

# Disrupting 'Expertise': Learnings from a Grassroots Lived Experience and Social Work Academic Partnership

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## Abstract

The involvement of consumers, families and carers in mental health service delivery is mandated by legislation, recommended in policy, and promoted in professional accreditation standards internationally. While social work academics have an established history of collaborating with organisations and practitioners, examples of industry partnerships between social work academics and service users, families and carers have emerged more recently. This change invites a critical examination by social work of its relationship with service users and their supporters. In this article, we document a successful partnership between a grassroots, lived experience group and two social work academics based on genuine engagement and significant positive impact for both parties. Entrenched power imbalances and ideas about expertise are disrupted and recast through consideration of the importance of clear objectives and purpose; the need for deep listening; the prioritising of relationships over task; the possibility of transformation; and new knowledges. The significance of witnessing to promote epistemic justice, along with recommendations for building and cultivating non-tokenistic partnerships are offered.

**Keywords:** *Industry partnership; Challenging expertise; Lived experience; Professional privilege*

## Introduction

This article details the partnership between a grassroots, lived experience systemic advocacy group and two social work academics in Western Australia. It is a co-produced and co-authored article; an approach which reflects our intentions, commitment and behaviour towards each other. While social work academics have a long history of partnering with organisations (government, not-for-profit, clinical, grassroots) and practitioners (individuals and teams), examples of partnering with service users, families and carers or service user-led research in social work have only emerged recently (d'Cruz & Gillingham, 2016; Fleming et al., 2014). The current times are calling social work and other disciplines to critically examine and recast the types of relationships built and sustained with people with lived experience.

We support Zuchowski, Miles, Gair, and Tsey's (2019) claim that social work academics are failing to document the nature of their industry research engagements and associated impacts comprehensively enough. We seek to address this gap by sharing our experience and examples of successful and not-so-successful instances of partnership, drawing out the opportunities, provocations and transformations that can result. The significance of witnessing as a tool for legitimisation of epistemic injustice and the danger of collusion also are considered. We discuss our encounters with deeply entrenched power relations which speak to ideas about expertise and professional privilege. To conclude, we share recommendations for building and cultivating non-tokenistic partnerships between grassroots, lived experience groups and social work academics. These non-tokenistic arrangements are reflected in our decision to have the lived experience authors take first and second place in the authorship order of this article. We see this as a minor example of how social work academics can unsettle dominant ideas about expertise and act with integrity in academic climates where performance is rewarded for first author publications.

## The partners

The grassroots, lived experience group, Mental Health Matters 2 (MHM2), is an unfunded, volunteer community action and advocacy group. The focus for MHM2 is improving service responses to, and outcomes for, individuals and families with combined, multiple, unmet needs of mental distress, alcohol and other drug use, compromised physical health and criminal justice involvement. The two social work academics have a deep commitment to embedding and valuing lived experience in their teaching and research. The partnership between MHM2 and the academics is based on shared interests in systemic advocacy with, and for, marginalised individuals and groups. We offer up our individual introductions to provide context to our partnership and this article.

**Margaret:** I came into the worlds of mental health education and advocacy through my experiences of supporting two family members who navigated mental health, alcohol and other drug and criminal justice services. In investigating why things were the way they were and believing there needed to be different and better responses, I founded MHM2 in 2010. MHM2 provides an umbrella for advocating for systemic change for individuals with living experiences of these tricky spaces, while maintaining the privacy and safety of the individuals

and their families. I have too often found a disturbing dissonance between engaging with services in my professional roles and as a family member walking alongside individuals who are navigating siloed systems of service design and delivery. This dissonance fuels my commitment to ensure that individuals and family members are meaningfully partnered with in all levels of decision-making and that lived experience leadership is cultivated.

**Ann:** I have more than 20 years' experience supporting two family members with mental ill health while also working full time as a university teacher. My involvement with MHM2 has allowed me to bring together those two forms of expert knowledge. My research focusses on narrative, and I have recently written about storytelling as a means of understanding and negotiating the experience of mental distress, both for those directly affected, and family and supporters. My research background and my own experience of the effects and after-effects of psychosis for everyone involved have thus come together to underpin my contribution to grassroots advocacy. I have a keen interest in the process of co-production as a space where lived experience can be valued as a specific kind of expert knowledge.

**Robyn:** I occupy the role of social work academic which nests alongside my other identities, including having lived experience of violence and trauma. My 30 years of social work practice is concerned with justice and injustice; in particular how some voices and experiences are heard and valued, and others are silenced and diminished. My work over the last 10 years has sought to address epistemic injustice, mostly in mental health, violence and trauma. My practice is based on dismantling traditional ideas about expertise and power relations with a commitment to creating the conditions for people with lived experience to lead those without lived experience. This means stepping back, letting go and critically recognising the epistemic privilege I have, even though I have survived family and sexual violence.

**Sue:** I, too, occupy the role of social work academic and have had 30 years in social work practice, teaching and research. In 2012, I was a researcher on two small evaluation projects with mental health organisations. When a larger mental health evaluation project emerged, Robyn and I began to work together. While each project was unique, we sought to underpin our evaluation work with the frameworks and principles of personal recovery and co-production, and to privilege service users and their families in the drafting of evaluation materials and reports, and the co-presentation of findings at conferences. After I was introduced to Margaret and MHM2, I was part of ongoing conversations about the inclusion of the perspectives of families, their lived experience, and the notion of family recovery in the development of our mental health units.

## Background

The engagement of, and partnership with, individuals, family members and carers in mental health research and service, delivery is increasing, as is the expectation that involvement will be “authentic and effective” (Daya, Hamilton, & Roper, 2019, p. 1). There is no shortage of international, national and state mental health frameworks, policies and standards that promote the principle of consumer and family engagement. For example, the United National

General Assembly's Convention on the Rights of People with Disability (2007) was ratified by Australia in 2008, and requires engagement and partnership in service design, delivery and review. Locally, Australia's Fifth National Mental Health and Suicide Prevention plan advises that "governments are committed to equitable, practical, authentic co-design with consumers and carers in the implementation of Fifth Plan actions" (Commonwealth of Australia, 2017, p. 4). The National Safety and Quality Health Service Standards demand the active involvement of consumers and carers in developing, planning, delivering and evaluating services (Australian Commission on Safety and Quality in Health Care, 2017).

In the local context, the Western Australian Mental Health and Alcohol and Other Drug Services Plan 2015–2025 embeds consumers, families and carers as key partners, arguing that the engagement of people with lived experience is "critical to achieving long term, sustainable system reform" (Western Australian Mental Health Commission, 2015, p. 16). These principles are reflected in the recent Western Australian Sustainable Health Review Report where "citizen and community partnership" (Department of Health, 2019, pp. 11, 20) are framed as the bedrock for transformation of health care.

There are many forms of partnership and engagement, ranging from tokenistic or one-off to longstanding and deeply relational. Oliver, Kothari, and Mays (2019, p. 1) described collaborative research practices as including "co-production, co-design, co-creation, stakeholder and public engagement and integrated knowledge translation". Co-design and co-production approaches rest on service user and family involvement and share similarities with the mental health recovery paradigm by positioning service users and families as self-determining experts who have multiple identities beyond those ascribed through diagnosis (Slade, 2009). Importantly, academics, practitioners, policy makers and other professionals are required to step back from leading and, instead, take on the role of facilitating, thereby creating the conditions for people with lived experience to create their own meaning and purpose (Slade, 2009; Slay & Stephens, 2013). These approaches require a paradigm shift and a willingness to actively share power.

The literature points to a range of hurdles to achieving meaningful engagement between grassroots groups, service providers and social work academics. In the area of mental health, "relational" factors and processes such as meaningful participation, sharing power, clear communication, and positive personal relationships are highlighted (Braganza, 2016, p. 2). Challenges around building and sustaining trust are pivotal (Baiardi, Brush, & Lapidés, 2010; Fouché, 2015). Conversely, superficial relationships characterised by poor communication, hostility, diversity of perspectives, major differences which are too difficult to reconcile, and unequal power sharing are noted as problematic (Braganza, 2016). More recently, the Australian Research Council (2019) has taken up the issue of engagement between researchers and end-users, emphasising mutual benefit to both parties.

Having established the background related to social work and industry partnerships, we now describe the origins, characteristics, strengths of, and challenges to, our partnership.

## Our partnership

Our partnership has its roots in the relationship between Robyn and Margaret. In 2011, Robyn invited Margaret to deliver an undergraduate social work lecture on family perspectives in mental health. The lecture was shared with another family consultant and, for Robyn, the contrast between the two speakers highlighted the differences between the identities of carer and *family member/supporter* and the consequent positioning of both the family member and the consumer (i.e., the term *carer* implies the service user is unable in part or full to *care* for themselves and is lacking agency and the capacity for self-determination). These guest lectures have continued and now include teaching into tutorial groups. From this initial invitation, Margaret and Robyn continued to build their relationship through their involvement in committees, research and advocacy in the local mental health scene.

The relationship between Margaret and Robyn took a different shape when Robyn and her lived experience academic colleague invited Margaret, in her role as convenor of MHM2, to partner in the co-design of a unit in a Masters of Mental Health Recovery. The unit focused on family inclusion in mental health which incorporated a critical understanding of psychiatry and philosophy and deeply valued the meaningful involvement of families and consumers. The unit learning outcomes focused on students recognising the importance of family inclusion and leadership, as well as developing skills which promoted this approach. Family member consultants from MHM2's peer-led, peer-run Families 4 Families WA (F4F WA) bi-monthly support group, were contracted and paid by the university to co-design the unit.

MHM2, through its F4F WA group, promoted the project and recruited family members to mentor and work alongside the students. The negotiated, paid roles for MHM2 were wide-ranging and involved providing peer support to family mentors, delivering lectures and co-designing and assessing student assignments. One of the co-designed assignments involved the production of resources for families. The co-design process involved students listening, reporting back to the families what they heard, developing first drafts of resources, taking them back to the family mentors, incorporating feedback, and returning with the next draft until a final version was endorsed by the family mentors. The family mentors identified this was a new experience as having one's experiences heard, valued and incorporated was reported to be a profoundly different and enriching encounter. The co-designed resources were given to MHM2 and this was considered to have lasting impact because, as a voluntary, unfunded group, MHM2 did not have the capacity to develop resources like these.

In 2017, a second opportunity for expanding the partnership's commitment to valuing family experience arose when Sue invited Margaret and Ann to co-supervise an Honours student's dissertation on family recovery in mental health. The topic was of deep interest to MHM2, given the lack of contemporary research in this area along with the wish to encourage a student embarking on this area of research. The student identified she had chosen the topic of "family wellbeing and recovery in mental health" because of her own lived experience as a family member and as she had been inspired by Margaret when she delivered the annual lecture mentioned previously.



Several meetings between the student, Margaret, Ann, Sue and another university supervisor, took place in cafes where the environment contributed to informal, purposeful and supportive conversations. This allowed all parties to respectfully explore the scope, depth, perspectives and processes involved in the topic. Margaret and Ann shared their expertise with the student and were particularly mindful of, and responsive to, safeguarding her around hearing family experiences which could be experienced as vicariously traumatic. Supported by her university supervisors, the student attended F4F WA group meetings in order to familiarise herself with the approach, introduce herself and the research, and collect data. At the time of preparing this paper, the student had been graduated for over a year and our efforts to invite her to participate in the paper were not successful. Because of the processes by which this Honours project was developed and supported by MHM2, the decision was made to include it in this article while ensuring the student's anonymity.

The third partnership opportunity occurred when MHM2 unexpectedly received a substantial financial legacy for the specific purpose of improving the health outcomes of people with multiple, unmet needs and enabling the inclusion of family lived experience in services. The MHM2 Steering Group decided to use the opportunity to work in partnership with a service provider to co-design, pilot and evaluate a model that changed culture and practice in how services were delivered to individuals and their families with multiple unmet needs. This was motivated by the observation that the language of co-design and co-production was growing across the human services sector without necessarily demonstrating the principles of empowerment, equity and participation. This was particularly important to MHM2, as their members frequently report disempowerment, unequal power relations, discrimination and marginalisation when interacting with mental health services and systems (the antithesis of co-production).

MHM2 was keen to capture the processes of developing the relationship between the community service provider and themselves as a grassroots, lived experience group. It was hoped that examining and documenting the process would provide useful information about the types of changes required to enact meaningful co-production, and therefore it was agreed that the project needed to be researched from inception. For MHM2, it was a critical and non-negotiable requirement that the academics involved would have a values-based approach as well as significant demonstrated experience in working with and privileging the voices of lived experience. In seeking to de-centre themselves and the privileges afforded to them as academics, MHM2 had witnessed the two social work academics enact what Slay and Stephens (2013) name as a commitment to coproduction by honouring and integrating lived experience, seeing people as active and capable participants, critically examining individual power and privilege, challenging dominant ways of doing business and facilitating lived experience leadership. As a result, Robyn and Sue were invited to undertake the research. While MHM2 had an existing relationship with Robyn and Sue, this project heralded a new relationship between MHM2 and the service provider. Of note, Robyn and Sue had an existing relationship with the service provider, having undertaken funded evaluations of their programs. Institutional ethics approval was granted by the Curtin University's Human Research Ethics Committee in 2015.

The project steering group asked the academics to draft a research design which reflected the project values and mission. This was shared with the steering group who provided comprehensive feedback and requested changes. In this process, Robyn and Sue were mindful of needing to articulate why the suggested methods and the overall methodology were a good fit for the project (rather than a reflection of their preferred approaches and methods).

The research design comprised three phases. Two were completed: the critical review of the literature on the involvement of families in mental health services (see Martin, Ridley, & Gillieatt, 2017), and the second, an examination of the partnership processes between MHM2 and the service provider. Observational methods were used by the social work academics during steering group meetings and other project activities. Additionally, throughout the project, steering group members were asked to share online anonymous reflections on emergent areas. These methods allowed for an independent perspective to be provided by the academics on interactions, relationships and emerging issues.

Owing to insufficient progress with the development of the new service, different understandings of co-production and a lack of continuity of involvement by key service provider staff, MHM2 decided not to proceed with the project after 18 months. This meant that phase three of the research design, which was to involve the evaluation of the new service response did not eventuate. While the project did not complete all it set out to do, it produced multiple meetings between MHM2 and the service provider (all witnessed by the social work academics); co-designed and co-produced community education events; a published scoping review by the social work academics; and scheduled updates from the social work academics on their observations of the development of the relationship between MHM2 and the service provider with respect to co-production.

Despite the project not reaching its full potential, many rich learnings and reflections emerged, including MHM2 developing a clear position about its future approach to partnerships with service providers and academics. Further, the scoping review provided “evidence” about the lived experience of MHM2 and other family representatives, as it told the story of the minimal and usually tokenistic involvement of family and carers in the “treatment” of their loved one (Martin et al., 2017). Given the project’s potential to put lived experience at the centre of service design and delivery, and promote culture change, the social work academics were saddened by its premature conclusion. While disappointed, Robyn and Sue were reminded of the possibilities associated with emancipatory and critical social work practice which disrupts and dismantles dominant discourses and ways of knowing, doing and being. Now that we have set the scene by sharing three examples of our partnership, we turn our attention to describing the features and characteristics of our partnership.

### **Key features of the partnership**

While we characterise our partnership as healthy and successful, we have been involved in projects which have not reached their potential. Since 2015, the authors have met regularly to

attend to, and reflect on, our work together. More recently, this has involved the consolidation of our reflections and learning for the preparation of this article. The values which underpin our work together are a commitment to achieving shared understandings, recognising and learning from the expertise of families, honouring lived experience, and being willing to share power. Openly and honestly sharing reflections and vulnerabilities with each other in our many meetings together helped us to clarify and articulate the key themes which we believe have contributed to our successful partnership. We share these themes in the belief that they have much to offer social work practice and education.

### **Shared and clear purpose**

The significance of mutually understood and negotiated purpose, objectives and aims cannot be understated. We have found that, when negotiating the start of each project, building shared understanding about what we are doing, and why we are doing it, is important. This requires continual and ongoing attention throughout the life of the project. Even when we think we understand our purpose, it can slip and morph into something else, for example, when key representatives frequently change and are not sufficiently briefed on the project and its progress. This can manifest in different understandings of approaches like co-production and lead to large amounts of time spent orienting new representatives and renegotiating the focus and parameters of a project. While returning to the purpose and aim of a project can be time-intensive, we believe that checking in, clarifying, adjusting and connecting saves time because we are more likely to land where we intended to land and achieve the objectives of the project.

### **Deep listening**

There are many ways to listen in a partnership; ranging from partial to deep. Our partnership seeks to create what we call a “deep listening stance” which is characterised by an open stance of “not knowing” what is about to be said, or not directing conversations to meet other agendas. Assumptions tend to be unsettled or disrupted in deep listening spaces, inviting listeners to reflect on themselves and the views and values they hold dear. At other times, we have found deep listening can confirm our shared value, purpose and vision. More often, it requires the listener to be fully present to the other’s experience and to avoid a problem-solving stance. For Robyn and Sue, deeply listening to Margaret, Ann and others from MHM2 meant stepping into painful, often irresolvable spaces characterised by invalidation and disregard for lived experience. An example of this was when MHM2 invited Robyn to be present at a debrief session with the MHM2 Steering Group at a critical juncture in the project which was not progressing according to plan. The MHM2 Steering Group invited Robyn because of their level of trust in her integrity and her demonstrated ability to deeply listen and hold a witnessing perspective in what was described by one member as a “sacred space”, such was the level of shared pain, vulnerability and need for safety. Deep listening creates the conditions for validation and legitimisation. It has a lasting impact when lived experience has resulted in epistemic injustice when one’s opinions and views have been discounted or disqualified in the past.



### **Prioritising relationships**

Relationship is the basis of the partnership between MHM2 and the social work academics. This includes knowing each other personally and professionally and deeply caring for each other. While we assert that relationship should be the highest priority, it is not to say that we neglect or avoid completing tasks; yet without this foundation, we cannot achieve our tasks. Our approach to writing this paper exemplifies the centrality of relationship for us. We have spent many hours together exploring our ideas and further strengthening our relationships. There have been confessional moments where we have shared vulnerabilities and concerns from various projects and points of engagement (and which were not shared at the time).

Just like constantly attending to shared purpose and understandings, relationships take time to cultivate and nurture. In the Master of Mental Health unit, this meant careful discussions about ideas, meanings and intent of the academics and students. There were times when MHM2 provided feedback of a corrective nature to Robyn; yet this only strengthened the relationship because of shared intent to privilege lived experience (rather than, for example, assuming to know what it meant, and felt like, to be a family member supporting someone involved in the criminal justice, mental health and substance misuse service systems).

As mentioned previously, MHM2 was conscious of safeguarding the Honours student given the potential for data collected to trigger or unsettle. Ann and Margaret know, from their roles as peer group facilitators, that when family members are asked about recovery and wellbeing, they often need to talk about distress and pain first. Therefore, they strongly advised the student to take care of herself, to avoid going too deeply in discussions and to be conscious of being activated around any issues that might be present for her, her family or close friends. The two university supervisors met the student fortnightly and were available for debriefing after each interview and attendance at F4F WA group meetings. While MHM2 members are engaging with Robyn and Sue, they are most often also managing difficult and unpredictable scenarios relating to their living experiences. In other work-related situations, both Margaret and Ann have experienced the need to conceal what they are managing and experiencing in their family lives in order to project and protect capable and competent professional identities. While working with Robyn and Sue, the relief of not having to “split” in this way as well as Robyn and Sue’s flexibility and acceptance of the realities of these ongoing experiences is inclusive and strengthening.

### **Transformative experiences**

Partnerships between grassroots, lived experience groups and social work academics offer many opportunities for transformation in knowledge, thinking, skills and relationships. Specifically, the relationship, deep listening and continually attending to shared purpose have created enduring trust amongst us.

The academics are aware of the positive learning that social work students derive from mental health lived experience education being taken into social work practice (Dorozenko, Ridley, Martin, & Mahboub, 2016; Ridley, Martin, & Mahboub, 2017). They have a deep

commitment to valuing lived experience and consistently seek to reflexively check their privilege and power. They do not always achieve this but have a commitment to it—evidenced by their willingness to deeply listen to, and be corrected by, people with lived experience in both their teaching and research activities. This means letting go of ascribed “expertise” from their social work practice and academic work and suspending their professionally formed knowledge in order to be influenced and transformed by lived experience. It also means letting go of the need for certainty and contained, easy-to-manage projects with “neat” endings. For Robyn and Sue, this means recognising their privilege as well-paid employees when they stand alongside their lived experience colleagues who undertake advocacy and activism as volunteers. Practically, this means ensuring experts by experience are offered fair payment for their contributions, thinking about what it takes for someone to visit a university (for example, can complimentary parking be offered?) and recognising the amount of voluntary labour contributed by those with lived experience, alongside dealing with the factors which make them experts by experience.

Margaret remembers clearly the moment when she realised that her lived experience and expertise was of value to others. It was in 2011 before her first presentation at Curtin University when Robyn sent her information which included details of her payment as a Guest Lecturer. This title and her remuneration in line with any other guest lecturer was a transformational moment. She used this experience to begin an ongoing journey of advocating for people with lived experience to be meaningfully reimbursed for sharing their expertise in other forums and settings. In one of the projects mentioned earlier, MHM2 piloted a tiered payment approach for lived experience. This approach subsequently informed the development of the Western Australian Mental Health Commission’s Paid Participation Policy which is regarded as a leadership document.

These encounters and the relationship in this partnership have transformed Robyn’s approach to her academic practice. Not only does she continue to value emancipatory approaches, she also seeks to embed them practically in her teaching and research practice. The slogan from the consumer rights movement: “nothing about us, without us” is held dearly. The experience of working in partnership with experts by experience has strengthened her resolve to navigate institutional requirements and expectations to embed learning from lived experience in all parts of her work. She recognises that, as a senior academic, she accesses social and cultural capital to find her way around higher education institutions to enable privileging of lived experience.

Through the process of co-design in the Master of Mental Health unit, careful attention was given to using language which positioned the family members as resources with their own valued and unique expertise. One example was the use of the term *family mentors* with the students. While a new experience for the family mentors, they valued this thoughtful positioning which caused them to more fully understand and acknowledge the value of their experiences.

## **New knowledges**

As a result of our partnership and the elements previously described, we have contributed to the formation of new knowledges, particularly in relation to family inclusion. As part of the project with the service provider, Robyn, Sue and their colleague Sophie Ridley, completed a scoping review on family inclusion for people with multiple unmet needs (co-occurring problematic mental health, substance misuse, offending and poor physical health) (see Martin et al., 2017). This work highlighted how unquestioned assumptions regarding the family role in causing mental distress due to their over-involvement or that they actively obstruct treatment, are persistent and perpetuate the ongoing exclusion of families. As a team, we noticed and reflected upon our anger at the injustices associated with the lack of involvement of families, particularly when they were asked to perform “assistant” roles such as ensuring compliance with medication and treatment while also being excluded from discussions about plans for their loved one.

Margaret remembers her first reading of the scoping review as rarely spilled tears flowed down her cheeks due to the depth of validation the published work gave to her experience as a family member. This review provided the irrefutable evidence that the experiences she, her family, and other families shared in the F4F WA group were not unique nor due to their own failings. Instead, the review clearly named their experiences for what they are—unjust responses from systems that discriminate, marginalise and dismiss expertise which does not fit dominant understandings or systemic approaches in spite of the commonly used language of person-centred approaches, trauma-informed care, family-inclusive practices, culturally secure approaches and recovery-oriented frameworks (Council of Australian Governments, 2012; Slade, 2009).

## **Why is this partnership significant?**

### **Witnessing legitimises experience**

This discussion on the power of witnessing is written by Margaret and Ann and highlights the power and impact of being witnessed when representing a lived experience perspective. We assert that witnessing is a powerful act in any partnership as it validates and legitimises experience and voice which is often subjugated or silenced. Our discussion here specifically draws on the project with a service provider where expected outcomes were not realised. Ann tells the story of joining the project’s steering group as a representative of MHM2 and notes how she was pleased to be invited to join the project because of its emphasis on co-production and the active participation of people with lived experience. Based on her extensive professional experience of groups and meetings, negotiating with stakeholders from different contexts, teaching and research, she began her membership of the project’s steering group feeling confident and optimistic that it would be a level playing field amongst the members. While deeply familiar with marginalisation and disempowerment as a family member of an individual with mental ill health, Ann had not expected this to occur in the context of a formal project specifically set up for co-production and co-design. Yet increasingly, a sense of being “othered” and marginalised emerged in the dynamics of the steering group for reasons that were difficult to fully understand at the time. This highlighted the significance

of how the physical presence of Robyn and Sue as observers and researchers at meetings became increasingly important when an “us and them” (professionals and people with lived experience) dynamic emerged. This was exacerbated by the frequent changes of representatives who had not been adequately briefed on the project. The reliable attendance of the social work academics meant that the challenges emerging in the project were documented and shared with the whole group for consideration and action.

Apart from their physical presence at the meetings, Robyn and Sue also provided another kind of witnessing by collecting reflections from group members on key issues. The analysis and re-presentation of the reflections were circulated in a timely way with the steering group and highlighted themes of “partnership” and “power”. In this analysis, Robyn and Sue noted that problems around achieving the ideal of “equal partnership” could perhaps be explained by anxieties over status, authority and power held by the service provider representatives. This re-presentation of findings by Robyn and Sue legitimised the tacit knowledge of the MHM2 representatives and acted as a lens to help them name, discuss and focus on the issues in the partnership.

All of us are reminded of Judith Herman’s (1992) work on trauma and recovery when it comes to witnessing, in particular, her arguments that, to bear witness is to say “you are real”; “what you have been through/are going through did/is happening”; “this is not in your head”; and “your contribution is valued”. Bearing witness has a relationship to epistemic justice and injustice (Fricker, 2008), in that the claims made by the person based on their experience are not discounted because they challenge or undermine the values and sensibilities of others. The social work academics consider their witnessing as an act of epistemic justice in that it was a reflexive act, subject to questioning and critique, yet it involved taking a stand (Herman, 1992). This stand is one that promotes epistemic justice and social justice, resists relativistic notions of individual truths and works from the position that some voices and experiences are silenced through enactments of power and privilege.

### **Resisting collusion**

The notion of “the seduction of inclusion” was developed by Margaret to describe the tempting pleasure of pride and relief at finally being invited to the table as a lived experience representative. This is especially the case as a family member who has spent years being blamed, either openly or subtly, for what has happened with their loved one. Representations in the media, and society’s assumptions in general, define the families of the mentally unwell, especially if there are associated issues around substance use and/or involvement in the criminal justice system, as dysfunctional and having somehow caused their relative’s problems (Martin et al., 2017). Because bringing one’s lived experience to the table leaves one vulnerable to such stereotypes, it is often tempting to be the compliant representative, the one who readily agrees to the positions put by the “real” experts in the room—the professionals who represent the service provider.

Margaret and Ann have taught the social work academics much about this seduction and co-option of lived experience. They have encouraged Robyn and Sue to be aware of this dynamic in their research and advocacy work. This dynamic undermines the value, commitment and contribution that people with lived experience bring to projects. Ann feels that, in relation to the MHM2 and service provider project, without the participant observation records produced by Robyn and Sue and their steady presence at project meetings, the lived experience representatives might well have been more readily silenced or even co-opted in the face of the service provider's stance in relation to co-producing all elements of the project.

As social work academics who have been involved in industry partnerships and conducted many program evaluations, Robyn and Sue are mindful of the need to resist collusion of a different kind. In the last seven years, Robyn and Sue have observed what Elahi, Kalantari, Hassanzadeh, and Azar (2015, p. 18) called the pitfalls of "pseudo-evaluations" which they characterise variously as "public-relations-inspired", "politically controlled", and "pandering". We have also observed other research collaborations where consumers are included as a tokenistic, tick-box mechanism. For some university research projects, as Daya, Hamilton, and Roper's (2019) report, consumer tokenism is rife, and such approaches are exploitative and replicate previous harms caused by institutions and the professionals who work within them.

### **Ideas for building meaningful, non-tokenistic partnerships**

We are familiar with the literature which speaks to the importance of co-production and collaboration as a way of organisations and grassroots groups working together successfully. Hayward and Cutler (2003) argued that top-down approaches are ineffective in mental health services and that to not engage with the grassroots is a policy failing. Further, when representatives of universities are involved in research partnerships and have a fiduciary interest as the social work academics did, we too have a critical role to promote social justice in the research work we undertake (Yassi et al., 2010).

There also are inherent challenges in partnerships which include protocol, procedural and resource management differences (Gilchrist, 2009; Kadushin, Lindholm, Ryan, Brodsky, & Saxe, 2005). Gilchrist (2009) asserted that key characteristics of partnerships such as strong interpersonal relationships; sharing resources, trust; "cooperation" (p. 55) and shared vision can be at odds with the features of service provision such as "formal procedures", control of resources, "accountability, bureaucratic arrangements, rules and relations, contracts and directives" (p. 54). Numerous authors make the point that resources are required to harness harmonious, collegial ways of relating especially in a partnership situated in an organisation where sometimes there is little interest for such investment (Baiardi et al., 2010; Braganza, 2016; Fouché, 2015; Gilchrist, 2009).



## Recommendations

Our partnership is enriching, mutually supportive and life changing. It has yielded a peer-reviewed scoping review which affirmed family members and allies by providing an overwhelming sense of vindication which spoke to how family members of people with mental health distress feel discounted, ignored or trampled upon. Our experience of this collaboration reflects themes in the literature on successful industry partnerships such as trust, relationship, shared purpose, clear communication and commitment (Fouché, 2015). In contrast, Braganza (2016, p. 9) asserts that “failing to recognize, mitigate, and respond to challenges in collaborative relationships can damage relationships and cause collaborative efforts to be unsuccessful”. The literature and our experience lead us to strongly recommend that preparation for any project involves a wellbeing check which considers the readiness of each partner, the knowledge and skills needs of the various parties, and whether they will proceed. We view this as the first step in co-design which creates shared understanding and vision. Key elements of this check would include ensuring all parties can dedicate the required time. Further, processes and preferences for managing conflict and competition, steps to identify and overcome biases, and establishing goals, roles and responsibilities (Braganza, 2016, p. 4) can be considered. Based on our partnership, other steps we suggest include:

- Take time to build relationships and get to know members of the collaboration. This is a key opportunity to test commitment and capacity to actively and consistently participate for the duration of the project. This could take the form of exploring times when regular and reliable attendance may be tested (for example, a crisis in service delivery or staff absence due to illness).
- Assess and audit the skills and interests of each representative, consider the values and vision of the project and appoint champions for parts of the project. For example, having a co-production or co-design champion who ensures all parts of the project reflect these principles, and if there is slippage, return the project to its intended values.
- Continue conversations about values; both those shared and differing and return to consider how these similarities and differences strengthen or undermine the collaboration and the project.
- Have conversations about the vulnerabilities for all parties and what the manifestation of trust will look like in the group.
- Critically and continually consider how lived experience is valued and not discounted. For example, shared exploration of the concepts of epistemic justice and injustice has the potential to uncover deeply held views about the value placed on lived experience testimony and influence.
- Agree on language and terminology for the project.

- Commit to a written MOU within three months of starting the project and frequently return to it to assess if it is fit for purpose.
- If money is involved, ensure agreement for transparency around budget from the outset (including who is responsible for the budget and who in the partnership has influence over the budget).
- Determine who leads the collaboration. For example, will it be co-led by a grassroots member and another partner? Other considerations include determining the mechanisms for checking the partnership is living its stated values.
- Consider engaging a process evaluation team which is connected to, but separate from, the project. This provides a mechanism for independent observation and input to the project.
- Consider regular reporting from the evaluation team which provides observation and analysis of progress, identifying what is going well, reporting in on group trust and cohesiveness.
- Develop capacity-building opportunities and plans for sustainability.
- Develop a shared commitment and set of processes to attend to early warning signs of issues in the partnership.

These recommendations sit on a foundation of commitment by those who benefit from privilege (either through roles or status) to critically examine their power. This power might be through knowledge, qualification or access to resources. We believe that this critically reflexive stance promotes the conditions for a reassessment of the distribution of power, promotes epistemic justice, and sets the tone for respectful relationships with experts by experience.

## Conclusion

Through sharing our experience of a powerful and enriching partnership between a grassroots, lived experience group and two social work academics, we hope to inspire others to embark on such collaborations. Like Fleming et al. (2014), we know, through this experience, that the impact of these partnerships is meaningful and validating through attention to power, relationships and deep valuing of lived experience. Not only the authors, but also social work and other students and members of MHM2 have acquired new knowledges and had transformative experiences as a result of this successful partnership. We also have learned that such partnerships face challenges, and perhaps more so when there is involvement of other parties who may not necessarily share the same values and commitments. We have sought to outline the sources of these challenges and make recommendations from our own experience as to how grassroots and lived experience groups and social work academics can develop and sustain non-tokenistic partnerships.

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