Consumers and carers as partners in mental health research: Reflections on the experience of two project teams in Victoria, Australia

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ABSTRACT: A successful working partnership in research between a consumer project team from the Victorian Mental Illness Awareness Council and a carer project team from the Victorian Mental Health Carers Network was forged during their collaborative involvement in an innovative 2-year pilot project funded by the Victorian Government of Australia. This project trialled new ways of capturing consumer and carer experiences of mental health services, and that feedback was integrated into service quality improvement. Towards the end of the project, an external facilitator was used to enable the two teams to reflect on their experience of working together so that their joint story could be shared with others and used to promote further use of this approach in the mental health field. Main findings included the importance of having strong support and belief at leadership levels, opportunities to build the relationship and develop mutual trust and respect, a common vision and a clearly articulated set of values, targeted training appropriate to the needs of the team members, independent work bases, and mutual support to overcome challenges encountered during the project. The experience forged a close working relationship between the two teams and has set the scene for further participation of consumers and carers in research and innovative quality-improvement processes in the mental health field.

KEY WORDS: carer participation, consumer participation, mental health, partnership, research.

INTRODUCTION

Historically, the relationship between mental health consumers and carers in Australia has not been easy or straightforward. Here, the term ‘consumers’ refers to people who use or have used mental health support services, and the term ‘carers’ refers to those in an active, personal support role for a consumer. Anecdotal evidence and research indicate that important differences in perspectives and agendas can lead to fraught relationships between consumers and carers (Goodwin & Happell 2006). However, in an era where policies require participation and collaboration of consumers and carers across all levels of the mental health system (Australian Health Ministers 2008; Council of Australian Governments 2006), there are a growing number of cases where consumers and carers have overcome their differences and benefited considerably by working together.

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Accepted December 2010.

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International Journal of Mental Health Nursing © 2011 Australian College of Mental Health Nurses Inc.
This article describes the experience of a successful working partnership in research between a consumer project team from the Victorian Mental Illness Awareness Council (VMIAC) – the peak body for consumers in Victoria – and a carer project team from the Victorian Mental Health Carers Network (VMHCN) – the peak body for carers in Victoria. The relationship between the two teams was forged during their collaborative involvement in a pilot project funded by the Victorian Department of Health (formerly the Department of Human Services) between 2006 and 2008 called the Consumer and Carer Experience of Care and Support Initiative (C&C Experience Project). This project trialled new ways of capturing consumer and carer experiences of mental health services, and of integrating that feedback into service quality improvement. Towards the end of the project, the two groups reflected on their experience of working together so that their joint story could be shared with others and used to promote further use of this approach in the mental health field.

BACKGROUND

Since the 1950s and 1960s, the mental health consumer movement has been a part of the international disability movement to protect the basic human rights of mental health consumers. Victorian consumers have been a strong voice influencing changes in the Australian mental health system for many decades. While the mental health carer lobby in Victoria began with the Mental Health Auxiliaries of Victoria as early as the 1950s, it was not until the 1990s, when several groups came together, that the mental health carer movement gathered momentum.

Since the 1990s, policies to increase consumer and carer participation at all levels of mental health service planning, delivery, and evaluation have been developed at the international (World Health Organization 1990), national (e.g. Australian Health Ministers 2003; 2009), and state levels (e.g. Department of Human Services 1996; 2005). While giving greater emphasis to consumer participation, the latest international trends also set family/carer participation as a benchmark for assessing service quality (Australian Health Ministers 2002) and for creating mental health policies that are consonant with human rights (United Nations General Assembly 2006).

In Australia, the VMIAC has been conducting a number of consumer research projects to support consumer involvement in mental health service planning and provision since the mid 1990s; for example, the Understanding and Involvement project (Wadsworth & Epstein 1996). Consumers and carers have also been employed by mental health services as consumer and carer consultants to help implement participation strategies. Services are now expected to maximize the opportunities for consumers and carers to be involved in treatment and care, not only at an individual level, but also at a systems level (Department of Human Services 2006). The most recent national mental health policy (Australian Health Ministers 2008) has called for consumer ‘participation and collaboration across multiple sectors, levels of government and government agencies’ (p. 10) and for carers to have an ‘integral role . . . in service planning, delivery and evaluation’ (p. 22). Some examples of participation include suggestion feedback boxes, close involvement in personal treatment planning, systemic advocacy, consumer/carer-led clinician training, committee membership, leading research, evaluating client experiences (Byas et al. 2003), and developing implementation tools (Viney et al. 2004).

However, Goodwin and Happell (2006) noted that most policy documents seemed to assume that all consumers’ and carers’ needs could be met through the same initiatives. Very few policy documents make reference to the different issues or agendas facing these two stakeholders (Goodwin & Happell 2006). For example, Lamners and Happell (2004) reported disparity between consumers’ and carers’ scopes for participation, making it more difficult for carers to participate in services, although there was significant variation from service to service. This requires strategies to support greater carer participation (Lamners & Happell 2004) and clearer guidelines about how participation should take place (Hayman & Fahey 2007). In addition, a working partnership between consumers and carers might suit some areas more than others. There are instances where carer involvement in a consumer’s situation is inappropriate, and at times, carer imperatives have seemed to directly impose upon the much-valued rights of consumers (Goodwin & Happell 2006; Szmukler & Bloch 1997). This is particularly so in the realm of privacy and confidentiality (Leggatt & Furlong 1996; Wynaden & Orb 2005), although it is generally accepted that consumers’ rights are afforded priority (McSherry 2006). Attempts to collaborate have been further strained by a legal context that limits consumers’ rights, causing frustration and potentially fostering conflict between carers and consumers (Baker 2007; Moynihan 1992). Ongoing stigma experienced by families around mental health issues has also added pressure (McCauliffe et al. 2009; National Mental Health Consumer & Carer Forum 2010). Overall, such tensions have at times resulted in a lack of trust and respect between consumers and carers (and clinicians),...
which can lead to a ‘culture of blame’ (Gray et al. 2008, p. 379), creating tenuous ground upon which to build collaborative relations.

Notwithstanding these issues, there are now many examples of successful bridge building between consumers and carers in systemic advocacy, although there is a general paucity in the literature covering this emerging collaboration (Lammers & Happell 2004). Inevitably, some instances of collaboration between consumers and carers begin in a tokenistic fashion and require several attempts on both sides to bring about true partnership and understanding. Examples of collaborative developments within Victoria include combined workshops and training for clinicians on confidentiality; collaborative work with clinicians to improve the use of mental health outcome measures; more joint presentations at conferences, such as the Australian Mental Health Services Conference; and the work of the consumer and carer subcommittee of the Victorian Ministerial Advisory Committee.

Significant bridges have also been built between the mental health consumer and carer peak bodies in Victoria following initial challenges. In 2005, the VMHCN staged a regular conference for carers with the theme, ‘Talking Together, Working Together – Carers with Consumers and Clinicians’. Last-minute changes to the programme had drastically reduced consumer representation, resulting in a campaign by the Director of the VMIAC, Isabell Collins, to address this issue. This led to more cordial dialogue between the VMIAC and the VMHCN that laid the foundations for a strong and fruitful partnership between the consumer and carer peak bodies (E. Bailey, pers. comm., 2008; I. Collins, pers. comm., 2008). Given the history of discrimination and powerlessness experienced widely by consumers in relation to mental health, it is not surprising that the issue of equitable representation was critical. For example, Happell and Roper (2006) cite numerous articles that identify the negative attitudes of mental health professionals as being a major barrier to effective consumer participation.

Another major milestone of consumer and carer collaboration was the inaugural meeting of the National Mental Health Consumer and Carer Forum (NMHCCF) in 2004. Developed under the auspice of the Mental Health Council of Australia, it was designed to report to the Australian Health Ministers’ Working Group. Initial meetings were very difficult, and there were great tensions largely stemming from differing agendas between consumers and carers, and among consumers themselves. However, with the creation of consumer and carer co-chair positions and the development of a culture of trust, the NMHCCF has become very productive. The Consumer and Carer Participation Policy (National Mental Health Consumer & Carer Forum 2004) that was endorsed by the Australian Health Ministers Mental Health Working Group is an example of their achievements to date (E. Bailey, pers. comm., 2008; I. Collins, pers. comm., 2008). Recent evidence of this can be seen in two NMHCCF publications (Harvey et al. 2009; National Mental Health Consumer & Carer Forum 2010), the first of which is an issues paper relating to privacy and confidentiality; the second, a consumer and carer workforce development position paper.

Another opportunity for consumers and carers to work together is in the field of research. Consumer participation in research has expanded greatly over the last two decades (Sweeney et al. 2009; Wallcraft et al. 2009), while carer research participation is less developed, although recognized as vital and requiring development (Lammers & Happell 2004). Consumer and carer contributions to research range between being simply ‘the icing on the cake’ to taking full project control (Stacey & Herron 2002). There are worldwide examples of consumer and carer partnership in research and evaluation, such as the Consumer Quality Initiative in Massachusetts, USA (Plachta-Elliott & Delman 2009) and the South West Yorkshire Mental Health National Health Service Trust project, UK (Minogue et al. 2005). Such research processes create ongoing opportunities for collaborative partnerships between consumers, carers, and clinicians (Horsfall et al. 2007).

C&C Experience Project

The C&C Experience Project, which has now evolved into the Mental Health Experience Co-Design (MH ECO), provided an opportunity for consumers and carers in Victoria to work together in a research capacity. The C&C Experience Project was a pilot project aiming to capture consumers’ and carers’ experiences of public mental health services with a view to facilitating quality improvements in services. The Victorian Department of Health funded the VMIAC and the VMHCN to employ consumer and carer teams, each made up of two project workers and a project manager. The two teams were housed in separate locations in the offices of the respective peak bodies, allowing them to have a high degree of independence in their day-to-day work, and afforded good opportunities for separate debriefing (Wadsworth 2004). The two teams worked in partnership with the Department of Health, four clinical mental health services, and four Psychiatric Disability Rehabilitation and Support Services, and encompassed a total of 12
programmes across the eight services. Design and implementation of the project was overseen by a survey working group – of which the two teams were members – that met monthly. The reference group, which met quarterly, provided expert advice and access to networks.

The tasks of the two teams were wide ranging and included giving presentations about the project to staff at the eight services involved in the pilot, conducting an initial consultation with consumers and carers of those services, developing appropriate methods to collect information from consumers and carers about their experiences of care, implementing the methods (including conducting interviews and focus groups with consumers and carers), analysing the data, reporting the findings, and providing feedback to participants.

One aspect that has frequently been cited as a barrier to consumer and carer involvement in research is a potential lack of expertise in research methods (Happell & Roper 2007; Horsfall et al. 2007). Although members of both teams did in fact bring a great deal of professional skill to the project, they were provided access to ongoing needs-based training and development through a training coordinator from the Health Issues Centre (HIC). This training covered all aspects of the project, ranging from research techniques to group facilitation and problem-solving skills. Given the HIC’s dual specialty in working with consumers and in research methodology, they were strategically placed to offer targeted training (Lynne 2007). Their literature review identified how training would require a flexible and accessible process in keeping with adult learning principles (Tough 1973; Vella 2002), as well as the close involvement of participants in choosing the content and timing of sessions (Buckley & Caple 1995; Watkins 1991). This consultation reflected the trainers’ convictions that the training programme should, ‘as far as practicable’, be consumer and carer driven (Meehan et al. 2002, p. 38).

Another issue facing consumer and carer researchers relates to the specific vulnerabilities they might face in the work environment. While consumer/carers research has the stigma-breaking effect of demonstrating they can handle ‘professional’ jobs, consumers and carers nonetheless experience particular issues that must be acknowledged (Plachta-Elliott & Delman 2009). Difficulties facing any consumer or carer will be specific to the individual and their team (i.e. severity of mental health difficulties and caring responsibilities), so these vulnerabilities are hard to generalize. In the case of the C&C Experience Project, ongoing training served a dual process of not only identifying training needs as they arose (i.e. presentation and group facilitation), but of providing a reflective space for discussion and problem solving any difficulties. This created an essential check against job stress and any workplace health and safety issues (Lynne 2007). The literature supports the view that consumers (and by extension, carers) can successfully contribute as employees of mental health services (Nestor & Galletly 2008) and can take a lead role in the evaluation of mental health services, if they are provided with resources and support for training and infrastructure (Delman & Beinecke 2005).

Further challenges associated with consumer and carer collaborative research include having sufficient time (and money) to enable mutual respect and trust to develop, and ensure the viability of the project (Alliston et al. 2009; Horsfall et al. 2007; Lloyd & King 2003; Wells & Jones 2009), clarity of planning and processes, and having a supportive organizational culture (Alliston et al. 2009; Horsfall et al. 2007). In the C&C Experience Project, there was no guarantee of funding beyond the first year, which was a cause for uncertainty for the two project teams; however, funding was extended to enable the completion of the project. In terms of planning and processes, the potential for conflict between the agendas of consumers and carers has been identified as a possible challenge (Goodwin & Happell 2006) that was addressed in a number of ways in the processes set up in the C&C Experience Project. For example, the consumer and carer research teams worked independently in the field, and separate questionnaires were developed for consumers and carers. Finally, both teams worked in a supportive organization where there was (and remains) a strong belief in the value of consumer and carer participation. In a sense, this enlarged the power base of the two teams, balancing some of the power inequities encountered, and constituting something akin to a ‘critical mass’ of people holding a similar critical perspective (Wadsworth 2004), which Wadsworth posited was a key factor in successful mental health research collaboration. The commitment of other partners, particularly the Department of Health and participating service providers, was also pivotal to the success of the project. This enabled the two teams to carry out their project responsibilities in an environment that was largely supportive of their efforts.

Given the paucity of literature describing partnership between consumers and carers as researchers, particularly in Australia, the aim of this study was to enable the consumer and carer research teams to reflect on their experiences of working together. In addition, it was hoped that their joint stories could be used to promote further use of this innovative approach in the mental health field.
METHOD

Towards the end of the project, the VMIAC and the VMHCN teams approached the HIC training coordinator to conduct a discussion with them about the nature of their experiences working together on the project. This method allowed the members of the two teams to describe their experiences in their own way, and was symbolic of the way the two teams had worked throughout the project.

This discussion took place over two 1–1.5-hour sessions, held over two separate days, and revolved around three key issues that the teams and the facilitator had jointly decided on beforehand. These included the teams’ original perceptions and expectations of the project, the challenges or barriers that they had faced in the project and how they were overcome, and the ‘glue’ that had held the two teams together. These sessions were digitally recorded and later transcribed by an independent transcribing service.

The two teams analysed the transcripts in a systematic way to identify categories and themes, drawing on the principles outlined by Strauss and Corbin (1990). This rigorous method of analysis, using independent coding, was selected because it is recognized as contributing to the trustworthiness of qualitative data analysis (Lincoln & Guba 1985). This involved members of the two teams separately engaging in an ‘open-coding’ process, after which the project workers, working independently of the other team, checked each others’ codes, discussing the material until they reached agreement about codes and categories. Key quotes and comments relating to the various categories and subcategories were collated. The two teams then met to share their analysis of the discussion, and were able to establish agreement about the categories and the related quotes.

FINDINGS

Expectations and fostering the partnership

Two themes emerged clearly from the discussion about the perceptions and expectations of the team members at the start of the project, which included preparedness to work together and establishing mutual trust and respect.

Preparedness to work together

A couple of years ago consumers and carers (didn’t) even want to sit in one room to discuss things. (Consumer)

However, as one consumer project member reported:

Things move on, and when we started this project, I think the culture (was) already there, so that consumers and carers can work together collaboratively to achieve (their) common goal.

The consumer and carer project team managers both affirmed the role that the Director of the VMIAC and the Chair of the VMHCN played in making the partnership possible:

They laid the groundwork really for us to work together, and we wouldn’t be where we are today . . . if (they) didn’t have that really good understanding of each other and that great sort of relationship. (Carer)

This preparedness to work collaboratively is also reflected in the comments from other project team members:

I thought this is going to be really innovative and an interesting thing to do, but my focus wasn’t (on) how odd it will be to work with consumers; it was more how interesting it will be to affect some sort of change through this research. (Carer)

I guess working in the (mental health) sector for quite a long time I’ve seen both sides of the spectrum. I came in with a great feeling of maybe this could really break down some of the divide that happens (between consumers and carers). (Consumer)

Establishing mutual trust and respect

Members of both teams felt that it was essential to have mutual trust and respect at the core of their working relationship, as the following quotes illustrate:

Probably the first thing was getting to know each other as individuals and as a team or as teams, and building up a real trust, working relationships, and getting to know each others’ sense of humour and building that trust first. (Carer)

The working relationship was built on respect and . . . whatever we do, we respect each others’ opinions. (Consumer)

Quite early in the project, the teams quickly established a high level of respect and trust, which is reflected in the following quote:

I came in (to the project) a little later . . . I think the teams were quite . . . established, and how they related to each other was fairly well worked out. So for me it was kind of good coming in at that stage because there was a set way, a very respectful way of dealing with the teams. (Carer)
The initial training session provided a good opportunity to begin the process of getting to know each other and establishing respect and trust:

Just to have that opportunity on that first meeting to sort of find out more about each other and what had happened in our lives and what had brought us together on that project... that was a really good starting point just to have that opportunity to have that little bit of personal sharing and... what are our hopes for the project. (Carer)

Other team members expressed their recognition of each person’s talents and abilities, which were more important than divisions, in terms of the labels of ‘consumer’ or ‘carer’:

I’ve come to appreciate everybody’s talents and contributions. You know, the unique things that we all bring to the project over and above who’s a consumer and who’s a carer. (Carer)

This respect and trust enabled the acceptance of differences between the two teams, which is exemplified in the following quote:

We don’t have to do everything the same because consumers and carers will have different needs and we operate in slightly different ways, and there will be times when we diverge, and there has been enough scope in the project to be able to do that and then come back together... I think it’s good having it together and separate as well. (Consumer)

Overcoming challenges and barriers

In addition to getting to know each other and establishing trust and respect, the two teams used the training sessions to clarify the tasks associated with the various phases of the project and to learn the various skills they needed to carry out those tasks. However, as with most pilot projects, there were a number of unanticipated challenges and barriers that arose, which were experienced as being unsettling for the teams. These challenges included changes in personnel in the two teams, different work cultures of the two teams, and changes in Department of Health management with associated shifts in vision and methodology for the project.

Changes in personnel

During the first 3 months of the project, one project worker resigned from each of the consumer and carer teams, which was felt very deeply by remaining team members. With hindsight, they were able to appreciate that this was perhaps to be expected. Pilot work often involves uncertainty because there is no pre-existing structure or experience on which to anchor the work, conditions that can be very difficult for some people. In addition, both teams were made up of individuals, with their own lives as consumers and carers to be reconciled with their work roles, which added to the complexity and reinforced the need for support for team members.

On reflection, this experience was perceived by team members as a time when the teams provided mutual support to one another, thereby enhancing their relationships. As one team member said:

I thought one thing that was really great to me was the way everyone sort of rallied around and supported each other and ‘hey this has happened, but we’ll get through it, and we’ll grow and we’ll move on from there’. (Consumer)

Different work cultures of the two teams and sensitivity to differences

The collaborative nature of the project was at times challenging in terms of the different work cultures of the two teams. The team members attributed this to both the differing organizational cultures to which the teams belonged and personal preferences as the following statement shows:

I guess my challenge has been working with two different organizational cultures... I work within a sort of organization that is quite planned... and that likes strategies planned out and documents... I think my personality is also like that, that I like to be a bit planned. I guess there have been times when I’ve looked for more planning or more structure from you guys. (Carer)

On an individual level, this sensitivity to difference between the two teams raised some concerns in both teams about what was and was not acceptable to talk about. This was a particular challenge for some project team members when the two teams were working closely together in the field, as can be seen in the following comments:

During that time of doing those sort of joint things, perhaps I held back... a few times... I was incredibly aware of not wanting to put my foot in it and not to upset relationships. (Carer)

You know, if there’s (sic) issues, we need to just respect each other and talk to each other as people. That’s certainly how we deal with you guys. (Consumer)
Changes in Department of Health management and direction

Shortly after the appointment of the two project teams, the Department of Health appointed a new manager for the project. At the same time, it appeared that the vision for the project within management levels of the Department of Health had also shifted somewhat. For example, while the original vision had primarily involved drawing on the experiences of carers and consumers through the use of interviews, it had shifted to being weighted towards the development and use of a questionnaire. This reflected an emphasis on quantitative methodology, while the two research teams thought it was vital to retain the direct ‘voice’ of consumers and carers:

It is sort of part of our movement of consumers and carers that we value social research that is qualitative and that allows people to have their own voice, that is of their own subjective experience and that we value that over some other types of knowledge. (Consumer)

The message from the Department of Health had become much more fuzzy and not in alignment with what we had originally been told and anticipated would be the vision and aim of the project, and so we had to reclaim that. (Carer)

This propelled the project teams to reassert what they saw to be the priorities of the project, because methodologies that were originally agreed had been altered. As one team member commented:

I think with each new change in management, there was a change in slight emphasis in what the project was about, how to get there, and what the priorities were. So that was very frustrating for both (consumer and carer team managers), wasn’t it? I think we had to work really hard to try to get our agenda back on the table, particularly with the qualitative methodology and stuff. (Carer)

Encouragingly, rather than having a detrimental effect on motivation or disheartening the teams, it helped them to clarify their goals and preferred methods:

The changes in... the management at the Department of Health... could have really had the potential to dishearten the teams. You know, wipe out the motivation and all of that, but it didn’t. It actually had the opposite effect. It made everyone more determined to work together to get it happening. (Consumer)

Glue: What held the two teams together?

There were a number of elements that the teams identified that helped to hold them together or acted like ‘glue’, including having commitment to a common goal, negotiating key tasks, sharing regular training sessions, and valuing fun and humour.

Commitment to common goal

Both teams were strongly committed to the project and their desire to help tap into and express the views of consumers and carers in relation to their experiences of mental health services, as can be seen in the following:

Also the thing that I think is very important is the common goal that we have. We all wanted this project and (to implement it) in the way that best reflects consumer and carer needs. (Consumer)

We all feel that this is much more than a job; that there is something very meaningful in all this for all of us. (Carer)

Negotiating key tasks

Within the context of the training sessions, the teams worked together on a number of key tasks, which helped to build the bond between the two teams. Three such tasks were conducting discussion sessions with consumers and carers, the development of a vision statement and programme logic, and developing a proposal relating to research methodology for the project. The following quote illustrates this process in relation to planning and running the discussion groups:

I reckon one of the biggest defining moments was the preparation for the discussion groups, where both teams were independently developing protocols and strategies for the discussion groups... all of a sudden, things started to come together and we did role plays, and all of a sudden, it wasn’t two independent teams working out things: it was a group sort of backing each other up... and we were all as one... There was that feeling of ‘hey, we have accomplished and we’ve done it as one’, and to me, that was one of the real starts of the uniqueness of this project. (Consumer)

The task that the teams identified as being a cornerstone in the development of cohesion, and which helped to crystallize the common goal, was working on the teams’ vision statement and programme logic. The latter is a systematic, visual way to describe how a particular programme works, including the relationships among the resources available to operate the programme, the planned activities, and the results the programme is expected to achieve:

I think we have been working with a common goal in mind for quite some time, but I think it really came together around the development of the programme
logic. We worked on our values and we just really got down to tin tacks, and had to spell it out in absolute detail that we were all able to agree to. Coming up with that common vision statement was really an important part of that. (Carer)

As one team member pointed out, the process of developing the programme logic itself was testimony to the value of collaboration between the consumer and carer teams, and thus:

That is why the programme logic has become symbolic and a document that set up the direction for the whole project. (Consumer)

The vision statement: yeah, that was very powerful. (It was a) small number of words, but constructed in such a powerful way. (Consumer)

Another related task that helped to strengthen the bond between the teams was acquiring more knowledge, through training sessions, of research methodology. Building on this foundation, they were able to write a research proposal for the Department of Health, which spelled out the value of a combined quantitative and qualitative methodology. Both the development of the programme logic and methodology document yielded real benefits, not just in terms of re-establishing the direction of the project, but also the strength and confidence of the teams:

For us to be able to get up and do that stuff on qualitative methodology, and exploring values and putting together the programme logic, we’d sort of got to the point where we were building confidence in our own skills in this area, and that enabled us to really insist, yeah, we can do this . . . and show them what we’re made of. (Consumer)

Regular training sessions
As discussed earlier, the training sessions had a valuable role in providing a way of working together on challenges as they arose, and facilitating an ongoing relationship characterized by warmth and mutual sharing. This was important not only in terms of working on project tasks, but also on the personal level, as can be seen in the following quote:

The opportunity to meet regularly, usually through training, was really a good way for us to be able to gradually get to know each other, work together, and . . . it was through that forum that we were able to also then work on the values and the programme logic and the methodology. (Carer)

I thought it was a really good . . . team-building exercise . . . and that concept that we’ll meet at your place, you come over to our place, and what are we going to eat? and all that. (Consumer)

The team meetings also helped the project teams maintain or reactivate momentum. It was not always possible for the two teams to meet together on a weekly basis, especially at times when both project teams were busy running discussion groups with consumers and carers at the pilot sites across the state of Victoria. As one project worker said:

It (regular meetings as teams) was more scattered; it wasn’t necessarily a weekly team meeting, and I think it took a little while to get that momentum going again. (Carer)

The facilitator’s experience working with pilot projects meant that she understood the associated demands and could provide sensitive support through the training meetings. Moreover, she was also a member of the Survey Working Group, and understood the nature of the challenges of working with other partners on a project, such as the Department of Health and participating pilot sites. Thus, as one team member said:

(The facilitator) was privy to conversation with the Department of Health, so it felt like . . . we could do reality checks with (the facilitator), which was, I think, incredibly important. (Carer)

Valuing fun and humour
Both teams valued opportunities for sharing fun in the course of the project work, as can be seen in the following exchange between the facilitator and team members:

Do you know, one of the bits of glue is definitely the humour? (Facilitator)

You have a lot of fun, you have a laugh, all of that, but at the same time, there is that real professional ethos there that (the work) is done right. (Consumer)

DISCUSSION
The findings from the discussion between the consumer and carer research teams confirm the importance of a number of the issues previously identified in the limited available literature as important for successful collaboration in mental health research. These include having appropriate training, the opportunity to develop trust and respect, a supportive infrastructure taking account of job stresses, considered planning processes, and having a supportive culture.
During the course of the C&C Experience Project, the consumer and carer research teams demonstrated that they had the research and other skills necessary to meet the demands of a large-scale evaluation project. The regular needs-based training, which they undertook together, updated their knowledge to conduct their work in an efficient and effective manner. This is consistent with the position adopted by Horsfall et al. (2007), who posited that limitations in consumer (and carer) education and training in research can be remedied by adopting an ‘adult teaching–learning approach’ (p. 1205). The training also went beyond simple information and support provision, and ended up providing essential support, as the following statement from one of the teams illustrates:

(The training) is about the project process and its impact on us as project members, and I think we would have fallen in a heap if we didn’t have that... opportunity to process what was happening as team members. So that’s been vital, I think, to the survival of the teams (Lynne 2007, p. 39).

Thus, ongoing training provided both skills training, as well as responsive and recurrent support for the wellbeing and work safety of the research teams, supporting Delman and Beinecke’s (2005) assertion that consumers and carers can take a lead role in the evaluation of mental health services if they are themselves provided with resources and support for training and infrastructure.

The findings from this dialogue between the consumer and carer teams highlighted the importance of mutual support to overcome the ups and downs of the pilot project in a challenging, uncertain, and evolitional environment. Because of their lived experience as consumers and carers, including their experiences of stigma and discrimination within mental health services (National Mental Health Consumer & Carer Forum 2010), they shared the same enthusiasm and energy to achieve the desired outcomes of the pilot project, which helped sustain them during difficult times in the project. In addition, a common vision and clearly-articulated set of values guided their work and assisted the teams when the direction of the project became unclear.

The consumer and carer project teams worked closely together, but were separate at the same time because they were employed by two different organizations. Sharing their experiences and expertise and getting to know each other as colleagues and friends was an especially important component of building trust and respect, as was creating opportunities to have fun together. They also had differences; most importantly, the need to have their own space to which they could return for debriefing, and to regain strength after challenging times (Wadsworth 2004). Nevertheless, they were able to come together as one team to provide mutual support to each other when there were challenges and difficulties. In addition, the structure of the project allowed them to attend to both their separate and joint agendas (Goodwin & Happell 2006). Thus, despite some differences in perspective, they were able to maintain ‘respectful engagement’ (Wells & Jones 2009) and a constructive working relationship.

While this discussion focuses primarily on the relationship between the consumer and carer project teams, supportive and committed leadership was also vital to the two teams and took account of the need to provide the teams with a strong base from which to engage with other partners where the power balance had the potential to be inequitable (Horsfall et al. 2007; Wadsworth 2004). On the whole, the management of the two peak bodies, the Department of Health, and the participating pilot sites all provided strong support to the project teams.

This reflection on the experiences of the consumer and carer teams makes a significant contribution to the literature regarding consumer and carer participation in mental health care, particularly within Australia. It is the first time in Australia that consumer and carer research teams have worked as partners in the mental health field.

It is important to acknowledge the limitations of this analysis, which given the small size of the research teams and the qualitative methodology adopted, means that it is not possible to generalize the findings to other consumer and carer research teams. However, it is hoped that it will stimulate further work of other consumer and carer research teams and provide some guideposts for further partnerships in mental health.

The consumer and carer teams became a united force during this innovative pilot project. They benefited from the provision of targeted training, regular opportunities for team building, independent work bases, and strong support and belief at leadership levels, and have since worked successfully together on several more quality-improvement projects. The future is promising in Victoria for consumers and carers working together for mental health system reform and improvement.

Prior to the commencement of the C&C Experience Project, a number of stakeholders agreed that the prospect of engaging consumer and carer research teams to investigate experiences in mental health carried with it a certain degree of risk. Would the teams have the necessary skill to carry out the research and negotiate with powerful stakeholders? Would they be able to work together, or would they be side-tracked by conflicting agendas and work methods? This analysis has identified

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the key elements that contributed in making both the process and outcomes of the C&C Experience Project so successful: training that was targeted to need, regular opportunities for formal and informal team building, independent work bases, and strong support at the leadership level.

REFERENCES


CONSUMERS AND CARERS AS RESEARCH PARTNERS


