

Pathfinders: New Research on Consumer Participation in Mental Health

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A consumer-based research project suggests that consumer consultant projects have been very effective agents for innovation and change in Victoria's Area Mental Health Services - probably more than any individual stakeholder could have expected. This has been despite considerable barriers, including a severe shortage of funding and resources, stresses on consumer workers in a difficult role, and problems gaining acceptance within some service cultures. This article describes some of the findings from this research project.

Aims

The Pathfinders project was undertaken as part of my Bachelor of Arts in Community Development. It aims to help in building a much-needed information base in relation to consumer participation and consumer consultant-based advocacy work in the mental health field. The project aims to provide something of an overview of progress so far and identify possible action strategies to strengthen and enhance these projects.

Consumer consultants are diverse and multi-skilled workers with personal experience of being consumers (or service users or patients) of mental health services in Victoria. They are employed to go "back into the system" to facilitate a range of consumer participation activities, aimed at enhancing consumer rights, empowerment and gaining more say for clients in their own treatment, as well as other consumer led improvements in mental health services.

One of the motivating factors behind this research project was that there had been many and varied accounts of the consumer consultant projects at Victoria's 22 Area Mental Health Services. These accounts seemed somewhat sporadic, often contradictory, lacked a wider overview, and it was often difficult to draw thematic analysis or learning opportunities from them. As a consumer consultant, I was determined to help provide a strong information resource for these projects, and it also seemed important for it to be largely consumer-generated.

As with much of the good new models and innovative projects going on in the health and human services field, much of this work tends to go under-documented. The Pathfinders project aims to address at least some of the aspects of this problem.

Methodology

A key factor to this research was having an agency placement with the peak consumer group, the Victorian Mental Illness Awareness Council (VMIAC), which over a long period, has helped put consumer needs and wants on the map.

The project was partly guided by two meetings and further telephone contact with a very experienced Critical Reference Committee comprising five consumers and two service provider staff.

The interviewees mainly emerged from informally "putting the word out" for participants. Semi-structured individual interviews were held with five consumer consultants/advocates, two service provider managers, and two senior service staff. A further 11 consumer consultants took part in a workshop session. Three case studies with three very experienced consumer consultant/ academics were included to illustrate issues involved with working as educators of clinicians, gaining financial control of projects, and equipping consumer consultants with skills for their role.

The research followed a structure, or progression addressing problems and solutions. Participants were asked:

- * to identify achievements in their projects;
- * about what factors had helped or hindered the results;
- * to speak in more detail about problems, barriers and constraints encountered;
- * to identify possible causes of these problems and by inference try to generate some possible solutions; and
- * in the event further changes were possible on the ground, what new participation developments or projects they might visualise or hope for.

The Pathfinders project also included a literature review that made considerable use of consumer-generated material, part of which traces the history, achievements and potential of the mental health consumer movement.

The Pathfinders project found substantial and widespread evidence of much progress, and many success stories, over the past decade or so for consumer participation in mental health services, despite a lack of resources and other significant barriers.

Funding and support was described as having many direct and indirect effects such as shortage of paid hours for consumer consultants and sitting fees for other active consumers for advisory groups or projects, and low rates of pay. consumer consultants, who may be part disability pensioners, can find themselves at risk of Centrelink's "poverty traps." Some local projects reported a shortage of necessary office equipment, such as computers, or even a dedicated workspace. Published
Funding and Resources

Materials such as newsletters, books, and flyers were sometimes poorly finished and lacking appeal, due to inadequate printing budgets. However, the research shows how consumer consultants and active consumers made limited resources stretch a surprisingly long way.

Severe funding limitations for VMIAC have restricted its ability to provide support, coordination, training, and government liaison services for consumer consultants in the field, despite many heroic efforts. The research found that many consumer consultant respondents warmly embraced the idea of consumer consultant projects having a central "nucleus" or strengthened support base, which could well be within VMIAC.

A more immediate and critical concern for VMIAC, is the difficulty of accessing adequate funding, especially "developmental" type funding. This has meant that VMIAC often finds itself trapped within a reactive role rather than having the resources to do more agenda-setting research, policy development or systemic advocacy work. Much of the existing resources and staff time are necessarily used for individual advocacy for consumers having trouble in the system - another chronically undersupplied need. There has also been a lack of funding for public events, conferences, public relations campaigns, or publications like those of group with more resources.

A number of suggestions came out of the study including:

1. The need for more consumer consultants to be employed in the Psychiatric Disability Rehabilitation and Support (PDRS) services in addition to the larger coverage that currently exists in clinical Area Mental Health Services. PDRS services also want dedicated funding for this purpose.
2. VMIAC could establish a Consumer Information Library and Clearing House, including on-line access and with enhanced services for consumer or other researchers. At present the large collection of print materials is languishing, with insufficient staff time to look after it.
3. The establishment of a consumer publishing unit that could publish and distribute consumer-generated materials. This valuable but often forgotten "grey literature", which often lacked organised circulation and struggled to gain profile alongside the professional publications.
4. The need for services to recognise the benefits of, and seek to provide opportunities for, consumers to be actively involved in education and training of service staff.

Consumer Consultants

The role of consumer consultants also comes with inherent complexities and difficulties, and they face a number of barriers in their work including:

1. Consumer consultants stretching commitments way beyond allocated paid working hours, putting themselves under heavy stresses that is unhelpful or hazardous to their mental and physical health.
2. Larger allocation of project working hours, larger operating budgets, and sufficient money to pay consumer members serving on committees or special projects may ease this burden and allow for more job-sharing between consumers at local services.
3. Lack of administrative support or adequate office space and equipment can be a problem at some services. Some consumer consultants spoke of time they could be using for specialised consumer-knowledge work being filled with generic tasks..
4. Working in isolation from other consumer consultants and lack of effective support or professional supervision It has been suggested that having consumer consultants working in teams should be the norm.
5. Consumer consultants and representative need access to high quality and relevant training.
6. Consumer consultants being denied access to actual clinical meetings (such as handover or case reviews) can, according to some, hinder their ability to get to know how the services work. If consumer consultants had access to such meetings (even on occasion or with special conditions attached), this could allow consumers to have a greater "say" in relation to the quality and effectiveness of treatment, and support methods within services.
7. Difficulty gaining direct access to service consumers through mail-outs of surveys - or perceptions that clients might be reluctant or discomforted to be approached in waiting rooms - means that staff, such as case managers, could play a key role in helping build some of these bridges, and some of them are willing and able to do so.

Factors such as these have meant a high attrition rate from these projects over time.

On a more positive note, consumer consultancy can be viewed as a new hybrid form of work, which is becoming much more of a mainstream feature of the way mental health area services manage and provide services. Consumer participation is becoming an increasingly accepted and expected part of service planning, development and quality improvement.

The very role of the consumer consultant, in terms of representing consumers as the prime stakeholder group, can be argued to have a certain built-in credibility - because of shared experiences and knowledge with the subject group - and have made it their concern to gain a studied understanding of some of the issues at hand.

Service Cultures

It is interesting to note that, perhaps contrary to expectations that funding and resources would be the biggest barrier; the most significant determinant to success in consumer participation projects was identified by consumers as the area of staff attitudes and service cultures. A major determinant of success was said to be:

'..whether services would listen to and recognise the value of consumer perspectives - or constantly act in ways which frustrate the attempts of consumer consultants and reps to try to discuss often difficult issues and get changes made.'

Some consumer consultants spoke of negative or tokenistic expectations or responses towards their projects and a few said the services where they worked seemed "resistant and entrenched" against consumer perspectives, with some maintaining a strong "us and them mentality" and leading to frustration for consumers.

However, the levels of support varied across Victoria and in probably a majority of local Area Mental Health Service; at least some staff and managers can be considered supporters or "allies" for consumer participation.

Some of the suggested means for making services more consumer-friendly, which come from consumers interviewed include:

- * consumers being allowed greater control over the development of their own treatment plans;
- * consumer knowledge being used to enhance and widen various debates for improving services;
- * consumers and staff being more aware of the consumers' rights within the system;
- * services becoming better equipped in providing services to diverse groups in the community, including people from culturally and linguistically diverse backgrounds, youth, people with dual-diagnosis (mental illness and drug problems) and other needs groups;
- * building up over time a capacity for consumers to be involved with actual service provision, culminating in employing consumers working on treatment teams (with a client's informed consent) as Peer Support Workers or Assistant Case Managers, as happens in some services overseas;
- * staff adopting more self-reflective practices in communicating with consumers - important in both information provision and interpersonal style; and,
- * encouraging acceptance of consumer participation as an integral part of service planning and operation.

Emerging Change

Interestingly, over the ten-year period in which the relationships between consumer consultants and services became closer and more trusting in many localities, projects have been able to become increasingly developmental and work more within the framework of partnership.

This contrasts to the more rights - based approach to advocacy that was, probably understandably, a more predominant mode in the earlier stages. The quality of relationships has varied widely, according to many informants to the study, and there are still areas where there are problems or fluctuations, and other areas where the work is powering ahead.

The workforce itself has really changed in many ways. One of the standout findings, perhaps the largest trend noted within the research, were the many reports indicating much improved communication and information provision practices of mental health services staff. Many service provider staff are perceived as being more consumer aware and having more self-reflective practices. There also seems to be a much more intensive rigour in terms of intellectual engagement, communication skills, ethical values, empathy, resourcefulness, resilience, perseverance, and more.

There is also some evidence emerging that services which put a high premium on consumer participation - such as the award winning initiative of placing trained consumer representatives on staff selection panels in Melbourne's Northern Area Mental Health Service - may be more likely to attract high quality, motivated and consumer-aware staff, could produce better morale and an enhanced service environment for both clinicians and consumers, and could more readily move towards a therapeutic partnership, which could also involve carers and other services in the community.

Factors for Success

The research found there were some factors that active consumers and service providers identified as promoting success in projects. These included the project:

- * being presented in ways perceived as constructive;
- * making a compelling case for areas of change or improvement;
- * having an evidence base strongly tied to consumers' experiences and reflections;
- * being readily translated into practical actions, with consumer service dialogue informing every stage of implementation;
- * being pro-active, seeking to bring genuine improvement in services and better outcomes;
- * being respectful of persons, and the contribution all stakeholders can make, avoiding stereotyping others' positions;
- * aiming to build communication and new understandings, rather than being unduly adversarial, hyper-critical and blaming;
- * staying open to new ways of conceptualising issues, allows thinking "outside the square," going "back to the roots" of issues and rebuilding from the ground-up;
- * being conducive to building partnerships for creatively working towards change; and,
- * building on and enhancing strengths, while seeking to minimise problems in the system and resultant problems.

Beyond that, the effectiveness of consumer participation activities largely seems to revolve around:

- * the quality and authenticity of the knowledge emerging from consumer experience;
- * the ability of consumer representatives to draw parallels, demonstrate relationships, and extract principles and practical strategies for change and improvements within service provision; and
- * skilfully applying the consumer knowledge through various processes involving problem solving, gap and opportunity identification, development of new and more effective service models, treatment methods, community linkages, education campaigns, community development projects etc.

Conclusions

One finding that has crystallised for me is just how well accepted consumer participation programs have become, how deeply influential they have become in service planning and development, and the whole culture within many services.

An important part of this is to have a number of active consumers on hand who become skilled in making problem and solution analyses in virtually any meeting or forum they find themselves.

It was also clear that the consumer consultant model could have wider applications across other types of services, - such as advocacy within disability, health, and primary health services. Many consumer advocates in the mental health field are proud of the achievements so far in developing the consumer consultant model and how this consumer participation, combined with other elements of movement building, could make a difference within policy making forums, in services, in communities, and people's lives.

Like so many mental health active consumers (including people doing many and varied roles in the consumer movement) I am proud of the way that people with mental illness were working away at campaigning for social change, using new methods and strategies that could be adapted by other groups.

As a result of this research, a report, "Pathfinders - Consumer Participation in Mental Health and Other Services: Evidence - based Strategies for the Ways Ahead" was written. The report identifies 18 key result categories in consumer consultants projects and lists 55 action strategies for strengthening consumer participation projects throughout Victoria. Other sections seek to identify factors believed to have promoted success; identify barriers and constraints facing consumer participation projects and their possible solutions; and provide a short history of the consumer movement.

* To order copies of "Pathfinders - Consumer Participation in Mental Health and Other Services: Evidence Based Strategies for the Ways Ahead" (96 pages), contact Allan Pinches at: PO Box 85, Kingsbury, Vic, 3083 or alpin@alphalink.com.au Cost: \$35 per copy including postage. GST does not apply.

I undertook this project in part fulfilment of my Bachelor of Arts in Community Development at the Victorian University of Technology, from which I graduated in 2004. I have been an active consumer for more than two decades and a consumer consultant for eight years. As a former journalist, I have become a well known writer and speaker on mental health consumer issues; many of my articles can be seen on my website at <http://www.alphalink.com.au/~alpin>

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