

Doing peer research



The experience
of a Tasmanian community
service organisation

JUNE 2012

Teresa Hinton and the Peer Research Advisory Group,
Anglicare Tasmania

Doing Peer Research: the experience of a Tasmanian community service organisation

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Anglicare retains ownership of the research reports produced through this project. However, the research findings, conclusions and recommendations developed by the Peer Researchers and identified as such in this report are their work. Those sections attributed to the Peer Researchers should not be attributed to Anglicare. Any errors in the sections authored by Anglicare research and policy officers are the responsibility of those authors and should not be attributed to the Peer Researchers.

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Executive Summary

This report describes Anglicare Tasmania's first peer research project, what we did and how we did it. It also describes the outcomes for those involved – for peer researchers, for programs and for the organisation as a whole – and draws out key lessons for conducting future peer research. The project was funded by Anglicare's mental health stream and facilitated by Anglicare's Social Action and Research Centre in partnership with people accessing community-based support programs for people with mental illness in Southern Tasmania and the staff of those programs.

Six people from the programs were recruited to form a Peer Research Advisory Group to explore the potential for consumer engagement in services. The Advisory Group developed a research question, designed a sampling frame and questionnaire, undertook training in research methods and interviewing techniques, conducted telephone interviews with fellow service users, analysed the data, and made recommendations for service improvements which they then presented to program staff. The Group wrote up the research findings and made a DVD about their experiences. The process was evaluated by Anglicare's research team. The key findings were that:

- The peer research project produced valuable information about service users' experiences in accessing and using the programs and how to encourage people to participate in the design and delivery of services. Using peers as researchers encouraged a freer flow of information and insights from consumers.
- Being involved in the Peer Research Advisory Group was a positive experience for members in terms of personal satisfaction, being valued and respected and an increase in self-esteem and confidence. All six members felt empowered to do more, including being more confident in voicing their opinions, participating in future projects, seeking employment and/or training and getting involved in Tasmania's mental health consumer movement.
- For programs and program staff the project provided valuable findings and insights about program delivery and consumer engagement activities. In addition staff were keen to emphasise how involvement in the project had benefited members of the Peer Research Advisory Group and promoted their recovery.
- The project was not without its challenges, which included working within a small budget, the mechanics of facilitating the group, liaising with programs, meeting support needs and time constraints. However it has generated recommendations for improving services and consumer engagement activities as well as lessons which could usefully inform future peer research projects.

1

Introduction

by Teresa Hinton, Research and Policy Officer,
Anglicare Tasmania

In 2010 Anglicare Tasmania began a process to build on current consumer participation activities by developing an organisation-wide consumer engagement strategy led by its Social Action and Research Centre (SARC). As part of the development of the strategy a number of demonstration projects were set up to highlight different approaches to involving consumers in the design, development and delivery of services. One of these demonstration projects was about involving consumers in research that contributes towards developing services. This became the Peer Research Project and it ran for a six-month period from August 2011 to January 2012.

This report describes the project, the research undertaken by consumers and the outcomes for the consumers involved, for staff and for Anglicare Services.

1.1 Background

Anglicare operates community-based support programs for people experiencing mental ill health: the Personal Helpers and Mentors Program (PHaMs) and the Recovery Program. These programs support people accessing the service in their recovery journey. There are three PHaMs teams in southern Tasmania, covering Sorell/Tasman Peninsula, Brighton and the Central Highlands and most recently in Greater Hobart, and one Recovery Program for Southern Tasmania. Staff have a range of qualifications, skills and backgrounds and some have experienced mental illness and living in recovery.

These programs have been exploring ways of improving their client satisfaction data as well as mechanisms for involving people who access services in engagement activities. A decision was made to capitalise on these opportunities by developing a partnership between the programs, SARC and current service users to explore these issues through peer research.

1.2 The peer research approach

Consumer participation in research is understood as the process of involving consumers not only as subjects of research but in setting the research agenda, designing data collection tools, undertaking data collection, analysing and interpreting research findings and disseminating the results. It is emerging as a popular form of community-based research with members of the target population trained to participate as researchers. It is a recent development in mental health system reform (Ning et al. 2010) where consumers are invited in as partners to work alongside professional researchers and/or as researchers in their own right (Wallcraft et al. 2009). They can be called 'peer specialists' or 'peer researchers', 'experts by experience' or 'service user researchers', and they bring their personal experiences openly to the task of research. Academic user researchers do the same but also have research qualifications.

Peer research is seen as having positive outcomes and informing many different strands of services including entry points, relationships between staff and people accessing services, highlighting good practice and improving service quality. In particular it can:

- enhance the quality of data collected by providing insights and consumer perspectives which would not normally be identified in more traditional research;
- offer positive role modelling for other people using the service;
- ensure the expertise of lived experience is incorporated so that those most affected by a problem can become part of imagining new solutions;
- promote capacity building for those involved by providing opportunities to acquire and build new skills, develop confidence and self-esteem and build recovery (Flicker et al. 2010);
- provide an effective mechanism for getting people involved in developing services;
- support cultural change in mental health research and system reform; and
- assist the recruitment of particularly marginalised sections of the population as research participants.

The Wellesley Institute (Roche et al. 2010) has outlined three different models of peer research:

- the advisory model where peers play an advisory role on steering or advisory committees;
- the employment model where peers are research staff on studies and involved in tasks like collecting data; and
- the partner model where peers are partners or leaders in all aspects of the research.

Anglicare committed to a partner model with consumers involved from the beginning and provided with training to shape the research, conduct it, do the analysis, write up the findings and participate in the dissemination.

There is a limited literature on what constitutes good participatory research (Roche et al. 2010; JRF 2000) but from what there is it is possible to highlight the key ingredients of project design critical to success. Good practice in community based peer research requires:

- consumers to be actively involved with all stages of the research including the initial research design and planning, data collection, data analysis and writing up;
- flexibility to change the project as the need arises and to adapt the model to provide skill development and employment opportunities;
- the researchers overseeing the process to consider themselves to have a facilitative rather than expert role but to motivate, drive and support;
- an acknowledgement that it is impossible to collect data untainted by our own values, beliefs and involvements particularly when using a peer approach and that consumers should be encouraged to impose their own expertise, experiences and emotions on the process;

- widely advertising the project to ensure a diverse group of peers have the opportunity to be involved and clarity about what the work will entail and the level of commitment expected;
- peer researchers to be able to define themselves and their role within the project – not all individuals have to be involved in all research tasks. But roles and responsibilities must be clear to minimise the potential for miscommunication;
- an acknowledgement that conducting interviews may raise potentially sensitive issues for peer researchers about their own background and experiences. This means they should be provided with appropriate mechanisms for ongoing support, supervision and debriefing and advised about the implications of disclosing their own circumstances to participants and others;
- appropriate training and reasonable remuneration; and
- the careful management of expectations of what is involved. This should include thinking about appropriate wrap-up activities and a sense of closure so that people can disentangle from the project.

In addition the process of participating should be fun and enjoyable.

These aspects of good practice were acknowledged and written into the design of the project from the beginning.

1.3 Aims of the research

The Peer Research Project aimed to:

- pilot the peer research approach and comprehensively document, monitor and evaluate the process and outcomes;
- undertake peer research to explore the perceptions of consumer engagement among people who access Anglicare’s mental health programs; and
- showcase the learnings across Anglicare programs and services.

It was anticipated that the outcome would be a range of ideas about how to better engage people who access services in the programs, as well as a group of people who potentially have benefited from being involved and might want more involvement either within or outside Anglicare. In addition the project would also result in information about how it had impacted on consumers, staff and services, the costs involved and how replicable it might be in other Anglicare programs. It was recognised that throughout the project, due to the pilot nature of the work, it was essential to avoid being too prescriptive beforehand and there would be a need to deal flexibly with issues as they arose.

1.4 The research process

The Peer Research Project represented a partnership between the Social Action and Research Centre (SARC), peer researchers and the PHaMs and Recovery programs. SARC provided overall facilitation of the process and inputted research expertise, training and mentoring for the consumers involved; the consumers undertook the work; and staff encouraged their participation, provided on-going support and assisted their transitioning out of the project.

Undertaking the research involved a number of stages which are documented below.

Involving staff

An important factor behind successful involvement in consumer engagement activities is staff support, understanding and enthusiasm. The SARC researcher attended a staff professional development day to explain the Peer Research Project, its aims and intended outcomes, provide examples of how this kind of approach has worked elsewhere, outline possible support implications for staff and answer any concerns or question.

Recruiting consumers

A flyer was designed and distributed to people accessing the programs to elicit expressions of interest in the peer research project and to invite people to an introductory session to explain in more detail what the project involved (see Appendix 1). The flyer aimed to be easy to read, to sound fun and inviting and to explain the role and time commitment required. The introductory session outlined the nature of the project and the timeframe. It discussed the budget for the project and presented a flow chart of a typical research process. Lunch was provided and travel expenses reimbursed. Two levels of involvement were outlined. These were:

- as peer researchers involved in refining the research question and methods, basic training in research skills and interviewing techniques, collecting and collating data, analysing it and producing recommendations. A position description was developed (see Appendix 2) and those interested asked to produce a brief written statement about how they met the selection criteria, with an emphasis placed on communication skills, empathy and respect rather than formal qualifications. It was anticipated that two peer researchers were required to conduct interviews/collect data;
- as a member of an Advisory Group for the research in order to ensure than anybody who expressed an interest could be involved in some way. The Advisory Group were responsible for guiding the project and providing their advice, support and expertise in refining the research question and methods used as well as interpreting the findings (see Appendix 3). They also received basic training in research skills and supported the peer researchers in refining their interview techniques.

Nine people attended the initial introductory session and seven of these expressed an interest in being part of the Advisory Group and four in being peer researchers. One person subsequently withdrew and a further two decided to be members of the Advisory Group rather than peer researchers. This left an Advisory Group of six people including the two selected peer researchers.

As the project evolved so did the roles of peer researchers and other members of the Advisory Group, depending on people's backgrounds, experiences, interests and skills. So although the peer researchers were solely responsible for conducting interviews and collating the data, other members of the Advisory Group volunteered to write up the research findings, present the findings to program staff and consider the design of the front cover of the research report.

The Advisory Group met regularly over a six-month period from September 2011 to January 2012 on Anglicare premises.

Reimbursement

Reimbursing the Advisory Group for their time and covering travel costs was important both to ensure that people were able to attend meetings and to demonstrate the value put on their contributions. It was also highly valued by members of the Advisory Group, who were reimbursed an hourly rate for their input into the research with additional reimbursement for travel expenses. Providing reimbursements involved discussions about how they would be processed through the financial systems of the organisation and how to ensure that there were no insurance issues for consumers undertaking research tasks on Anglicare premises.

Developing the research question

Although the research area was outlined prior to establishing the Advisory Group – the perceptions of consumers about engagement – clear research questions had yet to be defined. This was the first task of the Advisory Group and they discussed the most important issues for them as users of the programs and the kinds of issues they would like to research. These included how to better promote services so that people have accurate information about them as well as how people benefit from using these programs. A decision was taken that the research questions would be:

- What is the best way(s) to involve people accessing services in the design and delivery of services?
- How can we empower people to want to be involved?

Answering these questions entailed exploring people's experiences of getting in touch with and using the programs (or giving them the opportunity to feedback about access to and the benefits of the programs) as well as their views about and experiences of being involved in the design and development of services.

Designing research tools and sampling

The Advisory Group were involved in discussing different survey approaches and then in designing a telephone questionnaire that included both closed questions in order to generate quantitative data and open-ended questions to generate qualitative data and to explore experiences in more depth. The questionnaire included questions about people's experiences of accessing the programs, experiences of using the services, examples of involvement activities, views about involvement and basic information about the respondent's age, sex, length of time with the service, employment and living situation. It was proof read by a member of Advisory Group. The questionnaire was piloted by the Advisory Group to find out how well the questions worked, the time it took to administer, whether interviewer instructions were clear and whether any changes to the layout were required. An information sheet (see Appendix 4) to recruit people accessing services into the survey and a consent form (see Appendix 5) were designed.

The Advisory Group considered data about the age, sex, location and length of contact with the service among the current population of people accessing services in all four program teams. In order to recruit a sample broadly similar to the people using the programs they developed a sampling frame to guide recruitment to the telephone survey:

- 3 men and 3 women from each team with
 - at least 1 aged under 30 and 1 aged 50+
 - all to have used the program for more than three months

There were concerns that whether people lived in a rural or urban area could affect their experience of programs. Recruiting from the four teams would ensure a mix of locations.

Support workers in the teams were responsible for recruiting people accessing services into the survey. The Advisory Group were concerned that support worker bias should not impact on who was recruited to the survey – i.e. the tendency to recruit those who are most articulate or most likely to agree to participate. To this end staff teams discussed ways of compiling a more random sample. This involved using a list of people accessing services from each team and another team choosing who should be approached to participate according to the sampling frame. Advisory Group members also participated as respondents in the survey. This meant potential respondent numbers of up to 30 interviews or approximately one fifth of the total number of people using the programs.

Training

Providing relevant training was seen as critical to the success of the project and the process of doing research was broken down into concrete but manageable steps. Most training was task specific, integrated into the work, focused on the duties of the Advisory Group and peer researchers and undertaken ‘on the job’. It was spread out over the life of the Advisory Group and included opportunities for practice and role play. Training involved:

- talking about the concept of consumer participation and the different ways in which people accessing services can use their experiences to help develop services;
- discussing current mechanisms being used by the programs to get feedback from people accessing these services;
- key research terms;
- research ethics, including why this is an issue, informed consent and Anglicare’s approach to informed consent, anonymity and confidentiality, data protection and storage, self care and safety for the researcher and the interviewee;
- research methods, including the difference between quantitative and qualitative data, importance of using the right research method to answer your research question, in-depth interviewing, focus groups, participant observation and surveys (telephone, self completion, online, mail);
- interview techniques – what makes for a good interview, active listening, remaining neutral, how to handle disclosures or emotional distress and trauma, recording data and practising interviewing skills through mock interviews, role plays and dealing with difficult situations; and
- data analysis, writing and presentation skills.

Training was delivered either by the researcher facilitating the project or by guest speakers from the University of Tasmania.

Data collection and collation

The peer researchers carried out a series of telephone interviews from Anglicare offices mainly over a period of two and a half days. Responses were recorded verbatim as far as possible and researchers used speaker phones to make it easier to take notes during the course of the interview. Interviews took between 15 and 30 minutes to administer and respondents were reimbursed with a \$20 voucher for their time which was delivered to them by post.

The peer researchers collated both the qualitative and quantitative data.

Data analysis and writing up

The Advisory Group explored the data and used a thematic analysis to highlight patterns and themes. They discussed the key messages from the research and what these might mean for improving services.

A member of the Advisory Group wrote up the research findings and the researcher wrote an introduction and conclusions. All members of the Advisory Group were involved in identifying and refining the recommendations which grew out of the research and inputted into the design of the front cover of the report.

Presentation and dissemination

The research findings were presented to the PHaMs and Recovery Program staff by the Advisory Group and the recommendations were discussed. The findings and recommendations from the research were distributed to all service users who had participated in the research and were also made available to other Anglicare services.

A DVD about the Peer Research Project was developed with the assistance of Anglicare's communications office, the Advisory Group and program staff. The DVD described the peer research project in order to disseminate the process and outcomes to other Anglicare services and to consider how transferable it might be to other programs.

Accreditation

Although none of the members of the Advisory Group had specific research training, they did bring a wealth of experience and different skill sets from previous employment, study and academic training. All members of the Advisory Group received a certificate of attendance for their involvement.

In addition, and because Anglicare is a registered training organisation, Anglicare's training coordinator explored ways of linking the research training with vocational training pathways. Advisory Group members were offered opportunities to undertake and be assessed for a range of units from Community Services Work Certificates II, III and IV to formalise the on-the-job learning in the Peer Research Project.

Evaluation

In order to comprehensively document the impact and outcomes of the Peer Research Project and assess its transferability to other Anglicare programs an evaluation was undertaken at the end of the life of the project. This was conducted by a SARC researcher who had not had any previous involvement with the project. It entailed

telephone interviews with members of the Advisory Group and discussions with program staff to collate their views about the costs, benefits, challenges and outcomes, identify the key learnings for other services and explore how the process might be improved in the future.

The results of the evaluation are documented in section 3 of this report.

Costs

The budget for the Peer Research Project was \$5,000. This covered all reimbursements to members of the Peer Research Advisory Group and the production of a final report. It did not include SARC facilitation of the project or training for Advisory Group members.

1.5 Limitations

The Peer Research Project involved conducting a piece of mainly qualitative research with a small budget based on a number of telephone interviews. This meant there were factors which limited the scope of the research and imposed some methodological constraints.

Firstly the Peer Research Advisory Group were concerned about the representativeness of respondents in any survey and how far they might be considered to be broadly representative of the total population of program users; for example only speaking with those who are well enough or articulate enough to participate. In order to address this concern the sample was collected randomly within a loose sampling frame rather than workers approaching those considered to be well and/or more articulate. This meant that those invited into the survey were possibly less well and less willing to participate than if workers had chosen individuals themselves. One team had to approach a number of individuals before people agreed to take part in the survey. This slowed gathering a sample to interview and may have impacted on their ability to engage with interviewers on the telephone and the quality of the data collected.

Secondly the choice of research methods – a telephone survey – was partly driven by the constraints of working within a small budget. Conducting telephone interviews can be challenging, particularly when seeking both quantitative and qualitative information, and relies on the interviewer's ability to quickly develop a rapport with the respondent. This may have impacted on the nature and quality of responses. A further challenge is the current prevalence of telephone surveys which most people now have experience of and a growing resistance to.

Lastly peer research faces the challenge of meeting concerns about reliability, validity and objectivity (Beresford 2003). Do interviewers ask leading questions? Are they able to be objective enough when considering the issues? These issues were addressed throughout the Peer Research Project through training and 'on the job' learning in order to achieve a reasonable balance between research objectivity and the added value of the lived experience.



2 The peer researchers' findings

This section summarises the research findings about access to and use of programs and consumer engagement activities. These findings are described in full in a report compiled for internal dissemination by the peer researchers with additional sections written by a SARC researcher. The peer researchers gave their report the title “You alone can do it, but you can’t do it alone”. The findings about consumer engagement activities written by the peer researchers are reproduced in this section in full.

2.1 Background information on the peer research

In order to explore peoples’ perceptions of consumer engagement and their views about getting involved they were first asked about their experiences of accessing and using the programs. Once they had provided this feedback the questionnaire contained a series of questions about their views and experiences of consumer engagement, their experiences of consumer engagement activities, what options for engagement activities they would like to see available and how to encourage people to get involved.

This section describes who participated in the telephone survey and summarises the research findings.

2.1.1 Profile of the survey respondents

Twenty-one people were interviewed during the telephone survey with representation from across the four teams. There were twice as many women as men and they were spread across the age spectrum from under 25 to over 60 years. The majority were long term users of services with only three interviewees using the services for under six months. This means that the Advisory Group were able to draw on the longer term experiences of people and fuller understandings of how services worked and the impact they had.

The majority were living alone (55%) with a further third (35%) living with their family and the remainder living with other people. None of the interviewees was working full time although 20% had part time or casual work and 30% described themselves as looking for work or as students. Fifty per cent described themselves as not in employment and not currently engaged in job seeking. This reinforces a picture of service users as commonly isolated, living alone and not in the workforce.

How do those who participated in the survey compare to the general population of people accessing the PHaMs and Recovery Programs? While there was an over-representation of women the age profile matched that of program service users generally. However an under-representation of people from more rural areas was taken into account when exploring the research findings.

2.1.2 Accessing and using services

Survey respondents were asked about their experiences of accessing and using Anglicare's PHaMs and Recovery programs. We asked them how they had found out about the program they were using, the process of making contact, their expectations and understandings of what the program offered and the information available about it. We also asked about their experiences of working with their support worker, the support they received to achieve their goals, the best aspects of their experience of the program and whether they had had any less positive experiences. They were asked to compare the Anglicare programs with other mental health services they had used and whether the programs could improve to better meet their needs.

The questions generated a wealth of information about people's experiences and indicated high levels of satisfaction with the way in which programs were delivered. They also highlighted aspects which could be improved. These issues were detailed by the Peer Research Advisory Group who then developed a range of recommendations about how to improve access to and contact with the PHaMs and Recovery programs.

2.2 Extract from "You alone can do it, but you can't do it alone" by the Peer Research team

2.2.1 Experiences of giving feedback

Respondents were asked whether they had ever given feedback or complained about services – not just Anglicare services but any mental health services they had used. Almost half (45%) of the respondents had given feedback, made suggestions and/or complained about a service. They had participated in surveys, on interview panels, directly in giving feedback to their support worker or team leader and a couple had made more formal complaints to services:

One complaint was about [other service]. They didn't please me at all. I've sat on the interviewing panel but that's all. I'd like to be asked to be more involved.

When I go into [other service] I always give feedback and sometimes put in a suggestion or complaints.

I can raise things with my worker. I did make a formal complaint at [another service] using the formal complaints procedure. I wrote a letter about an incident and there was a formal response and I was happy with that.

2.2.2 Perceptions of engagement

Whether they had complained or not all respondents considered that it was important to give feedback about services. Feedback was considered to be important, if not essential, to let the service know how they are going and make improvements where necessary:

Everyone has an idea of what is going on and to help improve programs.

I'm a great believer in thinking how can services improve unless we're prepared to give feedback. We are in the best position to give feedback.

How do you know if the program is working without feedback.

Although everyone thought it important to give feedback not everyone wanted to, and some voiced concerns about not feeling comfortable (16%). One person noted that the consumer movement in Tasmania is currently not strong so there are few role models and it means the onus is on individuals to give feedback. Any feedback needs to be voiced in a constructive way in order to change things for the better. People were motivated to give feedback by a desire to improve services and to help others:

To improve services and let people know there is help out there for those who need it.

We don't know how to improve services otherwise.

For sure I like to make a difference and help others in the future.

Most definitely. People complain about services but how can they improve if we don't complain.

2.2.3 Facilitating and supporting engagement

Respondents were asked for their views on the best way to encourage people to use their experiences to improve services and what the barriers and obstacles might be. And most had good ideas on these questions. They commonly commented on the need for people to be respected and listened to in order to encourage feedback:

Respect to people, this would encourage them to give their opinions.

By really showing them and encouraging them that what they say is important. They have been told what they think is not important for so long. You need to say we want to hear from you. We need to break that stigma down.

By research and surveys and feeling comfortable with a group. Encourage people and knowing people with mental illness get listened to and respected is very important.

Respondents saw workers as playing in key role in this and as one said 'I think it's up to the worker to encourage people'.

People were asked what activities should be available to encourage them to give feedback. Of the 21 people interviewed 13 thought that social activities such as barbeques, lunches and coffee get-togethers on a regular basis would be the best activities to encourage people to give feedback about their experiences. This would be an ideal way for people accessing services to get out and about, meet with their peers and enjoy a positive social experience without feeling threatened. Another suggestion was to set up an informal men's group to go for walks and have discussions:

Barbeques would be an ideal place for feedback as they have a lot of people there, everyone meets everybody.

Perhaps public speaking, telling other people, word of mouth.

Other people to share their stories. To be able to meet and be more social. Also to let them know they're not alone.

Making people aware that most services have complaint forms. Make sure clients have the

right to make complaints as well as compliments. Make clients aware that they have the right. Make them feel empowered.

We need a consumer advisory committee within the program. It makes absolute sense to have a consumer movement within the program. What better way to empower clients.

Overall it was apparent that a range of options should be available to suit different people:

Because we are all at different levels with our recovery one questionnaire for everyone won't work. My way is to contact the team leader. Others would be more comfortable with a questionnaire or a suggestion box. But they need positive feedback too. Some people are impaired cognitively by the medication and it's a struggle to understand the question and to formulate an answer and they need time to do this so a questionnaire they fill out in their own time might be better.

Respondents were asked about the barriers to getting involved and what might prevent them from engaging with services. Although one person said 'nothing whatsoever, I am not scared of anybody' others identified a number of obstacles with shyness, anxiety, lack of money or lack of transport being the most common. Some people said they would not feel comfortable to be involved or that they might not be well enough:

I haven't felt comfortable enough because I fear that they will be angry and I feel too anxious to feedback.

I am shy, I have panic attacks and would not be able to leave my house.

Depression is part of why I would not get involved.

My anxiety and depression and transport. I can't get on buses because it makes me anxious.

It's tricky but you must be able to be empowered to give honest feedback. When you are really sick you complain about lots of things and don't see the positives. You're depressed and life is shit. The services aren't fixing you and it's tricky for services to get useful information.

As one person said a key barrier is 'not to be asked in the first place'.

Another respondent described a crucial part of getting involved is both about feeling safe and feeling that your views will be taken seriously:

You need to feel safe. For me it's about self-stigma. My voice doesn't have the credibility it had before I was hospitalised and the reality is that when you're psychotic it might not be credible. So there is the fear that you won't be taken seriously. There is nothing worse than saying what you really think just to be shot down as this is what happens in treatment.

There is a psychological impact of being disempowered, having things done to you when you are really sick and if you have been in the system for a number of years and as you recover it's still scary every time in giving feedback. What if you're knocked down when you want to move forward?

A few respondents had attended the TheMHS conference with Anglicare staff. TheMHS is an annual international mental health conference for academics, clinicians, mental health practitioners and consumers. Respondents talked about how empowering this experience had been for them in both reflecting on their own situation and on broader issues about the mental health service system.

3

Evaluating the Peer Research Project

by Anita Pryor, Research and Policy Officer, Anglicare Tasmania

In order to understand the peer research process, its impact, outcomes and how to better facilitate peer research projects in the future, a member of the SARC team not previously involved in the project undertook an evaluation. The evaluation involved one-to-one telephone interviews with all members of the Peer Research Advisory Group to discuss their motivations for participating as well as their perceptions of the process and of the outcomes. The evaluation also involved conducting two focus groups with 16 program staff to gain their views of the process both in supporting Advisory Group members and as onlookers of the research process.

3.1 Views of the Peer Research Advisory Group

Motivations for getting involved in the project varied from simply wanting to be involved in 'something' and meeting other people, to wishing to support social change. They hoped they would be able to contribute their experiences and expertise and also help other people. Although the opportunity for accredited learning outcomes held appeal for some it was not a motivator for others:

I wanted to contribute knowledge from my personal experiences and maybe be able to help other people. Also, to gain friendship and companionship.

I wanted to contribute because there is a lack of people's voices being treated with credibility, especially those with mental illness.

Once involved, members of the Advisory Group were satisfied with the way in which the group was facilitated, how their skills and experience were utilised and the research training. Any difficulties and disagreements within the group had been sorted out through negotiation:

The facilitator said 'this is not my research, it's yours. You're the professionals in this area.' We felt empowered and felt good about ourselves and felt like we were able to contribute something.

We had quite a few sessions on what we'd be doing, we had a lot of say. We made up the questions, everyone had input.

Some members were particularly pleased with the way in which their time and costs were reimbursed and how that made them feel:

Me being a pensioner, means that every day I count the money, it counts. I would have done it for nothing but being paid makes you feel good – like you've got something to do. It's good for my self-esteem. It's like having a job, being paid to hear what I have to say, that's pretty awesome.

They were also happy with the outcomes of the research both in terms of the findings and the impact it might have on other people using the services and organisations, including Anglicare. They remarked on what the research had revealed about the isolation of people using services, how people accessed the programs, opportunities

for consumer engagement and the demand for more opportunities for social contact and activities. But they also commented on gaps in the research, how they would like to know more about aspects of respondents' experiences of the programs and how doing the research had raised a further series of questions for them which needed answering.

Advisory Group members felt that programs and the people accessing them would benefit from the research. These benefits included being heard, identifying where the problems are and making suggestions about how to fix them, providing Anglicare with a broader understanding and instigating real change. They emphasised that having consumers undertaking the work benefitted survey respondents and made them feel 'understood'. In this way the project illustrates how benefits may be multiplied by involving consumers in research relating to fellow consumers:

It [the research] values what they said, gives credibility to their voice and gives their voice some meaning and value. They've been heard. The negatives have been heard and taken seriously.

What did Advisory Group members feel they gained from being involved and what had the challenges been? Personal benefits included feeling respected, gaining self-esteem, confidence and self-worth, learning about different perspectives, feeling empowered, learning new skills, working with others and having the opportunity to help others. When asked what the most significant outcome had been for them responses were highly personal and included being able to talk about what has happened to them in their life, contacting an employment agency and gradually getting better:

I personally gained from researching something. I felt like a scholar. People were surprised and interested that I was doing research. I felt like we were achieving something, doing something to help improve someone's life, make life a bit easier for them.

I just bounced out of bed on those two days of interviewing and did a lot more around the house after I got home. It can be depressing if you feel you're not doing anything but to have something like this to do, I was so happy. I was loving what I was doing so it gave me energy.

There had been challenges including getting the courage to attend the initial information session, getting ill during the course of the work and the social dynamics of working with a team of people. In terms of achieving a balance between personal experience and having an 'objective researcher perspective' issues were raised about how to deal with situations where survey respondents' experiences re-traumatised peer researchers because they were close to their own situation. Some felt this was difficult while others felt that the balance was straightforward and that each strengthened the other. Appropriate support in these instances and the ability to debrief had been important:

Lived experience and research objectivity balance very well together. It's quite an equilibrium. Because you've been there it gives you greater understanding of those you're listening to. Each compliments the other.

Some of the interviews, the stories were very similar to mine and I felt for the person. We talked about this before beginning interviewing. I wanted to make sure we weren't

re-traumatised. The facilitator was there to talk to and the interviewers had each other, we also had support workers so people were available.

Finally there was extensive discussion within the Advisory Group about the stigma of mental illness. One outcome was an evolving group consensus that they were happy to be identified with the final report and a lessening of the self-stigma that they experienced.

Advisory Group members had suggestions for future research topics, program ideas and consumer advocacy and wanted to see Anglicare supporting similar projects. All six members expressed interest in being involved in future projects:

Oh yes, definitely. If they thought I had something to contribute, definitely. It's a good reason to get up and out. If I haven't got something on I can stay in bed or be in a heap. This gave me a reason to get up.

3.2 Views of program staff

Staff were asked how they felt the Peer Research Project had gone, about the research outcomes and any wellbeing impacts for those participating and for the programs themselves. They were also asked whether there had been any negative impacts and what advice they might give to other services embarking on similar peer research projects.

Overall staff agreed that the project went well and Advisory Group members seemed to have got a lot out of it. For many staff watching the enjoyment of those involved was a highlight of the project. The education and training they had received seemed to be empowering and people appeared to feel good about their contributions.

In terms of the research outcomes of the project staff considered that the findings and recommendations were useful for programs. Although there were not necessarily any surprises in the findings they were valuable in affirming programs' thinking on many issues. The findings also raised some points for further discussion among staff including issues associated with access to the programs and consistency in service delivery across programs. Of significant interest to staff was the finding that many respondents want to see more social activities facilitated by the programs and what this means for balancing the building of an individual's social confidence with building their independence and ability to engage in external community events. This instigated reflections on what programs could do to meet this need.

A number of positive impacts were identified as arising from the project for both people accessing services and for programs. All staff acknowledged that Advisory Group members had gained from being involved, enjoying it, having an opportunity to reflect on things, inputting and making a difference. As staff said:

It was clear to see what a change it had made in those six people's lives, in their self-worth and confidence.

When people are putting their hands up to do something for others, it's a good step in their recovery process, and a sign that recovery is happening.

In this sense staff saw it as a good example of people's recovery. They noted the willingness of Advisory Group members to appear on a DVD about the project. As

they said, agreeing to be on a DVD implies an acceptance of their illness and not being ashamed of it:

The invitation asks people to challenge their own self-stigma, as well as community stigma.

For program staff a key outcome was discussions about how to ensure the momentum from the project continued, including providing further opportunities for those involved in the Advisory Group. This might entail involvement in recruiting new staff, inputting into promotional materials for the programs and implementing the recommendations from the report. It could also include helping to induct people new to the programs and reviewing goal-setting, exiting processes and client feedback mechanisms. They were also keen to encourage people using services to get involved in Flourish, Tasmania's new mental health consumer network. Staff unanimously supported future projects of this kind in Anglicare and as they said:

This was a good process of reflection for workers to help us not take things for granted.

However there were also a number of ways in which staff thought the project could have been improved and they gave a wealth of feedback on how future projects might be conducted. These included:

- a more open recruitment process which could ensure that all people accessing the programs were given an opportunity to take part;
- longer time frames for programs to 'gear up' to distributing information about the project and encouraging people to participate as peer researchers, members of the Advisory Group and as survey respondents;
- promoting informality to minimise anxieties about 'starting a project' and the risk of 'failing' at something;
- encouraging peer researchers to 'tell their story' to each other rather than to survey respondents;
- a larger survey sample size and using a range of research methods including face-to-face interviews, written responses and online surveys in addition to telephone interviews;
- more communication between the Advisory Group and program staff about research questions and design to keep staff up-to-date with progress. This could include visits to staff teams and/or a research newsletter which gave biographies of the consumer researchers;
- involving existing peer workers employed as team staff in the development and facilitation of future peer research projects and other activities involving consumers;
- clarifying terminology. The terms 'peer researchers', 'service users', 'consumers', 'participants' and 'respondents' were confusing particularly given the roles of 'peer workers' employed by the teams. This requires clarification; and
- mechanisms which allow more time for the discussion of research findings and recommendations between consumer researchers and program staff beyond a brief presentation.

3.3 In summary

From the perspective of Advisory Group members participation in the project was beneficial to them in a number of ways. As well as contributing to research and the development of a useful set of recommendations to improve the delivery of the programs, participation supported the mental health and wellbeing of those involved through high levels of personal satisfaction, ‘ownership’ of the project and being better able to confidently voice their experiences and opinions.

Whilst the peer researchers came with little research experience, as a team they were provided with support, training and time to undertake a valuable research project together. It appears that no one individual would have had the desire, time or capacity to complete this project alone; part of both the appeal and ultimate success of the project had to do with its social, collaborative nature.

Program staff acknowledged that, despite some limitations, significant outcomes had arisen from this ‘small pilot’ project including thinking about how to build on and expand it. They saw future projects of the same size would be useful and larger projects welcomed. They listed some possible research questions which could be explored in any partnerships within Anglicare.



4 Conclusions and Recommendations

This research has explored the experiences of people who are accessing and using Anglicare community-based support programs for people with mental illness – the Personal Helpers and Mentors Program and the Recovery Program – and their views about consumer engagement and getting involved in the development of services. To do so it has used a peer research approach where those using the services have completed training to undertake research with their peers.

The findings have generated a wealth of information about service delivery improvement opportunities as well as a willingness to get involved in improving the way in which the programs work. In addition, the experience of being involved in undertaking the research has had a positive impact on peer researchers and those involved in the Peer Research Advisory Group. For services themselves the research gives some pointers about how to improve access to programs and the way in which they are delivered and how to empower those accessing services to get more involved in their development as well as clear insights about how to improve any future peer research work.

A number of recommendations about how to both develop services and improve the peer research process have grown out of the project and are outlined below.

4.1 Recommendations developed by the Peer Research Team

4.1.1 Accessing and using the programs

Overall survey respondents were very positive about the support they received to achieve their goals and about their relationships with workers. People particularly valued support from peer workers or those with lived experience. They found their experiences in the programs compared very favorably to other mental health services especially in being able to ‘meet people on their own ground’. Survey respondents wanted to see more publicity available about the programs generally and, once people were engaged with the programs, more information about how they worked and what could be expected of recovery workers. They also identified a number of possible improvements to the way in which services are delivered including wanting to see more social activities organised by services. This sets up a dilemma for services where one of their key aims is to ‘reconnect people with the community’ and to move them into a broader community than that of people with experience of using mental health services.

The Peer Research Advisory Group recommended that programs:

- review publicity information and its distribution and explore possibilities for involving people currently accessing services in promotional activities;
- prepare an induction pack for people new to the programs to reinforce information given verbally when people engage with the service and detail what

they can expect from the service. This is especially relevant as good information is the first step in good consumer engagement. Involving people accessing services in developing such a pack should be explored;

- remember the significance of relationships with workers in people's lives and ensure transitions between workers are managed well;
- explore ways of making social events more accessible to the wider community, including inviting people accessing services to 'bring a friend' and/or wider advertising in the local community;
- explore ways of bringing people accessing services together to 'share their story' as these opportunities are rare but very therapeutic; and
- ensure workers have high expectations when developing goals with people accessing services in order to 'let them dream'.

4.1.2 Consumer engagement

The survey demonstrated that people want to give feedback to services and think that it is important to do so, although not everyone is comfortable in feeding back. Barriers identified include shyness, anxiety, not being well, not being asked, not feeling safe or credible or that anyone will take it seriously. Respondents saw workers as playing a key role in empowering engagement and making people feel respected and listened to – an important first step in promoting engagement activities. Respondents wanted to see a range of feedback options available, but their preferred mechanism was informally at social events like barbeques. The Peer Research Advisory Group recommended that programs:

- ensure a range of feedback and involvement activities are available ranging from client satisfaction questionnaires and informal feedback to facilitating feedback at social events and activities;
- recognise that although leaflets/brochures alone do not provide people with the confidence required to give feedback, workers should ensure that people accessing services are aware of Anglicare's complaints mechanisms and ensure all have a copy of the feedback/complaints brochure;
- ensure workers are aware that they play a key role in empowering people to get involved by listening to what they say and tackling the self-stigma that so many people who use mental health services experience; and
- explore the possibility of setting up a cross-program consumer advisory group to meet on a regular basis and input into the development of programs. Some initial tasks for the group might be the development of an induction pack, consideration of promotional activities and material and monitoring the implementation of recommendations in this report.

4.2 Recommendations developed by Teresa Hinton, Research and Policy Officer, Anglicare Tasmania, in collaboration with the Peer Researchers

4.2.1 Doing peer research

The project has been a positive experience for members of the Peer Research Advisory Group and for programs in a range of ways. Members of the Advisory Group gained personal satisfaction and pride from their roles of advisor, interviewer, report-writer, role-player and expert based on lived experience. Being listened to, respected and valued was a significant and commonly reported benefit of being involved. All of them were interested in participating in similar projects in the future and felt empowered to do more – including to more confidently voice their experiences and opinions, to seek employment and/or training or to get involved in the consumer movement in Tasmania.

For program staff the project had gone well and generated positive outcomes for those involved as well as useful insights and recommendations for services. It had also led to a range of suggestions about how to make any future peer research process better.

The budget was satisfactory in order to complete a project of this size and with this number of people involved and members of the Advisory Group felt adequately reimbursed for their time and expenses. Although there were limitations to the research process particularly in the survey response rates, the sampling and the data collection tool, the standard of all aspects of the research was adequate to produce useful results and recommendations as verified by Anglicare staff. Regardless of specific research outcomes it was clear that the project supported the mental health and wellbeing of Advisory Group members and of survey respondents in being 'listened to'. The Peer Research Advisory Group and SARC recommended that:

- Anglicare consider the potential for using peer research to examine other aspects/issues for services;
- recommendations in this report should be reviewed in 12 months;
- Anglicare include in any consumer reimbursement policy the principle that taking part in consumer activities is an aspect of how Anglicare delivers services. This should inform how consumer reimbursements are processed through the financial systems of the organisation and provide insurance cover for consumer activities on Anglicare premises; and
- Anglicare develop an induction pack for consumers involved in participation activities. This should include the organisation's privacy and confidentiality policy and code of conduct.

4.3 Key learnings

A synthesis of feedback from the Advisory Group, program staff and the SARC facilitator and evaluator suggests the following might assist future peer research projects:

- Involving people in each aspect of the project works well and assists with a sense of ownership and personal investment in the project. This includes being involved in discussions about the budget, decisions relating to the research, development of recommendations and how to present the findings to various audiences.
- Identifying and utilising the specific skills and experiences of those involved assists them to feel valued for what they bring. People benefit from a facilitation style that is respectful, clear, supportive and empowering. Reimbursement for time and transport costs is an important aspect of valuing the contributions of consumers involved in research.
- Mechanisms should be available at the beginning of the process to enable people to tell their own stories and reflect on their experiences. This may assist people to acquire more objectivity in approaching the research, build a sense of understanding among members of the research team and experience the potential richness of qualitative data and how it might be used in any research project.
- Writing up research findings can be difficult and require high level skills. If those skills are not present among peer researchers there may be more creative ways of involving people in the writing up process. This should be explored in any future peer research projects.
- Support needs to be available when difficult feelings arise and when exiting the project – from support workers, the research facilitator and from partnered data collection so that interviewers can de-brief with their co-worker. Mechanisms are also required to facilitate the transition out of the project and may include involvement in dissemination of research findings, access to training and providing further opportunities to be involved.
- Facilitating peer research is demanding and time consuming. It requires the competency and capacity of a facilitator with research skills and the ability to manage group dynamics. It also requires regular communication between peer researchers and programs. Generous amounts of time for each step in the process are required.

There was a noticeable increase in the confidence of Advisory Group members as the work progressed. This may mean that there could be higher expectations for this kind of work building on increases in confidence if it was spread over a longer period. It also means there may be possibilities for using the momentum begun with this project by involving these ‘more experienced peer researchers’ as advisors in the development phase of any future peer research projects as well as in the research project itself.

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Appendix 1: Invitation to participate in peer research

The Peer Research Project — Can you help?

Anglicare believes that people who use its services should have a say in what they look like and how well they are working. You have knowledge and experience which is very important in thinking about these issues.

The Social Action and Research Centre at Anglicare is doing research about how best to involve people in improving the services they use. It is setting up **The Peer Research Project** in the Personal Helpers and Mentors Program and in the Recovery Program. This is about getting people who use these services to research how to involve their peers or other people using the services in improving those services. Being involved will mean:

- attending a number of meetings during September, October and November
- meeting other people who use the services
- helping to make decisions about the research
- some training in research methods and undertaking research
- making recommendations about how to improve services

Any expenses you incur in attending meetings and undertaking the research will be reimbursed.

If you are interested in finding out more about the Peer Research Project you are invited to attend a **two-hour introductory session** from 11-1pm on **Wednesday 21st September** at Anglicare, 18 Watchorn Street, 7001 (off Liverpool Street) with Teresa Hinton from Anglicare's research team. Attending the session does not commit you to being involved but it will give you more information about what it would mean to be involved. Lunch is provided and travel expenses will be reimbursed.

We hope to see you there! **Please RSVP** to your Anglicare worker or to Teresa on 6213 3565 by Friday 16th September.

Appendix 2: Position description for peer researchers

Purpose

To undertake research with participants in the Personal Helpers and Mentors Programs and Recovery South Program with support and supervision from Anglicare's Social Action and Research Centre.

Essential Qualifications

To be a current participant in Anglicare's Personal Helpers and Mentors Program and/or Recovery South Program.

Desired Qualifications and/or Experience

- the ability to communicate with and listen to a wide range of people
- an interest in and commitment to undertaking good quality research
- an ability to commit to the research timetable
- empathy and respect for other people

Role

Peer researchers will be involved in:

- training about social research and interviewing skills
- defining a research question
- designing the research
- collecting information and organising it
- writing up research findings and making recommendations

Much of the training will be about learning on the job.

Time Commitment and Reimbursement

Peer Researchers will be reimbursed for up to 40 hours of attendance at meetings and interviewing over a six month period.

Appendix 3: Peer Research Advisory Group — Terms of Reference

Purpose

The Advisory Group will be responsible for guiding the peer research project and giving their advice, support and expertise.

Membership

The Advisory Group will consist of people who use Anglicare’s Personal Helpers and Mentors Programs and the Recovery South Program and who are interested in participating in the Peer Research Project.

The Group will be serviced by Teresa Hinton, Research and Policy Officer from Anglicare’s Social Action and Research Centre.

Role

The Advisory Group will:

- use their expertise and experience to assist with the development of the research question, the research methods and in interpreting the findings of the research
- provide support to the peer researchers
- learn about doing research
- contribute towards the development of recommendations to improve consumer engagement in the Personal Helpers and Mentors and Recovery South programs

Time Commitment

The Advisory Group will meet regularly over a six month period.

Remuneration

Advisory Group members will be remunerated for time spent in meetings and for any travel costs.

Appendix 4: Information Sheet

Finding out what people think of services: The Peer Research Project

What is this project about?

The Social Action and Research Centre (SARC) at Anglicare undertakes research, and lobbies Government on issues which affect low income earners in Tasmania. The Research Centre is working with people using the Personal Helpers and Mentors Program and Recovery South Program to conduct research about what their peers or other people using the services think about those services. This is called the Peer Research Project and the research is being designed and led by the Peer Research Advisory Group.

Participating in the research

Taking part in the research involves being interviewed on the telephone by a peer researcher. The peer researchers are called Shirley and Julie. They have experience of using these programs and have been trained to conduct interviews. The interviews will take place on Thursday 17th November and will take about 30 minutes. Your participation in the research is voluntary. You can leave at any time during the process and it will not affect your access to Anglicare services or have any other negative outcome for you.

Reimbursement

Participants in the project will be reimbursed for their time with a \$20 voucher once they have participated in the survey.

Confidentiality

Your answers to the questions will be recorded but all the information you provide will be confidential. A report will be written about the research but your identity will be protected in any documents, and it will not be possible to work out who said what.

Results of the research

Information collected will be used to write a report about people's experiences of services. The report will be widely disseminated within Anglicare and possibly posted on the Anglicare Tasmania website: <http://www.anglicare-tas.org.au>. You will receive a copy of the report.

Contacts

For more information about the project please contact Teresa Hinton at the Social Action and Research Centre, Anglicare on 6213 3565.

Concerns or complaints

If you have any concerns about this project or the way the research is being conducted, please contact Rev. Dr. Chris Jones, Chief Executive Officer, Anglicare Tasmania on 6213 3555 or write to him at Anglicare Tasmania, GPO Box 1620, Hobart TAS 7001.

Appendix 5: Consent Form

Getting the Views of People Who Use Services: The Peer Research Project

- I have read and understood the Information Sheet for this project.
- I understand that taking part involves answering a questionnaire on the telephone to give my views.
- I understand that notes will be taken and the information used to write a report about what people think of the Personal Helpers and Mentors Program and the Recovery South Program.
- I understand that my participation in the research is confidential and that my identity will be protected in any documentation.
- I agree to participate in this project and understand that I may withdraw at any time without any effect on my access to services provided by Anglicare.

Any questions that I have asked have been answered to my satisfaction.

Name of Participant:

Signature of Participant:

Date:

Telephone number

(a landline would be best but we can also call you on your mobile)

