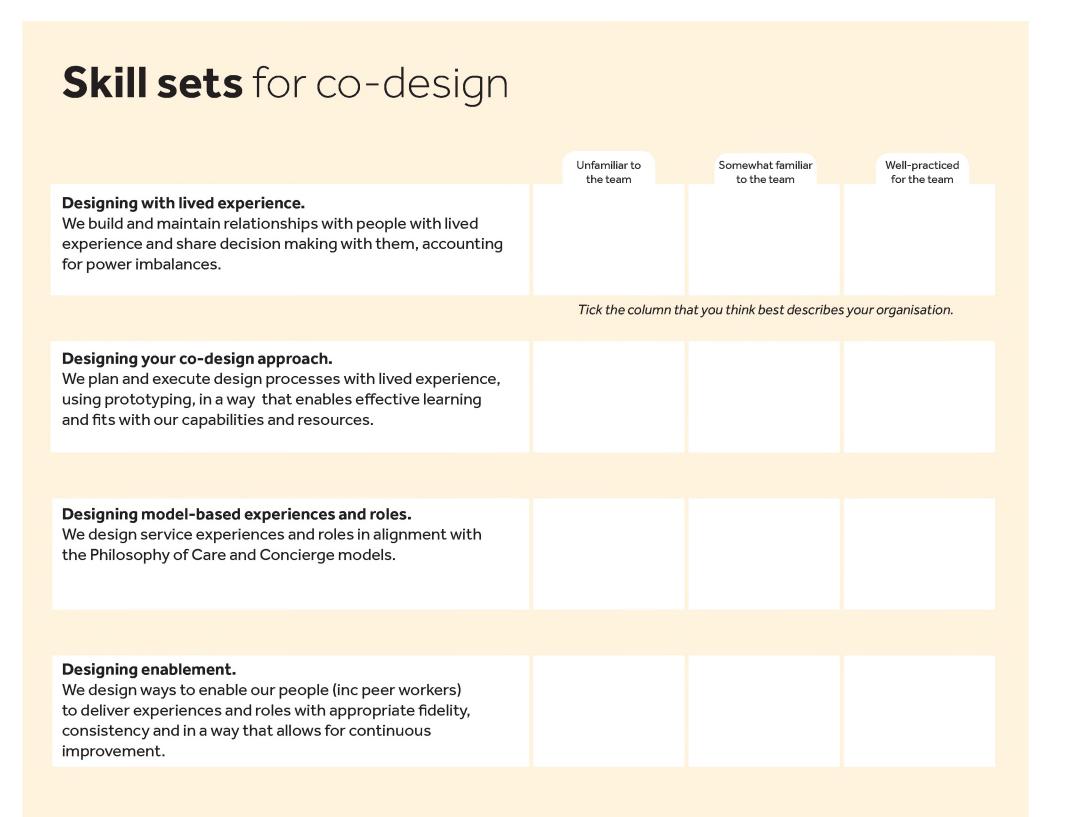
**Strengths** Which mindsets did you mark in the right column?

Weaknesses Which mindsets did you mark in the left column?

**Barriers** What do you think gets in the way of these mindsets?

Enablers

What do you think enables these mindsets?



**Strengths** Which skill sets did you mark in the right column?

Weaknesses Which skill sets did you mark in the left column?

**Barriers** What do you think gets in the way of these skill sets?

Enablers

What do you think enables these skill sets?

Project resources for co-design							
	No	Somewhat	Yes				
<b>Resources for facilitation.</b> We have appropriate time and money to spend on facilitating the co-design process.							
Tick the column that you think best describes your organisation.							
<b>Resources for participation.</b> We have appropriate time and money for staff and people with lived experience to participate.							
<b>Resources for solutions.</b> We have appropriate time and money to deliver what is being co-designed.							
<b>Resources for capability building.</b> We have appropriate time and money to build the required capabilities in facilitators, staff and people with lived experience.							

**Strengths** Which resources did you mark in the right column?

Weaknesses Which resources did you mark in the left column?

**Barriers** What do you think gets in the way of these resources?

Enablers

What do you think enables these resources?