

# Satisfying competing stakeholder needs in a depression awareness project

## depression

**Anthea Rutter**  
**Maggie McGuinness**  
**Suresh Sundram**  
**Wayne Chamley**  
**Kylee Bellingham**  
**Tom Trauer**  
**Neil Cole**  
**Catherine MacBean**

The Depression Awareness Research Project was funded to develop, implement and evaluate a community-focused model designed to raise awareness of major depression<sup>1</sup>. It was piloted in five locations in Victoria from 2001–2004. This paper presents the findings of an analysis of qualitative data collected from a variety of stakeholders during and after the project.

### **Purpose of the evaluation**

The purpose of the evaluation was to evaluate the effectiveness of the training program in the Depression Awareness Research Project (DARP) and the effectiveness of the DARP model in improving mental health literacy within the community (Sundram et al 2004). The evaluation of DARP incorporated both quantitative and qualitative approaches. The quantitative components involved administration of a survey that measured levels of literacy about major depression and sought basic demographic data. The qualitative components of the evaluation appraised educators, project coordinators and key stakeholders. Educators completed a questionnaire immediately after their training, evaluating the latter's quality and were interviewed using a semi-structured interview by their coordinator at their exit from the project to assess their experience of DARP. Project coordinators and some key stakeholders were interviewed by Mental Health Research Institute staff about their comments and impressions of being involved in the project.

### **Focus of this paper**

This paper focuses on one aspect of the evaluation. It examines the differing expectations of the majority of the stakeholder groups within the project and discusses whether their expectations were met by the project. In particular, the paper examines the qualitative findings and their relevance to assessments of program effectiveness.

The main author of this paper was involved with the *qualitative* data collection involving the groups below. The *quantitative* data obtained from the secondary contacts (who were the recipients of the messages about major depression) was analysed by other members of the research team.



*Anthea Rutter (photo), Maggie McGuinness, Suresh Sundram, Wayne Chamley, Kylee Bellingham, Tom Trauer, Neil Cole and Catherine MacBean work within the Depression Awareness Project, Mental Health Research Institute, Parkville, Melbourne. Anthea Rutter is the principal author of this paper.*

## DARP stakeholders

Multiple stakeholders were involved in DARP, including:

- the funding body *beyondblue*
- the sponsoring organisation, the Mental Health Research Institute
- the five community partner organisations which provided a base in the community for the project
- the project coordinators in the five regions who were responsible for advertising recruiting and supporting the educators
- the educators.

## Introduction

DARP was conceptualised by a former Victorian former Labor politician who was diagnosed with bi-polar disorder in the early 1990s (Copolov et al. 2001). His experience with mental illness made him keen to see if a community-based depression awareness initiative would assist in raising awareness of major depression<sup>1</sup> as well as in destigmatising the illness. A research project based on his idea was supported by the Mental Health Research Institute (MHRI) and was subsequently funded in 2001.

DARP was an initiative of MHRI in Victoria with funding from *beyondblue*, the national depression initiative.

During the implementation stage of the project volunteers were recruited, educated and trained to

supportive of the treatment process (Sundram & Bellingham 2002). However, recent Australian surveys of mental health literacy indicate a low level of awareness of mental disorders such as major depression in the general community, particularly with regard to effective treatments for depression (Jorm et al. 1997).

DARP was implemented over a three-year period in five regions of Victoria. Funding for the project was supplied by *beyondblue*, the national depression initiative, and MHRI implemented the research project. The purpose of the initiative was to develop, implement and evaluate simultaneously a community-focused model of raising awareness of depression, as well as attempting to reduce the stigma associated with major depression.

Local community members in five regions of Victoria (two rural locations and three metropolitan areas) were trained to deliver awareness talks and supported during the project. A research psychiatrist and a research psychologist developed the training package with input from VICSERV (a Victorian peak body for psychiatric support), and from consumers and carers (McGuinness et al. 2003). The message about major depression was simplified under four headings; that major depression is *common*, it is an *illness* not a character flaw, it is *serious*, and it is *treatable*. Trained community members or educators were then expected to make presentations about major depression to local community groups or workplaces in their particular community. These local educators were supported by coordinators who worked in community-based organisations in partnership with MHRI. There were three recruitment rounds to the project over the three-year period, resulting in the training of over 260 voluntary educators across the five regions, who in turn gave presentations to approximately 7500 people.

One of the criteria for recruitment of the voluntary educators was that they had to be connected to community networks. Also each educator was expected to talk to up to 100 people. The choice of groups to address depended on the particular educator's interests and contacts. Presentations were made to a range of audiences including to six mothers at a mothers group, a hundred Rotary members, and to large groups in the workplace.

## Data management

Each community educator completed a Depression Literacy Survey (DLS) when first selected into the project, then again at the end of their training and finally after the end of their time on the project. This enabled the researchers to track any changes in their knowledge base over time. At the commencement of each presentation given by educators, their audiences (secondary contacts) were requested to fill in an abbreviated DLS prior to the presentation. Telephone numbers of participants were requested, and if given, MHRI contacted them after three months to ask the

## DARP was conceptualised by a former Victorian former Labor politician who was diagnosed with bi-polar disorder in the early 1990s.

provide awareness-raising sessions for groups within their respective communities.

A number of stakeholder groups were involved in the project. These were: the community partnerships which provided a base for each of the five pilot projects located in various parts of Victoria; the funding body which supported the project; the project coordinators who were responsible for recruiting and supporting the educators; the audiences who were the recipients of the depression awareness message, as well as the educators themselves.

## Background to the issue

Increasing public knowledge about major depression is regarded as having an important role in decreasing the morbidity and mortality associated with the illness (Commonwealth Department of Health and Aged Care 2000). It is generally agreed that people who have a basic knowledge and awareness about depression are more likely to recognise signs of depression, seek help and be

same questions, in order to see if this core knowledge had been retained. It was hoped that the information received from these sources would enable researchers at the Institute to ascertain whether or not this model was a viable method of raising awareness of major depression in the community.

At the end of the project, the partner organisations, the MHRI project staff, the project funders, the coordinators and the educators were interviewed face-to-face and asked a range of questions about their experiences in DARP. The data forms the basis of the majority of this paper.

## Data analysis

Quantitative data were analysed using SPSS (Statistical Package for the Social Sciences). Standard statistical tests were used throughout the analyses. These tests include: Chi Square tests of independence to test associations between two variables; Fisher's exact test for two-by-two contingency tables; McNemar's test to test associations between two dichotomous categorical variables in paired samples, independent and paired samples; t-tests to compare the mean scores of variables; One-Way Analysis of Variance (ANOVA) to compare the means of more than two groups based on one independent variable or factor; and Tukey's post hoc tests to explore which associations within the ANOVA are significant.

Next, after the qualitative interviews were carried out the notes were transcribed, coded and displayed on Miles and Huberman-style grids (Miles & Huberman 1994). At the same time pertinent comments were highlighted.

The next section of this paper examines each of the stakeholder groups in turn and identifies the positive and negative aspects of their involvement in DARP.

## Partner organisations

DARP was conducted by MHRI in partnership with five organisations in Victoria:

- four Psychiatric Disability Rehabilitation and Support Services (PDRSS) organisations. Two were in metropolitan Melbourne, one in a regional city and one in a rural area of Victoria.
- one inner-city local council located in Melbourne.

It was important to have a mix of locations to see if the project worked in different environments. There was also a pragmatic aspect to these choices as these were the organisations that were enthusiastic about the project and were committed to it. All five organisations had representatives on the Steering Committee.

Representatives from the partner organisations were interviewed at the end of their involvement in the project on a one-to-one basis, using a semi-structured interview schedule. The types of questions asked were as follows:

- What were the agency's expectations of the project—and had they been met?
- Was being part of DARP a good experience?
- What were the highlights/lowlights (and why)?
- What is the potential of the model to make a difference (in raising awareness)?
- What changes would you have made, if you had been able to?

## Project coordinators

A local project coordinator was based with each partner organisation and was responsible for the recruiting and support of voluntary educators whose role was to present awareness-raising sessions with community groups.

The employment conditions for the coordinators differed across the five partner organisations and this created a level of tension for MHRI which was implementing the project. The regional PDRSS agency was the employer body for the coordinators situated in country Victoria, whereas MHRI employed the two metropolitan coordinators. Although the local council employed the original coordinator for that partner organisation, the subsequent coordinator was employed by MHRI and remained external to the council. The situation had the effect of splitting loyalties towards DARP. In some instances the project suffered as the coordinator spent more time on the agency's tasks rather than on those required by DARP.

The management of one PDRSS agency, which employed its coordinator directly, commented that there were some problems in terms of the dual accountability situation. As one person pointed out:

*... this has caused angst because of the competing demands of MHRI and [the agency]. (Regional city PDRSS agency)*

Furthermore, some PDRSS agencies expected that DARP would have a greater community development role than was the intention of the project. DARP was a research project involved in evaluating a community development model and focused specifically on outcomes in terms of numbers of presentations and secondary contacts. The agencies' preferred role was to focus on empowering local communities by using the coordinator to deliver talks rather than for recruiting and training educators. Consequently, agencies reported that:

*It would have been better to use the project worker for training and delivering depression sessions, rather than relying on volunteers. (Manager, regional city PDRSS agency)*

On the positive side for agency representatives, the experience with DARP had extended their knowledge of their community and given them

a resource in terms of volunteer educators. Two quotes illustrate the benefits of DARP:

*... it has opened doors in the community for us. We have enlarged our contacts in the region and have started genuine dialogue.* (Manager, rural PDRSS agency)

*We now have an emerging relationship with large employers in the area and we are starting to organise work with them.* (Manager, regional city PDRSS agency)

For the local council, there were a number of issues in terms of the project which made it an unsatisfactory relationship. All levels of management did not wholly endorse the project. This was not helped by a number of senior management changes during its implementation. One interviewee commented:

*There was not a defined project structure here at council with regular meetings etc. and the project has got a bit lost ... it should have had a firmer governance structure.* (Manager, inner-city local council)

Council workers who had been trained to become educators and deliver talks to their colleagues commented that some staff were reluctant to come to presentations because they felt that management was targeting them personally. The very stigma the talks were meant to ameliorate was being perpetuated by some individuals within the organisation.

One of the difficulties with DARP was that the research design was not clarified at the start of the project, but evolved as the project grew. Consequently, there was confusion and misinterpretation concerning the direction the project should take. When asked 'What were the lowlights of the project?', the following was noted by a representative of one agency:

*Firstly, there were changes which occurred in the first few weeks, that is, the action research model was changed to one which concentrated more on number of talks and number of audiences.* (Manager, rural PDRSS agency)

Another issue that concerned agencies was the health status of a number of their volunteers. All agencies felt concerned for the volunteers' health, as a large number of those attracted to the position of community educator were often sufferers of depression themselves. It was pointed out that:

*Sometimes some of the presenters were ill people, and often took on more than they could achieve* (Manager, rural PDRSS agency)

All of the project partners agreed that the DARP model has the potential to make a difference. The local council, in particular, was supportive of the idea of having in-house educators:

*Using peers (to deliver talks) is good because such intellectual capital is kept in the organisation. Outsiders just deliver and go, but insiders talk at morning teas etc.* (Manager, inner-city local council)

However, a word of caution was given by the manager of one of the agencies. He expressed concerns about over-emphasising the awareness message and blurring the edges between normality and illness:

*I worry that if we get an 'over-awareness' we might be in danger of pathologising normal sadness and grief. We need to differentiate between this and disabling, ongoing mental illness ... the message needs to be one of opportunity, not defeat.* (Manager, regional city PDRSS agency)

In terms of judging whether DARP was successful as an awareness-raising project, the agency's manager was cautious in his reply:

*We need to look at whether it [DARP] was successful because of the way it was delivered. Or was its success due to the media who have been putting messages about depression across to the whole community?* (Regional city PDRSS agency)

One of the difficulties faced by the local council was the failure of the project to become embedded in the organisation. As one person bemoaned:

*We needed senior management to back the project (a change in top management structure left the project without support).*

*Do not do [the project] during organisation restructure!* (Manager, inner-city local council)

## **Views from the project sponsor—MHRI**

Several of the staff involved in DARP were interviewed, including two staff members who were involved with the early part of the research project, and the Operations Manager.

The researchers considered that a health promotion project such as DARP would be a good way to bridge the gap between MHRI as a clinical research organisation and the general population. However, it was pointed out that community research was not seen to be without its difficulties:

*Pure research is very neat, whereas community research has so many players involved, so many*

*vested interests so that it muddies the water!*  
(Project Manager, DARP)

When asked to recount the difficulties they encountered with the project, it was acknowledged by DARP staff that the expectations of some of the agencies and the early educators differed because of lack of project clarity from the sponsoring organisation. It was complicated further by the different employment situations for the coordinators with the result that:

*Understandings between MHRI and the partners were not clear and the roles of the coordinators had not been made clear to either partners or employees.* (Operations Manager, DARP)

Asked whether he would organise things differently if the project was starting now, one of the researchers replied:

*I would do it differently now. We did not advertise, just asked around the networks for interested people. Now I would advertise ... we might get better people ... it needs to be clear who employs, who administers and who supervises.*  
(Research Coordinator, DARP)

MHRI staff also acknowledged that the research project lacked design initially and had not been thought through before commencement. It was explained that:

*A few key steps, which should have been taken at the beginning of the project, were omitted. We tended to always be catching up. The implementation of the project was not as good as it could have been. The original project could have been more specific—too many assumptions. We needed to be clearer about how the training would occur; about methods; follow up; sample sizes; catchment; methods of following up; having a consistent approach to employing coordinators. Also the staffing team—whose role was what. Definitely a learning curve, very stressful.* (Project Manager, DARP)

### Views from the regional coordinators

There was only one region where the DARP Coordinator stayed the full three-year time frame. Most of the other regions had two or three coordinators during the project term. Most of the early coordinators expressed their confusion in relation to the role they were expected to play in the project. The two examples below illustrate such confusion:

*I was told that the work would be predominantly networking.* (Early coordinator, south-eastern metropolitan region)

*I did not realise that my main role was to be a coordinator of volunteers.* (Early coordinator, regional city)

For most of the coordinators the important aspect of their work on DARP was working with the volunteers. As one coordinator expressed it:

*The day-to-day job is not particularly exciting but working with the volunteers is positive and exciting.* (Coordinator, regional city)

As coordinators have had to deal with volunteers who either had depression or were recovering from depression, it was essential for them not to feel swamped with their illness but remain positive and supportive. Most of the coordinators considered that the project was mostly positive because:

*Anything that raises community awareness is good. It is vital to de-stigmatise the depression issue and we are going a long way towards it.*  
(Coordinator, southern metropolitan region)

Coordinators made a number of suggestions regarding possible changes to the project. For instance, some coordinators considered that recruiting and training educators was not the only model of delivery; one coordinator felt that working within an organisation and training staff was the preferred model. For another coordinator, implementing a pilot in one area and then evaluating it before going wider would have been preferable.

When asked about the culture of their own organisation, most coordinators agreed that their organisation was supportive, understanding and flexible, and in general felt that they had benefited from DARP.

### Views from the educators

The voluntary community educators were interviewed by their project coordinators at the end of their involvement in the DARP project (around 6–8 months), using a semi-structured interview schedule. The issues covered during the interview were as follows:

- their general impressions on their time as a community educator
- what things worked well for them
- what things didn't work so well for them
- whether there were any things that might have helped them
- any other comments.

The comments from each educator in each partner organisation were displayed on a matrix for each training round and pertinent comments highlighted. This next section presents the combined material from the educators from all partner organisations.

## Educators' positive experiences

While some educators did not give presentations at all, for various reasons, they enjoyed the experience, even though they were nervous at the start.

Many educators commented on the enriching experience of being an educator and the self-confidence they achieved in the process.

Some educators also commented on the training and resources provided at the training weekend. Typically, the ones who enjoyed the experience were those who had received a good response from their audiences. A number of educators, particularly in the rural partner organisation, had no intention of delivering awareness talks in the community, and instead used their workplace and their clients to spread the message. For those who used their training in their professional lives, the project was a positive spin-off:

*I now talk about depression openly—at work with staff and clients. This was one of the aims of doing the training.* (Educator, round one)

Several educators gave a number of presentations to a large manufacturing company. The management was very supportive of DARP and their audiences appeared to gain from the presentations. The educators involved mentioned that:

*Participants also report that the message was good—it gave them information which they hadn't thought about before.*

One of the issues raised by those involved in the workplace delivery was the time it took to complete the questionnaires. In the manufacturing industry, it can be difficult to ask people to be away from the production line. A comment was also made on the content of the delivery materials and the need for customisation for certain environments. For example:

*This (material) is okay for tertiary-educated workers but our floor guys need presentations to be shorter so that they keep up their attention span.* (Educator, round three)

Meanwhile staff in the local council felt that the project enabled them to increase their networks within the organisation, for example:

*This project has helped me to get to know people in the council—we follow one another up.* (Staff member, local council)

Educators were provided with a number of resources during the training sessions. The majority of the comments on the DARP literature were

generally positive. One educator commented that the literature indicated to the participants that the project was external to the organisation, which reduced audience paranoia.

## Reports of negative experiences

Negative comments from educators included that the questionnaires took up too much time, there was a lack of time to contact groups, and difficulties were encountered when trying to find groups in rural areas. There is a scarcity of people to form groups in rural Victoria as well as a large geographical distances to cover. This leads to problems, as illustrated by the following comment:

*Because we are a small group in the country, we were competing for groups. I would have liked more time to get to other groups.* (Educator, round three)

Apart from the positive reactions, there were also negative perceptions of DARP. For instance, there was a perceived lack of management support for the work undertaken by the local council, which was echoed across both those who presented and those who did not. (Some trained educators didn't give a presentation, either because they were too ill to do so or because they had underestimated the time required to procure organisations to present to.) There was also a comment from an educator that people did not turn up for talks because:

*There was not enough support from higher up in council; they did not encourage people to attend ... People are too frightened to leave their work and if they go (to a talk) someone might think they are crazy.* (Educator, local council)

Clearly, the intent of the project to be an information-sharing session had not filtered through this organisation. A number of educators were also concerned that some of their audiences perceived the presentations as a tool to flush out those people who had depression. One educator commented:

*A couple of people weren't happy about coming to the presentation but when they realised that nothing was going on their personnel files, they were okay.* (Educator, local council, round two)

As well, some managers felt somewhat negative about the project because their staff were taking time away from their normal work role:

*Organisationally, it was very difficult to make the presentations although some areas were more open than others. People at management level did not give encouragement to us as we still had our*

*work and in some sections an hour out is hard to make up.* (Educator, local council, round three)

Another negative aspect for the two metropolitan projects when presenting community talks was the inability of the educators to present to young people less than 18 years of age in schools.

Educators from round one commented that they would have liked more specific instruction on presentation skills, as well as some help in getting presentation bookings. Some educators went further and suggested that presentations should have been organised for them—their only role being to turn up to give the talks.

All of the metropolitan partner organisations would have liked more support with finding organisations where they could present their depression-awareness talks, and so asked for some practical help:

*It would be a good idea to help each new educator by giving them two or three talks so that they are launched.* (Educator, southern metropolitan region)

Educators who worked full-time expressed problems in finding sufficient time to participate and a number of educators, both those who presented and those who did not, found the time frame of the project unrealistic.

Comments from educators showed a sense of regret that the project was over, and that acquired skills would be lost, as most acknowledged that the project had been important in their personal development. In general, the success of the project can be summed up in one educator's words:

*Overall, it was an excellent attempt to make the public aware of depression. If people were more educated and therefore more comfortable with the topic they would become more open about it.* (Educator, south-eastern metropolitan region)

It was clear from some of the closing comments that some educators did not really grasp the expectations of DARP or understand the roles of the participants in the project. One of the main aims of DARP was to educate community people who are not professionally trained in the area of depression. During the training, participants were also informed that the stigma of depression is a community issue. They were also told that as a research project, the completion of questionnaires by the audiences they talked to was a priority. These following comments illustrate a lack of awareness of project expectations:

*I think this project should be done by professional people who could answer/address issues raised.* (Educator, round one)

*I believe that the stigma against mental illness is mainly in the mind of the sufferer.* (Educator, round two)

*I felt it was embarrassing to ask people to complete questionnaires.* (Educator, round three)

## Discussion

The lack of a clear research design at the commencement of the project provided some difficulties for the project partners. This lack of clarity meant that some agencies interpreted the project to suit their particular interests in their communities. For example, some of the partners had a community development focus as their main priority for the project, and were at times hostile to the idea of measuring the outcomes of the project in terms of number of presentations made by educators. There were also issues of accountability for project partners where some coordinators had primary reporting lines to the partner agency rather than MHRI.

From the educator's point of view it was generally agreed that although the potential of successful outcomes is enormous in the local government area, to achieve this it is essential that all levels of management are committed to the project from the outset and that the organisation is

**The lack of a clear research design at the commencement of the project provided some difficulties for the project partners. This lack of clarity meant that some agencies interpreted the project to suit their particular interests in their communities.**

clear about project intentions. Assurances must be given to staff that attendance at a presentation on major depression does not mean that management have targeted a particular staff member to be present. It was also disappointing that potential fertile ground in the government school sector was denied, as permission was not granted by the Department of Education and Training to conduct talks on major depression in that sector.

Then, some educators found that the timeline was too short to achieve the project goal of each educator 'getting to an audience of 100 people'. Some organisations (Rotary and Probus in particular) often book their talks 12 months in advance, so this compromised the educator's ability to get groups together when faced with the reality of a 6- to 8-month time span for their time on the project.

The results show that the method of presentation in the rural sector differed from that in the metropolitan areas. The preference in the city was for more formal, structured talks whereas the rural areas tended to prefer a more informal, casual approach. There are also far fewer community groups in the country and this is compounded by long distances between them. Any replication of this model in such areas should take these differences into account.

The valuable lessons learnt from the three-year implementation of DARP will be included in any subsequent roll-out of the DARP model.

Ultimately, the success of public literacy campaigns such as DARP is whether they influence earlier recognition and appropriate help-seeking behaviour at an individual and family level, as well as whether there is a decrease in stigma at a community level. To evaluate these outcomes was beyond the means and mandate of DARP. The success of DARP, however, now provides a vehicle through which such a public health initiative in major depression could be implemented.

#### Note

- 1 The term 'major depression' denotes the debilitating illness which causes both physical and psychological symptoms. It does not refer to sad or 'blue' days which are a normal part of the human condition.

#### References

- Commonwealth Department of Health and Aged Care. 2000, *National action plan for depression*, Mental Health and Special Programs Branch, Canberra.
- Copolov, D, Cole, N, Chamley, W & Trauer, T 2001, 'The development of a training approach to enhance the levels of awareness and understanding of depression in the community', a proposal from the Mental Health Research Institute to *beyondblue*, March, Mental Health Research Institute, Melbourne.
- Jorm, AF, Korten, AE, Jacomb, PA, Christensen, H, Rodgers, B & Pollitt, P 1997, "Mental health literacy": a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment', *Medical Journal of Australia*, vol. 166, pp. 182-186.
- McGuinness, M, Rutter, A, Sundram, S, Bellingham, K, Morton-Allan, E, Chamley, W, Trauer, T & Cole, N 2003, 'The Depression Awareness Research Project', paper presented at the THEMHS Conference, Canberra, August.
- Miles, M & Huberman, A 1994, *Qualitative data analysis*, Sage Publications, Thousand Oaks. California.
- Sundram, S & Bellingham, K 2002, *Promoting positive mental health: a practical guide to planning, implementing and evaluating mental health promotion programmes*, Mental Health Research Institute, Melbourne.
- Sundram, S, Cole, N, McGuinness, M, Rutter, A, Bellingham, K, MacBean, C, Trauer, T & Chamley, W 2004, *Report on the Depression Awareness Research Project*, Mental Health Research Institute, Melbourne.