

The Refugee Consumer Voice

How to Ensure it Makes a Difference

Brisbane Inner South Division of General Practice

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EXECUTIVE SUMMARY

The Commonwealth's Consumer Focus Strategy has aimed to strengthen the role of consumers in health service planning, delivery, monitoring and evaluation. To document good practice in consumer involvement and to demonstrate, promote and refine resources developed under the Strategy, a series of small grants were provided to local partnerships of consumers and health providers. These grants were funded by the Department of Health and Aged Care as part of a Consumer and Providers Partnerships in Health Project (CAPPS), which was designed to further, develop the evidence base underpinning effective consumer participation. This project titled Refugee Health Partnership Project was undertaken as a CAPPS Project.

The refugee Health Project – a consumer participation project ensuring health services meet the needs of newly arrived refugees in Brisbane inner south suburbs.

The project had two main partners: The Brisbane Inner South Division of General Practice and the Queensland Program of Assistance to Survivors of Torture and Trauma (QPASTT). These two organisations have been instrumental in the existence of the project: BISDIV in the design and the successful proposal to the Commonwealth Department of Health and Aged Care, and QPASTT in the administration and support.

The project had two broad objectives:

- To obtain ongoing input from newly arrived refugees on the appropriateness and effectiveness of health services provided by Queensland Health, general practitioners and the Early Intervention Program of QPASTT
- To ensure consumer involvement in the planning and development of health services for newly arrived refugees

The project has focused on establishing the foundation of a solid group of consumer consultants who, through training, resourcing and support have been able to integrate as a team becoming active participants in the project.

In this project the consumer consultants were representative of the following countries: Bosnia, Somalia, Sudan, Iraq and Kurdistan. Most have been in Australia less than three years and are still working through their own issues of grief and loss, settlement and cultural adjustment. One of the consumer consultants represented the group of people who have been released from immigration detention centres and are at the moment on temporary protection visas. This is a highly traumatised and transient group, predominantly male; working with this group has taken extra support and energy.

The project was highly successful in the engagement of community members all in total 305 who participated in interviews, telephone conversations and focus groups. It has to be mentioned the capacity of the consumer consultants to involve as much people as they could, even though there was at the beginning some reluctance from a particular group that apparently is tired of being interviewed, questioned, researched, at the end their contribution was remarkable.

The level of participation did penetrate service provision structures in hospitals, community health services, community based organisations and General Practitioners, there was three feedback meetings with hospitals, two with community health centre, three with two community based organisations and one with a primary school management. Tangible achievements were obtained in three occasions from feedback and actions that followed.

Feedback obtained from the community has been disseminated amongst health service providers (appendix 3), at the same time, reactions, responses and results from service providers have been passed on to the community.

Partnership was easy to establish with a community based organisation, it's attitude, receptiveness and accessibility proved fundamental to develop a dialogue and ongoing communication, unfortunately as the project closes this valued opportunity will not be sustainable. Partnership with other government organisations is not impossible but it will need time to develop.

The participative model drawn from this project is recommended to other similar initiatives, having as central strengths the following: formation, development and empowerment of a team of consumer consultants; training is understood to be a continuum for the life of the project; feedback to service providers is given collectively not individually; validation and importance is given to consumer consultants' employment conditions; level of payment to consumer consultants is consistent to the importance and validation and value consumer participation deserves; clear and defined roles are delineated in the job description; consideration is given to the vulnerability of the team members, therefore briefing-debriefing, emotional and settlement/logistical support is available; the coordination of the project provides strong support on principles and action of advocacy, individual and systemic and social justice principles; where possible, to avoid conflict of interest, the project is auspiced by an independent community based organisation.

CONTEXT

1. About the communities

- All participants in this project come from emerging communities, new groups establishing in Brisbane. The average of staying in Australia is one year. All of them have left their homeland in traumatic circumstances, quite a few had endured torture, their emotional and psychological status is at the moment quite vulnerable. All adults are attending English classes full time or part time depending on the age of their children
- The great majority of participants are living in the Brisbane inner south suburbs such as Annerley, Greenslopes, Moorooka, Holland Park, Stones Corner, Yeronga
- The 1996 ABS Census Queensland had the following numbers: Sudan - 130, Somalia - 79, Iraq/Kurdistan - 267, Bosnia - 1506
- 90% of the participants in this project are either unemployed or part-time English students, part-time workers doing jobs such as cleaning, fruit picking, casual jobs for a day or a week, etc
- 80% of participants have Islam as religion, 15% are of Christian denomination

STRENGTHS

- These new communities are bringing a diversity of assets to Australia such as: new cultures, music, food, and different worldviews. The level of education is comparatively high, most of the participants have professional training: Engineers, teachers, nurses, technicians, etc

WEAKNESSES

It is well documented that refugees are more likely to have poor health status, have higher rate of long-term medical and psychological conditions than other migrants and visit health care services more frequently. By virtue of the means by which they have gained entry to Australia, refugees have been exposed to traumatic events and a significant number will have been subjected to severe physical and/or psychological torture.

- Becoming a refugee is a traumatic experience; most of them carry the scars of torture, abuse, discrimination, dispossession, dislocation, grief and loss. Not knowing how to

communicate properly in a new environment renders them vulnerable and fearful. The process and the need to learn English is a concern for all of them.

- Special mention goes to the TPV holders, mainly from Iraq, Iran, Kurdistan and Afghanistan, who due to hardship, persecution, war and imprisonment fled to Australia without proper documentation; upon arrival they were detained by Immigration authorities and accommodated in detention centres in Western Australia and South Australia. Mainly men comprise this group. Upon release (after 9 to 15 months) they are granted a temporary visa for 3 years during which they cannot initiate any application for permanent visa, family reunion is not permitted, health services are very restricted, their families are overseas waiting to be reunited

2. Project title

The Refugee Health Partnership Project – a consumer participation project ensuring health services meet the needs of newly arrived refugees.

3. Process and key learnings

The project coordinator was employed by the Brisbane Inner South Division of General Practice and was employed for 1 day per week. The process of selection included advertisement, short listing, interview and selection of six consumer consultants from the Horn of Africa, the Middle East and Former Yugoslavia.

The consumer consultants are representative of newly arrived refugee communities, some of them being recent arrivals themselves who have been recipients of the services provided by the refugee health partnership. There was also selection and appointment of three consumers who were trained and supported to participate in the Refugee Health Partnership Program Management Group

Contracts, job description and other administrative requirements were part of the process. The management of 9 consumer consultants was resource intensive and time consuming. In addition, there is the added complexity that they were employed by the partnership organisation (QPASTT) so considerable time has had to be invested in administrative arrangements between the two organisations (BISDIV-QPASTT).

These arrangements were formalised in a MoU between the two organisations.

The project coordinator conducted in a period of three weeks a 15 hours induction and training course for the consumer consultants. (See appendix 1) After training the consumer consultants were introduced to agencies programs and committees.

In response to networking and publicising the project, the consumer consultants were invited to participate in a number of meetings, seminars and forums addressing the health issues of refugees.

One group in particular, the Refugee Health Services Coordination Group, which is a group comprising key public health services and coordinated by the Brisbane South Public Health Unit, made one-off commitments with the consumer consultants so they could receive additional resources to participate in these networks. The consumer consultants provided culturally appropriate advice to printed materials in languages other than English. The consumer consultants were paid extra for this.

Ongoing support and resourcing provided by the project coordinator to the consumer consultants was fundamental. The development of a shared understanding of the collective needs of the groups represented was critical for the success of the project. Principles and values of social justice and human rights were discussed and their application explored. Individual and social advocacy principles gave strength and validity to the effort of collecting

feedback from communities, which because of their size and lack of social organisation, limited use of their potentials and personal vulnerability are unable to make their voices heard and therefore have their needs unmet.

Attention was always given to the consumer consultants' settlement process. Several discussions were held in the topic of the proposed journey of starting being mono-cultural then to develop into bi-cultural and finally becoming multicultural. This seemed to provide sense and meaning to the consumer consultants' contribution.

3.1. Broad findings and key learnings

Through the contacts with community members the consumer consultants collected feedback that reflected perceptions, opinions, feelings and the reality they were experiencing:

- Newly arrived refugees find it difficult to understand why a referral is needed from a GP to see a specialist. Some of them are coming from countries where people decide to visit a specialist as first port of call (some countries have more specialists than GPs)
- Most of the newly arrived refugees have a poor opinion of the health system in Australia, especially those who have been temporary refugees in Germany, Austria, Italy and Switzerland. The other reason is that most of them for obvious reasons have been in contact only with the public health system in Australia, so there is a generalisation of poor health services
- A substantial number of participants mentioned that they have some doubts regarding the GPs' competencies and skills due to the fact that hospitals routinely perform test on patients (blood, urine, x rays, etc) even though the GP has done it before. "It is like the hospital has no confidence in GPs, the system must be all wrong if they don't trust each other".
- There was overwhelming agreement that hospital waiting lists are unacceptable, even in emergency. In relation to this when the Patient Representative of a hospital was told by the consumer consultant about it she said, "That's a universal problem".
- Many of the participants would like to access GPs from their own culture who speak their language
- Many GPs are reluctant to use interpreters. Reasons mentioned: it takes too long; booking interpreters is too complicated. Hospitals complained about lack of funding to provide interpreters. A young refugee was told by the GP, "You have enough English we don't need an interpreter here".
- Some GPs and other service providers complained that many refugees do not keep appointments or are too late and don't follow prescription instructions, "Many don't notify change of address when they move, so we are guessing what happened to them".
- 95% of the participants did not know to whom or how or when or where to complain if things go wrong with health service provision
- The involvement of Temporary Protection Visa (TPV) holders in this project brought another dimension that included moral, legal, economic, ethical and human dilemmas. The focus group with TPV holders required extra attention. It was considered that it was an ethical responsibility to organise more focus groups with this highly traumatised group. Emotional and psychological issues were expressed in vivid fashion. The team of consultants has been very supportive of the TPVs' plea
- Many TPV holders recounted their experiences in the detention centres, the cultural shock, and lack of proper health assistance, emotional and psychological trauma, and examples of intimidation, coercion and abuse. "In Iraq we have been imprisoned, tortured, persecuted,

relatives have been killed or disappeared, our families are there without our protection, they live in fear”, “We came to Australia fleeing terror and the welcome was to put us in prison”

- Despair was noted in the idea some of them hold that “this government is providing us with a substandard health care, media attacks and policies that contravene the UN Charter of Human Rights in order to reduce us, to destroy our spirits, to get rid of us here in Australia or put us back at risk in the Middle East”
- Powerful statements were declared such as this: “This government has forgotten that the economic sanctions imposed by the UN on Iraq and Afghanistan were signed also by Australia, we think this government has the ethical and moral obligation to ease the pain and suffering the sanctions have brought upon innocent people, should our countries had not the present economical breakdown we probably wouldn’t be here”

4. Consumer participation

See Appendix 3.

THE PROJECT

1. Why this project

- The changes introduced by the Department of Immigration and Multicultural Affairs DIMA after 30 September 2000, to initial settlement service provision is causing great concern amongst services providers. An early health intervention approach had been established which was integrally linked to the settlement services. As these have now significantly changed there are concerns that many new arrivals will slip through the system and not receive the support they used to receive in terms of accessing health services.
- There was therefore a great deal of interest in this project especially with the demonstrated capacity to obtain feedback from consumers. There were networks in place that the project provided feedback to, which have demonstrated acceptance of the applied methodology.

2. Brief description of project and its objectives

The Refugee Health Partnership Project through Consumer Participation was based on the following principles:

- Participation is an ethical and democratic right
- Effective consumer participation means your organisation must be prepared to change as a consequence
- Consumer participation is only really effective across an organisation if it is supported by management at all levels
- Consumer participation makes service providers more accountable to the population they serve

A refugee health partnership has been in operation in Brisbane since 1997 and comprises the following partners: Brisbane Inner South Division of General Practice, Qld Program of Assistance to Survivors of Torture and Trauma, Qld Health, the Integrated Humanitarian Settlement Strategy funded service (previously the Australian Red Cross but currently not identified by DIMA and interim arrangements are in place in Brisbane) and the Department of Immigration and Multicultural Affairs DIMA.

Health services provided by the organisations that collaborate with the Refugee Health Partnership were introduced to newly arrived refugees within the first week of arrival in Australia. As the model currently in operation in Brisbane has integrated health and settlement services it was of vital importance to monitor the impact of the changes introduced by the Department of Immigration and Multicultural Affairs on September 30, 2000. Arrangements that have been in place to facilitate access to health services needed to be monitored and strategies to be implemented to obtain feedback from newly arrived refugees on the impact of these changes and how they were able to access health services and whether the health services provided were appropriate and effective.

The project had 2 broad objectives:

- (i) To obtain ongoing input from newly arrived refugees on the appropriateness and effectiveness of health services provided by Queensland Health, general practitioners and the Early Intervention Program of the Queensland Program of Assistance to Survivors of Torture and Trauma.
- (ii) To ensure consumer involvement in the planning and development of health services for newly arrived refugees.

Specifically, the project:

- Identified opportunities to obtain feedback from newly arrived refugees on health services by working with services providing both health and settlement support and designed on going feedback and data collection mechanisms
- Designed and implemented appropriate methodologies for feedback for newly arrived refugees taking into consideration linguistic and cultural differences, and issues relating to the refugee experience such as the impact of torture and trauma issues.

3. What have the consumer consultants done?

See Appendix 3.

4. Project activity

RECRUITMENT

Expressions of Interest were circulated to refugee communities, short listing and interviews were conducted (22 expressions of interest received). It was also considered beneficial to the project the appointment of three consumers as back up involved in group management their role was to support the consumer consultants in matters of interpreting, advice, going to meetings with them. The management group was comprised of members of the Sudanese, Bosnian and Afghani communities.

TRAINING

Having in mind their previous professional and personal experiences, training was focussed on the validation of their stories, which included painful memories, traumatic experiences, recognition of their cultural wealth and acknowledgement of their professional expertise. The team was comprised of a teacher, a civil engineer, a theologian, a housewife, a student, a marketing consultant, and a medical doctor.

The training subjects were also dedicated to becoming familiar with the health system in Australia; settlement and multiculturalism; the social determinants of health, mental health, advocacy, social justice, human rights and the social responsibilities of all individuals in our society to achieve and maintain the good health of the community as a whole. For detailed information (see appendix 1)

FEEDBACK METHODS

Obtaining feedback

A questionnaire was developed to help the Consumer Consultants (see appendix 2) to conduct interviews with members of their own communities. As four consumer consultants spoke Arabic the questionnaire was translated accordingly.

Focus groups were organised by each consumer consultant, which involved: organising venue, culturally appropriate catering eg. Halal food, avoiding pork, etc, designating co-facilitator, note-taker, interpreter. The team has been very resourceful in completing these tasks.

One-to-one interviews were collated and summarised in a monthly report. Interviews took part mainly in participant's homes.

Providing Feedback

The team had discussions about feedback and service providers' possible reactions. Concerns were raised and responses recorded, as for example, the organisation that had been scrutinised was the employer of the team of consumer consultants. Some consumer consultants felt rather vulnerable; conflicts of interest were declared, and at the end the team concluded that responsibility to the community and commitment to change were the priorities in this project.

Feedback was provided to a Community based organisation, GPs, Coorparoo Community Health Centre, State Primary School, Mater Hospital and Princess Alexandra Hospital. The team decided to meet in person with service providers rather than posting a report. They considered it more relevant to talk, look at, listen, feel, think, and be there. The presence of several consumers, 6, 4 or 2, when meeting service providers, provided strength, confidence, and peer support, as consumers usually feel intimidated and unable to send the message across when alone.

5. What the money was spent on

Financial statement - see Appendix 4.

6. Evaluation Plan

Activity	Timeframe	Progress and participants
Recruit Project Officer	1 st month	Brisbane Inner Sth Division recruited Marco Ramirez.
Recruit consumer consultants	1 st and 2 nd month	EOI were circulated to refugee communities. Interviews were conducted by Marco Ramirez

		<p>(project coord), Paula Petersen (QPASTT) and Rita Prasad-Ildes (BISDIV) and the following people were appointed</p> <p>Dhanojak Obongo – Sudanese Fadumo Muse Yusuf – Somali Nabaz Mohammad Amin- Kurdish Gordana Jelisavac – Bosnian Nermin Murselovic - Bosnian Saad Al Obeidy – Iraqi</p> <p>Consumer reps for management group: Mirzada Hadziahmelovic - Bosnian Deng Biong – Sudanese Rahila Hareer– Afghani</p>
Training Role clarification and definition	2 nd month	<p>Role descriptions developed 15 hr training program conducted</p>
Negotiation with management group of refugee health partnership re linkage of project and mechanisms for providing feedback to service providers	2 nd -3 rd month	<p>2 meetings held Nov-Dec</p> <p>Management group endorsed consumer input through official membership of the management group</p> <p>Management group members provided input to project coordinator about the type of information that would be helpful for their organisations to receive consumer feedback on.</p>
Develop or adapt mechanisms and tools and strategies for consumer feedback	3-4 th month	<p>Project coordinator and consumer consultants worked through a process of developing strategies to obtain consumer feedback from the communities that are culturally and linguistically appropriate. Each consumer consultant worked with the project coordinator to develop strategies that were most appropriate for their own particular community.</p>
Implement tools and strategies to obtain consumer feedback	4 th -6 th month	<p>Questionnaire designed, proposed and validated by the consumer consultant team Initiation of home visits for face to face consultation Planning/organisation of focus groups</p>
Obtaining and Recording of information	5 th 7 th month	<p>Seven focus groups carried out 97 participants From face to face approach 207 participants Consumer consultants providing reports</p>
Providing feedback to service providers	6 th -9 th month	<p>Feedback provided to: QPASTT (two sessions, ongoing dialogue, written response by the organisation on how initiate adjustments and change) General practitioners (3) Princess Alexandra Hospital Adult Mater Hospital Coorparoo Community Health Centre Moorooka Primary School</p>
Evaluation by consumer consultants	June	<p>Independent consultant facilitated focus group/evaluation Written report included</p>

ACHIEVEMENTS

1. Aspects that have facilitated the project

There were a number of factors, which have facilitated the project and have provided the support to maximise the impact of the work the consumer consultants undertook:

- The consumer consultants are representative of newly arrived refugee communities as all of them are newly arrived themselves, and a number have been direct recipients of the services on which we are seeking feedback. They are therefore able to provide useful insights into project development strategies
- Consumer health services coordination group, which is a network of public health services coordinated by the Brisbane South Public Health Unit, explored additional financial resources from Queensland Health; to fund the participation of some of the consumer consultants of this network after the project expired. This group indicated that it is timely to continue consumer participation in this network and some funding has since been released.
- The Brisbane Inner South Division of General Practice provided with invaluable assistance in management, administration, logistic and excellent working environment to work from, its premises were always available for meetings, focus groups and other activities.
- As funding came from the Commonwealth Department of Health and Aged Care there is general agreement that the project had autonomy, independence and self-determination free from State politics; conflicts of interest were reduced to a minimum.

2. Outcomes

- Successful integration of a team of six consumer consultants. Training was devised and organised in a way that after the sessions of "official" training, a developmental process continued for the life of the project: empowerment, validation of the work done, emotional support, self esteem and settlement support was provided.
- Through the initial process it was fundamental to create an environment of unity among the consumer consultants even though they come from different regions, religion, social and political structures. As a result the concept and practice of "team work" made easy the understanding of a common issue regardless of their original situation. As an example of this, some focus groups were co-facilitated in collaboration with other consumer consultants.
- Acknowledgement by several community organisations, government agencies and individuals of the relevant contribution of this project. In the past no such model had been attempted in Queensland.
- It can be said now that the refugee community demonstrated capacity to undertake with confidence an initiative that if properly supported and resourced can be reproduced and become an ongoing program, thus strengthening meaningful participation and partnership.
- The consumer consultants initiated the process of one-to-one contacts/interviews with members of their own communities in their own places, social gatherings, and by phone. With the input of consumer consultants a questionnaire was developed to help the process of obtaining information. 207 people were consulted.

- Seven focus groups were organised. Each consumer consultant had the task to identify, invite, plan the catering, logistics and co-facilitated the meeting. In total 97 people attended. Other team members assisted with note-taking, interpreting and catering.
- The Project allowed consumer consultants to attend and participate in Forums, workshops and seminars. Also, they attended coordination meetings (Coordination of Health Services for Refugees, Refugee Health Project Committee) they have been asked to give input/advice into specific project materials for distribution eg. Schistosomiasis, food ingredients from the Middle East in Brisbane and other translated materials that needed the input from the consumer consultants
- In relation to improving communication, after receiving feedback from the project, a major hospital was happy to support and conduct activities for newly arrived refugees, inviting them to visit the hospital facilities where refugees will be explained how the hospital sections work. Refugees will now have the opportunity to ask questions, request information, clarifications and other pertinent requests
- A community-based organisation has, after two feedback sessions, initiated a dialogue with the consumer consultants in order to respond to the observations, concerns and suggestions from them. The organisation prepared a written response addressing the issues highlighted during the dialogue, some of those were:

- Working with refugees and exercising cultural appropriateness
- The origins, concept and practice of counselling as a western practice
- Grappling with conflict of interest when protecting refugees and at the same time having a compromised position due to funding requirements.
- How to practice independent advocacy for their clients

In the response they acknowledge the impact of the Project: *“Your project has been able to produce rich and multifaceted feedback for us to consider. We felt it is important for us to consider all the issues raised. We would like you to identify 2 or 3 areas as a matter of priority for QPASTT to integrate into our 12 month work plan which is currently being developed.”*

- As a result of the consultation from the five mentioned communities a short report was prepared representing the views of each group. This information has been distributed to the participant communities and health service providers in Brisbane (see appendix 3)
- The project also submitted an abstract about the project to the Conference “Diversity in Health: Sharing Global Perspectives” which was held in Sydney in May 2001 in order to promote the outcomes of the project. The abstract was successful and the project was presented in symposia under the title “The refugee consumer voice – how to ensure it makes the difference”. As a result project health workers from NSW and WA showed interest in reproducing the model within their own programs.

3. Barriers and strategies

- A barrier that was identified is the casual employment of consumer consultants who are on Centrelink benefits and the difficulties that exist in negotiating their payments and the fear and reluctance they have in dealing with Centrelink over these issues.

The project coordinator spent a great deal of time trying to deal with these matters and advocating on behalf of the consumer consultants with administrative and financial staff who initially could not accommodate the consumer consultants’ requests but were able to be flexible and supportive for the rest of the project.

- Another issue that the project coordinator had to address was that some of the consumer consultants have personally had some very negative experiences with health services that may cloud their objectivity in relation to this project. The project coordinator had to develop strategies to deal with these issues by validating their experiences while at the same time being clear that they have a professional role with boundaries and limitations with a clear role description.
- Lack of information and understanding of the health system: a major component of the training has also been information provision about key health services to ensure that each of the consumer consultants had a similar level of knowledge about the health system.
- Dealing with expectations: it is clear that a project such as this can raise expectations about being able to achieve radical changes to health services in a short period of time. A major focus was the discussion of policy formulation processes and the bureaucratic nature of many of the health services involved to place the project in a realistic context.

4. Achievements against objectives

4.1. What has gone well

Evaluation Question	Possible Indicator(s)	Results
Do service providers follow the procedures agreed within the project?	◆ Feedback from key stakeholders, notes from meetings.	Meetings were recorded
Are all key stakeholders (consumer and provider) represented in the project?	◆ Proportion of eligible stakeholders involved.	All stakeholders identified in the original funding proposal were represented
Are stakeholders satisfied with the processes undertaken by the project?	◆ Level of satisfaction by stakeholders	Verbal feedback positive. Feedback recorded in meeting notes
Are stakeholders satisfied with the results obtained?	◆ Level of satisfaction by stakeholders	Positive written response Requests for more feedback

Did the project have sufficient feedback from a representative sample of users of the services?	◆ Proportion of identified sample of services users who provided feedback	From face to face consultation 207 people From seven focus groups 97 people
Did the project meet the needs of stakeholders involved (consumer and provider)?	◆ Stakeholder feedback	Feedback recorded small report produced Verbal feedback provided
Were the tools developed by the project useful to obtain consumer feedback?	◆ Consumer consultant feedback	207 people consulted 97 people attended focus groups
What did services do in response to feedback received from the users of the services?	◆ Number of changes introduced and implemented	Feedback included in yearly plan Visit to hospital premises organised Requests for consumer consultants participation in meetings and working parties

		Requests for report Apology from a major hospital
What did the consumer consultants gain from the training provided?	◆ Feedback from consumer consultants	Participant feedback recorded Evaluation focus group provided

Outcomes of Refugee Health Partnership Project

Did the project fulfil the original project aims and objectives?	◆ Measure outcomes against stated objectives	Aims of project fulfilled Evaluation showed project on target
Is the project a good investment of resources?	◆ Benefits from the project are a good return of the costs involved and are sustainable	See appendix 4 Small fund shared by a NGO and government partnership committed to ref participation
Are those who conducted the project and those who participated in project activities satisfied with outcomes of the project?	◆ Proportion of stakeholders satisfied with outcomes	Formal feedback Consumer report appendix 3 Feedback from NGO Continued consumer consultant involvement after the project

5. Evaluation by Consumer Consultants

On Monday 18 June 2001 a focus group was held with four of the consumer consultants. It was facilitated by an external person and recorded by a staff member of BISDIV. Two consumer consultants were unable to attend but had input into the focus group by reading the draft focus group report and adding their contributions. The project co-coordinator was also in attendance.

RECRUITMENT AND TRAINING

The consumer consultants had different motivations for applying for the position of consumer consultant. Two were motivated by the topic of consumer participation as they had an interest in this area and an interest in working for their respective communities. One person had known the project coordinator and felt positive about working with him again and was also motivated by the idea of gaining experience in this project. Another person did not have any motivations as it had been suggested to him to apply and he happened to be 'in the right place at the right time'.

All the consumer consultants had high expectations of the project and their own role within the project. Two consultants were surprised that their respective communities were easier to approach than they had thought and were also surprised to discover the magnitude of difficulties people had experienced with the health system in Australia. One consultant had conducted several other community projects and therefore had realistic expectations of her role but had high expectations of the project itself.

All the consumer consultants praised the training they had received at the beginning of the project. One of the highlights of the training had been the delivery style of the trainer (the project coordinator) and the egalitarian manner in which training had been delivered. The following aspects were best remembered and used in the project:

- experiential exercises involving self expression such as drawing
- the handouts

- listening & recording skills
- communication skills

All the consumer consultants felt that the training had prepared them for the job ahead but some felt that an extra day of training would have been useful. Additional topics suggested were: handling conflicts of interest, understanding the Australian context in terms of people feeling more free to speak out, and generally, more time could be given to the discussions.

COLLECTING INFORMATION

All the consumer consultants had experienced some challenges in approaching members of their community and encouraging them to participate in the project by way of completing an interview/questionnaire. Some of the issues encountered were:

- people were suspicious of the project and the questionnaire
- people thought the project would not achieve anything and therefore it was pointless to participate
- consumer consultants had to disclose personal information to people before they were willing to complete the questionnaire
- consumer consultants had to observe social customs before they could mention the questionnaire and proceed with an interview, and this was time consuming
- the interviews had a significant emotional impact on the consumer consultants
- some people questioned how much the consumer consultant was being paid

Some consumer consultants found that their role had placed them in an awkward situation of being blamed for inefficiencies in the health system with people saying things like: "See your project hasn't done anything to help my situation. When will your project change the system?"

It appeared that one consumer consultant, who was well known in the community for her participation in community projects, had fewer difficulties in explaining the consumer consultant role and experienced fewer difficulties in approaching people because her motivations were already established.

Most interviewees had asked for absolute anonymity and confidentiality.

The interviews had an emotional toll on the consumer consultants as difficult issues were discussed. It appeared that none of the consumer consultants had approached the project coordinator for emotional support but had instead sought such support from personal contacts. Despite the emotional toll, the consumer consultants also enjoyed the interviews. The main positive elements mentioned were: learning new things about their own community; feeling proud that community members could make worthwhile recommendations for change; being accepted by members of the community from a different religion; and the social contact.

The consumer consultants had some recommendations in relation to approaching people for an interview:

- be friendly and courteous
- observe social customs
- explain the role and especially the limits of the project clearly
- explain the role of the consumer consultant carefully

FEEDBACK SESSIONS

All the consumer consultants felt that the feedback sessions with service providers were difficult and sometimes disempowering. Service providers were generally defensive, mistrusted the consumer consultants or were disinterested in the idea of consumer feedback and/or participation.

Some of the suggestions the consumer consultants made to maximise the benefits of feedback sessions and to make the process easier for other consumer consultants included:

- Ongoing feedback sessions and dialogue so that consumer feedback is an ongoing process and not just a one-off project-linked event. This would lock services in to an ongoing response.
- Having all the consumer consultants present at a feedback session as this was not only important for gaining individual experience but there was also 'safety in numbers'.
- Consumer feedback should be face-to-face and not just in a written report.

Some consumer consultants had observed that their feedback had made an organisational impact on one service and this had heartened them. However, overall, the process was described by one consumer consultant as a '*brick wall*'.

CONSUMER REPRESENTATION

Overall the consumer consultants enjoyed this aspect of their role as they had opportunities to learn about other projects and areas of health care by attending seminars and forums. They also appreciated the importance of having a consumer voice at forums and seminars. However, some of the crowded health coordination meetings were perceived as merely lip service, with one consumer consultant describing them as '*empty talk*'. It was suggested that in the future, all consumer consultants attend the coordination meetings so that once again, experience could be gained and more numbers could provide some safety and back-up at difficult meetings.

ADMINISTRATION AND SUPPORT

The consumer consultants related experiences that indicate there were some administrative difficulties in the project. Some consumer consultants were still not entirely clear which organisation they were actually working for. They also questioned the logic of being paid by one of the organisations in the project – one consumer consultant joked that he didn't know if he would be paid after the feedback session with that particular organisation! There had also been some administrative obstacles in receiving correct pay and in tax arrangements.

In all, it appears that the consumer consultants were in need of clearer guidance about project structure, roles and relevant contacts in the project administrative team.

All the consumer consultants felt that the remuneration offered by the project was inadequate for the complex job they had performed. One consumer consultant described the pay as '*pocket money*' and there was also a consensus that the project was too short and therefore could only be expected to have limited impact.

Generally, the consumer consultants felt well supported and found the regular meetings to be very helpful and supportive. One consumer consultant had used a personal contact for emotional support even though she felt that the project coordinator was approachable.

All the consumer consultants were able to cite personal or professional gains they had made as a result of their involvement in the project. All had learned new things about their community and the health system and some consumer consultants had found the project to be a '*growing experience*'. One consumer consultant was able to use experience and skills gained in the project in another job and another consultant had built on her experience gained in other projects.

SUMMARY

- The training was a highlight and well received. Future training could be extended by one extra day.

- Approaching people for an interview was challenging at times and it was important to explain very clearly the role of the consumer consultant and the purpose and limitations of the project.
- Members of the relevant ethnic communities had been very suspicious of the project, sometimes of the consumer consultants, and were skeptical about the impact of the project on health services.
- The interviews had an emotional toll on the consumer consultants but generally, they felt well supported by the project.
- The feedback sessions with service providers were generally difficult and disempowering as service providers were defensive and lacked trust in the consumer consultants, or were simply not interested.
- It was recommended that for effective consumer feedback to occur, projects like this need to be long-term and ongoing so that a system of dialogue can be developed to encourage services to respond to feedback.
- Consumer representation had been a positive experience as it provided a learning opportunity about other projects and aspects of the health system
- There were some administrative problems in the project and the consumer consultants did not have a clear concept of the project structure and their role within it.
- The consumer consultants felt they were inadequately remunerated for their work, which had been difficult, challenging, complex, but overall rewarding.

CONCLUSION

In the area of newly arrived refugees, consumer participation, partnerships, consumer feedback and other terms have no meaning if the participants in projects, programs or initiatives are not valued and supported. There is overwhelming evidence of the need for consumer participation in the health system, reports, studies, research, consultation and other works repeatedly have indicated the poor assistance and resourcing of meaningful consumer participation. Responses usually are tokenistic, with restrictive budgets and lacking sustainability.

Community members and service providers were somehow surprised at the level of support/resources this project had. The key learning's and achievements clearly showed that consumers organised around a vision of collectiveness, solidarity and social justice can make the difference.

For some health service providers it was the first time they heard about community issues first hand without bureaucratic filters. A community based organisation is including part of the feedback in its strategic planning; a hospital management and heads of department were sorry and apologised to a newly arrived family who had a grievance against the institution; the management of a primary school said sorry to a single mother after an accident her son was involved in. The consumer consultants channelled all these actions/results as direct products of the Project. All service providers were thankful for the opportunity to discuss and understand cultural, social and religious differences and being able to modify, adjust or change practices.

The Refugee Health Partnership Project in Brisbane has been a success. However the new emerging communities are waiting the three levels of Government to commit themselves to resource programs that are sustainable, valued and value based. This kind of community participation would facilitate to newly arrived refugees the bases for a cultural and social adjustment that is empowering, rapid and proactive thus becoming productive members of our society.

Finally the Brisbane Inner South Division of General Practice is seriously considering the funding for a dedicated position having as one of its roles refugee and other humanitarian entrants health. It is envisaged that BISDIV will negotiate with the Commonwealth Department of Health and Aged Care and other potential funding bodies the terms and conditions for this overdue initiative.

REFERENCES

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