

FEEDBACK, PARTICIPATION AND CONSUMER DIVERSITY

AN ANNOTATED BIBLIOGRAPHY

Produced by the National Resource Centre
for Consumer Participation in Health

A Consumer Focus Collaboration publication

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The Commonwealth Department of Health and Aged Care has funded a range of projects to strengthen consumer participation in health through its Consumer Focus Strategy. These projects are overseen by the Consumer Focus Collaboration, which is made up of consumer organisations, professional organisations, Commonwealth, state and territory health departments, and private sector representatives. The Collaboration works to increase effective consumer participation at all levels within the Australian health care system.

Projects funded through the strategy are intended to promote, integrate and disseminate information and increase consumer involvement in health service planning, delivery, monitoring and evaluation. The Consumer Focus Collaboration publication series documents these projects.

A wide range of organisations participate in the Consumer Focus Collaboration, representing a broad range of views and interests. Consumer Focus Collaboration publications do not attempt to reflect all of the views of the individual organisations and jurisdictions represented on the Collaboration. However they do demonstrate the shared perspective on strategies for building a strong consumer focus for national action on quality and safety.

For information on the availability of the publications, contact the Information Manager, National Resource Centre for Consumer Participation in Health, ph: (03) 9479 3614, free call 1800 625 619, or check the web site (<http://nrccph.latrobe.edu.au>).

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Foreword

Building a safe, high-quality health care system means that people managing and working in the system need to work together with consumers and the community to achieve sustainable improvements and maintain public confidence in the system.

The Consumer Focus Collaboration publication series provides practical tools to support consumers and health care providers to achieve this goal. These tools have been developed through projects funded by the Commonwealth Department of Health and Aged Care.

The Consumer Focus Collaboration, established in 1997, has played an important role in taking forward work on consumer participation at the national level. The Collaboration is a national body with representatives from consumer, professional and private sector organisations, and all health departments. Its aim is to strengthen the focus on consumers in health service planning, delivery, monitoring and evaluation in Australia.

The Collaboration is taking the lead in fostering this active partnership between consumers of health care and those who provide that care.

The resource guides, reports and issues papers that make up the publication series have been designed to provide health care consumers, service providers and managers with ideas and information about how to work together in partnerships.

Strengthening the voice of consumers in the health system requires a multi-pronged approach. This publication series reflects the commitment of the Consumer Focus Collaboration to provide strategic resources in a number of areas including education and training, building consumer capacity to participate, building provider capacity to respond to consumer need, and research into aspects of consumer involvement in health services.

Consumer Focus Collaboration
June 2000

ANNOTATED BIBLIOGRAPHY

This bibliography is in alphabetical order by author's surname.

Author: **Abbott-Chapman, Joan and Easthope, Gary 1998**

Title: Participation and inclusion—a discourse of welfare or a discourse of rights?

Details: *Australian Journal of Social Issues*, vol 33, no 2, pp99–118

Purpose

To explore issues about inequality, disadvantage, participation and inclusion based on a study of students with physical and sensory disabilities in post-compulsory secondary education.

Participants

Eighty-two students with disabilities.

Method

Face-to-face interviews in which students were asked about their backgrounds, disability and its impact on education, self health image, social networks, expectations and wishes and feelings of control over education.

Findings

Some of the students that teachers and researchers identified as 'disabled' did not identify themselves as disabled and would not participate in the survey.

Key issues identified include that many students saw having a disability as neither a medical nor a welfare issue; students considered they had good health; students with disabilities were highly motivated and performed as well as students without disabilities in education; students felt they needed more time to complete assignments and tasks; and the biggest barriers to education included the attitudes of some teachers and failure of institutions to see that people with disabilities were not one homogenous group. Students wanted to be able to help themselves and participate in self help groups. Drawing on this study, the authors argue that the discussion about equity could be more usefully framed if it was located in discourses about rights rather than welfare.

Author: Bartram, Mike, Abell, Anita and Murphy, Rue 1999

Title: *Involving users: improving the delivery of health care*

Details: National Consumer Council, p29

Purpose

This work starts by recognising that often those with the poorest health have the poorest access to services and to participating in the development of services. In order to begin to redress this, this two-year project aimed to identify practical ways of involving black and ethnic minority communities in improving a health service located in an area where 28 per cent of residents are from these groups.

Participants

Consumers from black and ethnic minority groups and service providers.

Method

The project was overseen by a working group, chaired by the director of nursing and involving staff from each hospital division. Census information was utilised to identify relevant groups and letters asking for information about how the project should proceed were sent to 42 local black and ethnic minority groups and six national organisations. Groups that did not respond were contacted by telephone.

Through this process it was identified that hospital staff should go to speak to communities in community settings at times appropriate to participants. The five largest groups were selected and a senior staff member was given responsibility for organising these meetings. Community workers were also involved as the contact person for the project and in explaining the project, promoting discussion and in one case interpreting (for one group a professional interpreter was employed).

Open-ended questions about service quality were asked at the meetings. Notes from the meetings were sent to the community contact person for verification. A second round of meetings with the same communities was organised to see if further issues were raised. Key areas for action were identified, specific projects in these areas were developed and costed and a time frame was developed. A project leader was employed for one of the projects (developing the interpreting service) to be run as a pilot.

The hospital worked with community groups to develop solutions to many of the issues raised. For some of the issues, such as interpreting, this included developing a document about the interpreting system and where it could fail,

consultation with community groups about some of the best ways to find out when they needed an interpreter and how to best provide the service.

Findings

Initial contact by telephone was found to be more appropriate than contact by letter. Phone contact allowed staff to find out more about each community, how best to talk with community members, to explain the project and build support for it.

Key issues raised related to interpreting and translation, staff attitude, food, cultural awareness and complaints and comments. Some community groups also raised the issue of needing more nursing staff from different backgrounds and suggested that the hospital might run information sessions in schools about nursing as a career. Generally communities were very willing to participate and some identified that they had never been asked about services before.

Barriers to participation encountered in the project included that: only the five largest groups were included and that some of these groups had been consulted before and had never heard about the research results. In addition, the project team noted that while users' expectations were often low they did need to consider whether the project might raise expectations too high. They also noted that unpaid participants should not be expected to behave like paid staff. Barriers from the provider side included that staff often fear the unknown and see consulting with diverse groups as too difficult. The authors recommend that 'the best way of overcoming this fear of the unknown is to do some research about the communities and evaluate it'.

Involving community groups in problem solving around service development resulted in some creative ideas about improvements. In addition, consulting with five groups who hold different beliefs and have diverse needs resulted in developing interpreting services that were appropriate to a range of communities.

Key issues for services identified in this project were: understand the benefits and limitations of written documents; understand your starting point; allow enough time to build good relationships and implement change (and set realistic deadlines); allow enough money; establish wide support for the work (amongst communities and service management); utilise a range of consultation methods; have open-ended discussions with communities.

Useful tips for successful consultation include: involve community leaders; hold meetings in community settings at appropriate times to community members; give everyone a chance to contribute (this includes sometimes holding women-

or men-only meetings, waiting after the meeting so people who may not have wanted to speak in the meeting can speak individually); make the most of small group meetings where issues can be discussed in depth and some solutions proposed (keep in mind the limitations of consulting with a small number of people); build relationships with people from different parts of each community (such as men and women, younger and older people); go back to groups to further discussions and build relationships of trust; go with the flow in meetings; try to get everyone's views; use interpreters where appropriate; and have a longer-term plan which you tell communities about.

Author: Bhatti-Sinclair, Kish 1999

Title: Evaluating social work and medical practice with black and ethnic minority groups using the clinical audit model

Details: *British Journal of Social Work*, 29, pp303–320

Purpose

This paper argues for the development of quality assurance mechanisms that ensure services are developed to meet the needs of all members of a society and not just those from majority groups. An audit process to assist in the development of anti-racist and anti-oppressive social work practice is outlined.

The audit model can:

- assist in quality improvement, education and training and effective resource use;
- be done by internal or external auditors either from the same discipline or from different disciplines; and
- focus on a specific area or the organisation's practices.

Participants

The interviewees included 91 staff and 37 consumers. Nine of these staff and all of the consumers were members of black or ethnic minority groups. Service funders were also interviewed.

Method

The audit was undertaken by an external team of two women (one white and one black) at four general practices and two hospital departments. Funders and staff were consulted throughout the whole audit cycle.

The audit followed a cycle in which the area of focus was identified; standards developed; practice observed and compared to the standards; interviews

undertaken, recommendations made and action plans developed; implementation of changes; and re-audit.

Policies, practices, staff and client views were examined. The audit team offered advice, information and training to staff, identified ways of improving services for people from black and ethnic minority groups and provided feedback to the services.

Findings

Responses to the recommendations made after the initial audit were positive at only one site. At other sites responses were cautious, defensive or seen as an external attack.

Few staff were familiar with the Patient's Charter or equal opportunities policies and little training was provided about these. Information (such as preferred language) required for the provision of appropriate services was not systematically recorded. The communication skills of health care providers and employment practices were also significant issues.

Development of specific standards can be difficult and needs to relate to the specific issue and the service providers and clients. While external review creates great opportunities for improvement and collaboration, it can also create great anxiety amongst professionals.

It is suggested by the author that undertaking face-to-face interviews with clients in their own environments may overcome the biases recorded by service providers when they undertake satisfaction surveys. In addition, employing skilled interviewers from similar backgrounds to the interviewees may also improve the quality of the information obtained.

The author concludes that audit based on the principles of action research which includes planning, acting, observing and reflecting can be a very useful tool for developing organisational practice appropriate to both service users and staff.

Author: Boston, Vera 1999

Title: Building communities in inner Melbourne: a case study

Details: *Australian Journal of Primary Health-Interchange*, vol 5, no 1 pp70–75

Purpose

A community liaison committee was established by North Yarra Community Health Service Board of Management to address a range of issues created by amalgamation of three community health centres and large funding cuts. One

of the consequences of these two events was that the strong links each community health centre had with diverse community groups were broken and groups felt alienated from the amalgamated service.

Method

Three board members, one from each of the amalgamated services, formed the Community Liaison Committee. A staff member was given the role of developing links with communities in their own settings. Quarterly community liaison meetings were held in public venues, concurrently translated into eight languages, and were attended by between 100 and 150 people. The service pays local communities to provide refreshments and time is made for socialising and informal discussions. Transport is provided to all who need it.

Following the success of the original meetings, communities were invited to nominate representatives to join the Community Liaison Committee in order to provide input into the governance of the health centre.

Findings

Key elements of the success of this model include that all staff are committed to community participation; community liaison skills are valued and nurtured within the organisation; time is committed to community liaison; the provision of interpreters at meetings allows people to participate in complex discussions about policy, quality and service delivery and sends a message about the organisation's commitment to involving and listening to community groups; even when the area covered by the service is small, transport may be required to enable all to participate; and valuing community input into service development has many benefits including service improvement, building a service that the community is happy with and building social capital.

Author: Brown, Stephanie and Lumley, Judith 1997

Title: *Survey of recent mothers: women's views and experiences of maternity care*

Details: Centre for the Study of Mothers' and Children's Health

Purpose

To seek feedback about maternity care from recent mothers in Victoria

Participants

One thousand three hundred and thirty-six women who had utilised a range of maternity services in Victoria.

Method

This survey built on findings of a review of birthing services undertaken in Victoria in the late 1980s and was designed to seek feedback from women using different models of care. Questionnaires were posted to most women who gave birth in Victoria over one two-week period, six to seven months after they had given birth.

Questions about socio-demographic characteristics, risk status and views of care in pregnancy, labour, birth and post-natally were included and women were asked to rate them on a five-point scale. Any response other than the top level (very good) was taken to indicate some level of dissatisfaction.

Findings

There was a 62.5 per cent response rate. While the sampling procedure resulted in a reasonably representative sample of mothers, women of non-English-speaking backgrounds, younger women and single women were under-represented.

Women reported significantly different levels of satisfaction with different models of care, with private obstetric and birthing centres achieving the highest rates of satisfaction. When the social and obstetric characteristics of women using different types of service were adjusted for, these differences remained. Women who were the most socially disadvantaged tended to receive the models of care which got the least positive rankings. The authors make recommendations for changes to practice based on the survey results.

Author: Callan V and McElwain D 1980

Title: General considerations in the research of ethnic minorities

Details: *Australian Psychologist*, vol 15, no 2, pp181–187

Purpose

To outline some of the issues researchers need to reflect on when developing research projects with ethnic minority groups.

Method

Reflection on experience of research field work by the authors

Findings

Key issues include: develop detailed proposals and be open and honest about what the research is aiming to do; identify appropriate time lines around the needs and lifestyles of the relevant community; develop an understanding of some of the political and cultural issues and differences within communities

(try to ensure that these are the issues identified by the community and not the issues the researcher thinks are important); identify other work done in the same area and/or with the same community to promote consultation between researchers and to reduce duplication; spend time talking with people from the community to identify issues; if tools of measurement are going to be used, ensure they are relevant to the cultural background of the people in the study; employ appropriate interpreters and bilingual workers; provide appropriate training to people doing the interviews; develop ongoing links with communities; and provide feedback to communities.

Author: Campbell, Jean 1994

Title: *Consumerism, outcomes, and satisfaction: a review of the literature*

Details: Available online at
< <http://www.madnation.org/citations/consumerism.htm> >

Purpose

To review consumerism, outcomes and satisfaction in the context of trends in the American health system.

Method

Review

Findings

This paper highlights the importance of consumer participation in assessing and improving quality of care. Issues discussed include: context, measuring performance, consumerism, developing consumer core data sets, self-help outcomes, wellbeing and personhood outcomes, empowerment outcomes, recovery outcomes and iatrogenic effects and negative outcomes, measures of satisfaction and dissatisfaction. The review concludes with a discussion about developing a new theory of outcomes management in which consumer participation is central.

Author: Capetola, Teresa (1990)

Title: Non-English-speaking background women's experiences of hysterectomy

Details: Women & Surgery Conference Proceedings, *Healthsharing Women*, pp13–18

Purpose

Of the 2000 women who had a hysterectomy in Victoria in 1987–88, 751 were from non-English-speaking backgrounds. This paper aimed to address the gap in research about the experiences of these 751 women.

Participants

A total of 163 women, mostly from Greek, Spanish-speaking, Turkish and Vietnamese backgrounds.

Method

A literature search was conducted. The researcher approached ethnic health workers to seek permission to attend women's groups. Four meetings were arranged with each group. At the first the researcher discussed the research with the women; at the second a workshop was held to discuss hysterectomy; the third meeting was a follow up session to provide information and clarify information from the women and the fourth was an evaluation. Interpreters were briefed about the research and attended each meeting. The researcher was introduced to women by the ethnic health worker.

Face-to-face and telephone interviews were also conducted with women identified by health workers and were undertaken at a place specified by the women involved. Interviews were informal with no structured questionnaire.

Greek, Spanish-speaking, Turkish and Vietnamese women were chosen as they represented various lengths of residence in Australia of migrant groups.

Findings

There was no identified literature on the experiences of women of non-English-speaking background and hysterectomy. A key issue identified by women was lack of information. Lack of information resulted in: some women not knowing what had happened to them, not knowing how to cope with the effects of having a hysterectomy and experiencing real fear about their health. Women also received misinformation and did not know what sort of questions to ask. As a consequence, many women had not actually given 'informed consent'. Other issues included the impact on women's identity and sexuality, lack of interpreters and resultant poor communication, impacts on families, and lack of support for women.

Author: Cardone, Denise 1999

Title: Exploring the use of question methods: pictures do not always help people with learning disabilities

Details: *The British Journal of Developmental Disabilities*, vol 45, no 89, pp93–98

Purpose

The aim of this study was to identify a reliable, easy-to-score method for seeking information from people with a learning disability. Two previously developed methods, personal questionnaires and a pictorial questionnaire, were compared for reliability. Personal questionnaires are where participants choose one of three answers to a question; each answer is printed on a separate card. Pictorial questionnaires ask participants to view two pictures representing the extremes of a scale and draw a line which represents where their view falls between these extremes. While previous reports indicate that both methods are effective, with the pictorial scale being more useful for those with lower levels of language ability, the authors believed that some methodological problems may have biased the previous results.

Participants

Twenty-eight people with learning disabilities (13 men, 15 women, with an average age of 39.54 years).

Method

Confidential, semi-structured interviews at locations identified as convenient by participants were undertaken.

Findings

People with better language skills gave the most reliable answers using both questionnaire methods. Unlike similar studies, the use of pictures was not found to be more effective for people with lower language skills. Cardone suggests that rather than the nature of the method for eliciting responses (eg words or pictures), it is the way the questions are asked and the range of possible options that determine whether people respond and the reliability of their responses. Cardone noted that participants got frustrated by being asked the same question in different ways and concluded that while reliability checks for quantitative questionnaires are important, qualitative research may be a more appropriate way of seeking feedback from people with learning disabilities.

Author: Centre for Development and Innovation in Health, North East Women's Health Service and Women and Mental Health Advisory Group 1994

Title: *Community support for women of non-English-speaking background with psychiatric disabilities: strategies to improve access to services in the North East region*

Details: North East Women's Health Service, p86

Purpose

This project was undertaken in response to agencies identifying that women from non-English-speaking backgrounds with psychiatric disabilities were not accessing appropriate support services. The project was designed to explore the needs of these women after they were discharged from inpatient psychiatric services. This included identifying support services, barriers and issues, and strategies for meeting these needs.

Participants

Women of non-English-speaking backgrounds with psychiatric disabilities living in the North East Region of Melbourne, service providers and other key stakeholders.

Method

The project methodology included a literature review, face-to-face or telephone interviews with women and with service providers, focus groups with women of non-English-speaking background and a workshop with health and community workers. Women willing to be interviewed were contacted through community based workers and focus groups were conducted with existing women's groups.

To address the issue of not being able to obtain a representative sample of women from all the non-English-speaking background communities in the region, the researchers sought information from a range of the sources, including workers who had direct contact with women from the target group.

Methodological limitations included: the short time frame for the project did not allow relationships of trust to be built between the project workers, women and service providers, thus limiting the number of participants and the type of information provided; because of their illness some women were not able to participate or to answer some questions; women who were not utilising community services were not able to be contacted; and some services did not want to participate.

Findings

Many barriers and issues for these women in accessing community supports were identified. The project workers grouped these as follows: supportive family and community networks; good discharge planning; access to a range of services; practical support; outreach services; well coordinated services; services that are culturally and linguistically relevant and have expertise in gender, ethnic and mental health issues; choice of gender of service provider and women-only services and programs. Key recommendations addressing these issues were made.

Author: Center for Mental Health Services 1998

Title: *National people of color consumer/survivor summit meeting report/summary: Washington DC November 9–10 1998*

Purpose

A National People of Color Consumer/Survivor Summit was held by the Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Mental Health Services in Washington to involve consumers from these groups in developing culturally appropriate services. Key issues addressed included meaningful participation in system design, delivery and evaluation; access to high quality, culturally appropriate services; rights; peer-run services; and access to other community based services such as housing.

Participants

People of colour, including African-American peoples, Native Americans, Hispanic/Latino peoples and Asian/Alaskan/Pacific Islander peoples.

Method

Teleconferencing had been utilised for a number of years to facilitate the development of networks of people working to make the system responsive to diversity. A number of regional meetings were also held prior to the conference to identify the types of services consumers most need. The conference was held to provide a venue for face-to-face meeting to enable consumers to participate in changing the way the service system operates so that culturally appropriate and effective services are developed. Key decision-makers from SAMHSA also participated in the conference. The meeting was facilitated by a health professional who was himself a person of color and who had a great commitment to working on issues of diversity in healthcare. Participants were asked to think about and discuss their goals for the summit. Breakout sessions were held to discuss impacts of health care reform including resource development, access to services, networking and organising, service delivery and education. A range of organisations gave presentations about how they had involved people of color in health service development.

Findings

A range of common goals emerged including personal professional development and networking; group development to enable the development of effective action and strategic plans; learning about policy and managed care issues and establishing links to disseminate information; and a range of issues about influencing service delivery.

Participants identified a range of problems with managed care and thought that people of colour had unique problems in accessing managed care services. Some of the problems included reduction in services (and numbers of visits to services) to Medicaid consumers by managed care companies who have won Medicaid contracts; competition for services with other consumers; lack of choices about service providers; language issues (including lack of access to services provided in languages other than English and overuse of technical language and jargon). The group also identified a number of solutions to these problems such as: suggesting managed care organisations could encourage and sponsor peer support and peer run services; work towards having cultural competency scored by quality assurance committees and have it linked to patient satisfaction; build up the influence of consumer people of colour by SAMHSA employing them for their experience as much as for their educational background; encouraging other consumers to vote and provide transportation to polling booths if necessary; consider keeping a fee-for-service option. Other issues included that managed care companies should all accept Medicare and Medicaid consumers, that services should be accessible by public transport, that consumers/survivors should be hired by these companies and alternative treatments should be included in service provision.

Working groups were established at the end of the conference to further work on education and training, communication, resource development and coordination and oversight.

Author: Cheek, Julianne, Fuller, Jeff, Gilchrist, Sue, Maddock, Agnes and Ballantyne, Alison 1999

Title: Vietnamese women and pap smears: issues in promotion

Details: *Australian and New Zealand Journal of Public Health*, vol 23, no 1, pp72–76

Purpose

To explore issues for Vietnamese women around participating in cervical screening programs. This study was undertaken because while Vietnamese-born women living in Australia have a significantly higher incidence of cervical

cancer than other Australian women, little was known about their participation in screening programs.

Participants

One hundred and ninety-nine Vietnamese women living in Adelaide.

Method

The electronic telephone book was utilised to randomly select Vietnamese households from lists of the most common Vietnamese names. These households were contacted and if women agreed to participate a face-to-face interview was arranged. Interviews were undertaken in Vietnamese or English by Vietnamese women trained as interviewers. A structured questionnaire with close ended questions was used in the interviews. The questionnaire was translated into Vietnamese by an accredited translator, and a Vietnamese researcher worked closely with the interpreter to ensure the questions were well translated. The questions were piloted with Vietnamese health workers and their clients.

Women were asked to self report on a number of issues, such as their use of health services; their knowledge and beliefs about cancer and pap smears; and demographic details. The survey will be repeated after two years to determine if changes have occurred.

Findings

The study reports on women's beliefs about cancer; their knowledge of pap smears and participation in screening; where they get information about pap tests; and their views of them.

Author: Cockburn, Jill, Pit, Sabrina and Redman, Sally 1999

Title: Perceptions of screening mammography among women aged 40–49

Details: *Australian and New Zealand Journal of Public Health*, vol 23, no 3, pp318–321

Purpose

To interview women aged between 40 and 49 to explore their views on screening mammography and their support for targeting this group of women for free screening.

Participants

Two hundred women aged between 40 and 49 who could speak English and who had not had a mammogram.

Method

Participants were selected randomly from the phone book. Telephone interviews were undertaken by a market research company in the evenings and on weekends. A first phone call was made to identify women to participate and to ask women about whether they thought screening mammography should be introduced for women between 40 and 49 years of age. Women were asked if they would participate in a second interview and those who agreed were sent information about the benefits and disadvantages of screening so that all women had access to the same information.

Findings

Women in the sample tended to be better educated, more likely to be working and to be married than other women in this age group, using comparison with national data. Women thought that they should be fully informed about the benefits and disadvantages of screening mammography in order to inform their decision-making. Sixty-six per cent of women supported government funding for screening mammography. The authors conclude that 'Community views are a helpful contribution to debates about policy when existing data are ambiguous.'

Author: Cooper, David and Jenkins, Anne 1998

Title: *Obtaining consumer feedback from clients of home based care services: a review of the literature*

Details: Australian Institute of Health and Welfare, p53

Purpose

To review the ways services had obtained feedback from groups of consumers who were most often users of home and community care (HACC) services in order to inform the development of consumer feedback methods to be incorporated into a HACC service standards quality appraisal process. The key consumer groups utilising these services, and consequently chosen as the focus of the review, were frail and disabled older people, younger people with disabilities, and carers. The review also looked at issues for people with 'special needs' within these groups, including people with dementia, people from non-English-speaking backgrounds, Indigenous people, people who are financially disadvantaged and people living in rural and remote areas.

Method

Twenty-four reports published in Australia since 1996 were reviewed. The reports were identified by searching databases and by contacting 70 key individuals and organisations to identify unpublished reports. Information

from these reports was analysed in the context of an international literature review.

Findings

This review identified that while some studies used multiple methods, self-administered questionnaires were the most commonly utilised survey method (70 per cent of studies). In 17 per cent of the studies personal interviews were conducted, 13 per cent utilised focus groups and 13 per cent conducted telephone interviews. Seven key issues were explored in these surveys: consumer satisfaction with services, consumer outcomes, consumer characteristics, needs of consumers, consumer expectations and suggested service improvements, service experiences and consumer knowledge.

Key observations from the international literature include: satisfaction surveys often report high levels of satisfaction, suggesting that survey instruments may lack 'discriminate validity' or that data collection may be biased or confounded. High levels of positive results do not allow distinction between different service providers or models, nor are they useful in assisting in identification of how services can be improved. The authors propose that factors such as social desirability, acquiescent responses, fear of reprisal, gratitude, low expectations and loyalty to paid carers might all produce biases towards positive survey results. They also identify that while consumers were often unable to criticise their direct care givers, they were more critical of the system or of managers.

Low response rates (especially if those least satisfied are less likely to respond) and use of surrogate respondents can also result in survey biases. Response rates can be improved if health professionals personally deliver the questionnaire; however, consumers are more likely to respond positively if the 'researcher' is seen to be a member of the service delivery organisation. When a carer or health professional completes the survey on behalf of a consumer, it is possible that the perceptions of need and satisfaction of the surrogate respondent are quite different to those of the consumer.

Survey questions which ask about specific aspects of a service rather than global or macro aspects of a service were more useful for obtaining information for service planning and evaluation. In addition, those aspects of care important to consumers should be identified and included in the survey.

The report also explored structural and cultural barriers to participation in surveys for people from specific groups, including older people, Indigenous peoples, people from non-English-speaking backgrounds, younger people with disabilities, and people living in rural and remote regions.

In relation to methodologies in general, the authors make the following observations: qualitative methods can elucidate more of the doubt and anxiety than quantitative methods, but often have a small sample size; questionnaires allow time for consumers to reflect, can be targeted towards specific groups, are less expensive than many other methods, and enable larger sample sizes. The type and content of the data collected can be limited by the questions. Including open-ended questions can minimise this data limitation but creates more difficult analysis. In addition, low response rates can result in biases and 'poor questionnaires can act as a form of censorship imposed on clients'. The pros and cons of personal interviews, telephone interviews and focus groups were also discussed.

Author: Curtis, J Randall, Patrick, Donald L, Caldwell, Ellen, Greenlee, Heather and Collier, Ann C 1999

Title: The quality of patient-doctor communication about end-of-life care: a study of patients with advanced AIDS and their primary care clinicians

Details: *AIDS*, vol 13, no 9, Lippincott Williams & Wilkins, pp1123–1131

Purpose

To examine communication about end of life care between people with advanced AIDS and their doctors. This included developing and validating a tool to measure quality of communication and exploring doctor and patient characteristics which create good communication.

Participants

Fifty-seven people with advanced AIDS and their primary health care provider

Method

Before this study, focus groups had been conducted with consumers to identify four key items which determine quality of communication. Consumers participating in these focus groups were not included in the study.

Consumers were recruited through advertisements at community-based organisations, universities and clinics; sending clinicians letters about the study with posters to put in their clinics; and through a register of people interested in participating in studies held at a university. The consumer's clinician was then approached to participate.

Structured face-to-face interviews were conducted with consumers and structured telephone interviews were conducted with clinicians. These interviews included the previously developed questions about communication

and questions about satisfaction with care (using a generic set of questions and a set of questions developed specifically for interviewing people with AIDS).

Interviews with consumers and clinicians were compared to identify whether they had the same perceptions about what had been communicated. People who spoke languages other than English, who had dementia or who had been seeing their primary health care provider for a short time were excluded.

Findings

The internal validity check indicated that the questionnaire was a valid measure of quality of communication. In almost 30 per cent of pairs there was disagreement between consumer and clinician reports about the level of communication. There was a relationship between socio-economic status and ethnicity and the quality of communication. There was also a relationship between the level of reported communication and the level of satisfaction with care.

Author: Dagnan D, Dennis S and Wood H 1994

Title: A pilot study of the satisfaction of people with learning disabilities with the services they receive from community psychology services

Details: *The British Journal of Developmental Disabilities*, vol 40, no 78, pp38–44

Purpose

To develop question formats which enable the collection of information about service quality and which can be utilised for comparisons over time from people with learning disabilities. In addition, to determine patient satisfaction within a psychology service.

Participants

Eleven people with learning disabilities, all with reasonable levels of language ability.

Method

People with learning disabilities who had utilised the psychology service at least five times within the last year were interviewed in their workplaces. The interviews were semi structured and included some structured questions. The structured questions were asked in three different formats; a simple either/or question, provision of pictures at either end of a scale; and questions with three possible responses.

Findings

Reliable responses were achieved with all of the closed-question formats, with more sophisticated information provided when questions were asked in a way that gave people a range of answer options. Answers to open-ended questions provided valuable information about the psychology service. The authors conclude that people with learning disabilities are able to give useful information about the quality of services using their methodology.

Author: Davis, Barbara A and Duffy, Elaine 1999

Title: Patient satisfaction with nursing care in a rural and an urban emergency department

Details: *Australian Journal of Rural Health*, 7, pp97–103

Purpose

To explore and compare consumer satisfaction with nursing in emergency departments in rural and urban settings

Participants

One hundred and three consumers of rural and urban emergency departments.

Method

Consumers using emergency departments were given a questionnaire to fill in. There was a response rate of approximately 84 per cent.

A Consumer Emergency Care Satisfaction Scale (with a five point Likert scale) was used to measure satisfaction. Two open-ended questions were added to the questionnaire—one asking about what people liked best and one asking what could have made the experience better. Participants were asked to complete the survey while they were in the emergency department, and asked to put the survey into a plain white envelope and put it in a collection box. There was no identifying information on the survey. Consumers who were excluded from participating were those younger than 16, those with psychiatric illness, people who were unconscious, people in custody and Category 1 patients.

Author: Davis, Cindy, Girgis, Afaf, Williams, Phillippa and Beeney, Linda 1998

Title: Needs assessment of rural and remote women travelling to the city for breast cancer treatment

Details: *Australian and New Zealand Journal of Public Health*, vol 22 no 5, pp525–527

Purpose

Women living in rural areas experience considerable difficulties in getting appropriate treatment for breast cancer. Rural women are more likely to have mastectomy rather than breast-conserving therapy than their urban counterparts. This study examined the needs of rural women travelling to urban centres for breast cancer treatment.

Participants

Eighty women living outside a metropolitan area with a breast cancer treatment centre.

Method

Women were sent a letter explaining the study and inviting their participation from a member of the team that had treated them. Women were assured that their input would not have any influence on the treatment they would receive. A short telephone survey, including questions about social and practical supports and the needs of women, was conducted with those who consented to participate.

Findings

Key findings were that most women had to stay away from their homes for an average of almost seven weeks in order to receive treatment for breast cancer. Many women received some kind of social support, but only 39 per cent received financial assistance. Other issues reported by women included the availability of social and practical support, lack of information about travel and accommodation assistance, and disruptions to family life and to work.

Author: Dent OF, Broe GA, Creasey H, Waite LM, Cullen JS and Grayson DA 1999

Title: Satisfaction with medical and allied health services among aged people in Sydney

Details: *Australasian Journal on Ageing*, vol 18, no 3, pp130–133

Purpose

To examine the satisfaction of older people living in the community with health care services over three years

Method

Participants were selected randomly from households so that people's perceptions of a range of services could be ascertained. Interviews covering demographic information, use of services and satisfaction were undertaken.

Findings

Very high levels of satisfaction with general practice services, specialist medical services and allied health services were reported by participants. Levels of satisfaction remained high over time and were independent of sex and age.

Author: Department of Human Services, Victoria (1999)

Title: *Evaluation of consumer participation in Victoria's public mental health service: final report*

Details: Mental Health Branch, Department of Human Services Victoria p44

Purpose

To evaluate consumer participation in Victoria's public mental health system

Participants

Consumers, service providers, policy makers, carers and peak bodies

Method

An evaluation discussion paper including evaluation questions was developed and circulated to area mental health services and consumer consultants. Information about the evaluation was put into the peak service provider and consumer organisation newsletters. Information was sought through provision of a free phone line; a questionnaire to service providers; focus groups with consumers and service providers separately; interviews and focus groups with consumer consultants; interviews with service managers, with government department staff and with other stakeholders such as carers and peak bodies; inviting written submissions; and a literature review.

Findings

Policy directions and local consumer and provider-driven initiatives have produced positive changes both in individual care and in consumer participation within the mental health system in Victoria.

While acknowledging change, consumers reported being less satisfied with the way consumer participation occurred and the changes that had been made, than staff, who often considered that they had made many changes.

The evaluation recommended a number of strategies to further consumer participation in Victoria's public mental health services. These include clarification and reinforcement of policy direction; increased support for consumer participation in child and adolescent, aged persons and state-wide mental health services; implementation of procedures, structures and monitoring to ensure consumer input is sought, heard and acted on; and training and development for staff and consumers.

Author: Department of Human Services, Victoria 1999

Title: *A guide to participation by older Victorians: developed for people who work with and for older people*

Details: Aged Care Branch, Victorian Department of Human Services

Purpose

A guidebook developed to assist aged care planners, service providers and consumer organisations to further involve older people in decisions that affect their lives. This guide explores the practical meaning of participation in aged care, raises awareness of consumer involvement in service planning and delivery, identifies practical techniques for participation and identifies ways consumers can be strategically linked into service planning and delivery.

Method

A project working group of 10 people over 60 years of age was established to oversee the development of the guide. The group comprised five men and five women from diverse backgrounds and was set up through advertisements in local newspapers. The role of the group was to debate and consider approaches to participation of older people in health system decision-making.

Consumer consultations were also held with older people, with specific forums for people from culturally and linguistically diverse backgrounds and for people with high needs. The results of these processes were reported at two workshops for service providers and a consultation strategy was developed.

Findings

A range of strategies to ensure participation of older people was identified and discussed. The findings included: invitations to comment face to face were preferred over invitations to comment on submissions; face to face interviews were preferred over self completion surveys and telephone surveys; well

planned, small meetings were useful; working groups at all stages of planning processes should be used in association with other participation strategies; and consultation with existing support groups was a good strategy. In addition, older consumers supported establishing consumer reference groups linked to service decision-making structures; establishing action groups to address specific issues within a service; consultations with peak organisations for policy issues as part of a process; consultation with people in their homes; asking consumers to act as research advisers; and establishing user panels.

Author: Department of Premier and Cabinet 1997, reprinted 1999

Title: *Victorian government Services: responding to diversity*

Details: Multicultural Affairs Unit, Department of Premier and Cabinet, p79

Purpose

Documents current Victorian government department programs to ensure equal access to government services by Victorians from diverse language and cultural backgrounds. Information is also included on services provided by some non-government agencies funded by the Victorian government.

Author: Doyle, Robert and Visano, Livy

Title: *A time for action: access to health and social services for members of diverse cultural and racial groups*

Details: Social Planning Council of Metropolitan Toronto, p35

Purpose

This was a study of access to mainstream health and social services in Toronto for members of diverse cultural and racial groups. The report examined two aspects of access: client access to individual services; and the access of consumers of diverse backgrounds to representation or participation in service planning, development, delivery and administration. Recommendations for improving access were made.

Method

Face-to-face interviews and self administered questionnaires were conducted with service agency staff. Interviews were held with consumers in seven languages. Consumer participants were identified using snowball sampling. Focus groups and meetings were also held. Questions focused on barriers to access and perceptions about how access could be improved. Case studies of four organisations showing leadership were also carried out and funding policies and programs of government departments were reviewed.

Findings

While organisations appreciated the issues, little work had been done to address them. Services had little information about the characteristics of their clients and there was little representation of diversity in the workforce, on boards or as volunteers. Consumers generally reported being dissatisfied with services. Access issues described by consumers included lack of information, personnel issues, poor communication, lack of availability of services, and lack of service-provider understanding of cultural and linguistic issues.

Author: Drug Treatment Services Unit, Aged Community and Mental Health Branch Division, Department of Human Services (1998)

Title: *Report on cultural and linguistic diversity and drug treatment services*

Details: Human Services, Victoria, p43

Purpose

To develop a strategy to ensure drug and alcohol services are accessible and appropriate to people from culturally and linguistically diverse backgrounds.

Participants

Drug and alcohol services, ethno-specific services, Koori community agencies and consumers.

Method

A reference group was established, a literature review conducted and a range of consultation methods was utilised. These included telephone and face-to-face interviews, questionnaires, agency mapping, workshops, focus groups and site visits.

Findings

Firstly the authors note that while the original brief was to look at services for people of culturally and linguistically diverse backgrounds, it became apparent that they would also need to look at issues for accessible services for Koori people.

Issues which need to be considered when developing strategies for culturally and linguistically diverse backgrounds include experience of migration and cultural issues.

Issues of access included fear of mainstream services, inappropriate models for service delivery and inflexible services. In addition, services often did not have appropriate data about their constituency to inform appropriate service

development. There was also lack of information about services available in communities of non-English-speaking background and in Koori communities.

Aboriginal communities identified the need to develop specific services tailored to their needs.

Development of systematic rather than *ad hoc* approaches to providing culturally and linguistically appropriate services was emphasised. Some of the strategies identified included development of community education, employment of bilingual staff, use of interpreting services, utilising a community development approach, developing consultation processes within ethnic communities and with ethnic health workers, involving family members and developing models of service provision such as outreach. The need for cultural change within services was also highlighted.

A number of case studies were presented to illustrate best practice in these areas. Barriers to the sustainability of these models included that they are not incorporated into a systematic response and often depend on one worker. The report identified that for change to occur there must be leadership support, commitment from the service management and ownership by staff.

Key recommendations included the need for community participation, undertaking cultural diversity audits and producing cultural diversity plans, implementation of cultural diversity training, and that the Department of Human Services develop clear standards for appropriate service delivery in service agreements.

Author: E-Qual (consultants) nd

Title: *Review of approaches to satisfaction surveys of clients of disability services*

Details: Human Services Research Institute (HSRI) Western Australia

Purpose

This review was undertaken to inform a Commonwealth-level working group (the Disability Services Working Group) about survey methodologies appropriate for seeking feedback from people utilising disability services. The task of the working group was to develop a survey which could be done to elicit nationally comparable information.

Method

The review included a literature review, a review of five large-scale surveys and interviews/meetings with professionals working on large-scale surveys.

Findings

The reviewers identified a number of issues that need to be examined when developing satisfaction survey methods appropriate for comparing services. These include determining the type of comparisons that will be made (so that an appropriate measure and sample size can be developed); developing tools with appropriate discriminatory powers; developing some kind of baseline against which performance can be measured; and awareness that satisfaction ratings may not be independent of the type of service or the service location.

A number of good practice models were identified. This report also discussed concepts of consumer satisfaction within disability services; understanding ratings within these services; sampling procedures; ethical issues; and data collection methods.

Four different options were identified, with the researchers favouring a combination of telephone and face-to-face interviews with consumers and a mail questionnaire for carers and families.

Author: Epstein, Merinda and Shaw, Julie 1997

Title: *Developing effective consumer participation in mental health services: the report of the Lemon Tree Learning Project*

Details: Victorian Mental Illness Awareness Council, p135

Purpose

To describe a model for education and training for consumer participation. This project was consumer-led and consumer-controlled. It was undertaken by an organisation that aims to be a peak consumer self-advocacy body.

Participants

Consumers

Method

At the beginning of the project contact was made with services and consumers throughout Victoria. The training model was developed by consumers through a long process of discussion, exploration and experience of participation.

Findings

This is a very useful exploration of a range of issues about consumer participation, including discussion about consumer perspectives, collaboration and partnership, 'professionalism', reflective practice, structures supporting consumer participation, knowledge and learning, and decision-making. It develops a theory of learning for consumer participation and explores three

sites (consumer-only, provider-only and consumer-provider 'deep dialogue') necessary for consumer participation to take place.

The metaphor of a lemon tree was developed to describe a theory and practice of participation. It builds on previous work done by the 'Understanding and Involvement' project.

A board game developed as a training tool, when facilitated by consumers 'paid for their expertise, experience and perspective', enables service providers to see the system in which they work through 'new eyes'. Unlike many conventional generic kits, the board game is a tool which allows consumers and providers to explore experiences in their local contexts.

Author: Ethnic Youth Issues Network 1998

Title: *Developing best practice drug and alcohol treatment service and support models for young people of Cambodian, Lao and Vietnamese origin*

Details: Human Services Victoria, p117

Purpose

To evaluate current service provision to Cambodian, Lao and Vietnamese young people and explore how these services can be made more appropriate and accessible to these groups.

Participants

Service providers, policy makers, consumers

Method

A reference group was established to oversee the project. Existing links with service providers were utilised to facilitate contact with young people from the target groups and with services and individuals working with these groups.

Information was collected through literature review; review of relevant statistics and data; face-to-face interviews with individual young people (undertaken by a worker who had known the participant for a long time) and with service providers; telephone interviews, focus groups and group discussions with service providers, ethno-specific agencies and juvenile justice centres; and group discussions with young people. The researchers also attended a number of meetings and a community forum. A survey was sent to community correctional centres and a workshop on best practice was held with key community sector participants. Consultation with local agencies concerned with the welfare of Cambodian, Lao and Vietnamese people, representatives of community organisations and parents was also undertaken.

Findings

Successful elements of the methodology included utilising links with local agencies and with local outreach and support workers, and using a 'snowballing' means of identifying key informants.

The importance of recognising the differences between Cambodian, Lao and Vietnamese young people and the diversity within these groups was highlighted. Key themes identified include the importance of a holistic approach to service provision which takes into account the social, environmental and migration context of the young people and the impact on young people of the links between drug use and law enforcement and correctional systems.

Key aspects of good practice models included specific targeting of services to Cambodian, Lao and Vietnamese young people; cross-cultural training for staff; inter-agency collaboration; involvement of ethnic community organisations; employment of bilingual workers; involvement of families; flexible outreach programs; recognition and utilisation of the skills of young people and involving them in peer education, research and consultation; providing opportunities for young people; group approaches to support and treatment; appropriate information provision about services; understanding the spiritual needs of young people; and having appropriate withdrawal services.

A range of recommendations for improving services was made.

Author: Faulkner, Kathryn 1996

Title: *Community participation project*

Details: Royal Women's and District Health Service, Brisbane, p78

Purpose

This project was undertaken to increase community participation in a tertiary hospital. It included the development of a model for a coordinated organisational approach which included training for consumer representatives and healthcare providers

Method

The project was guided by a steering committee consisting of equal numbers of consumer and service provider representatives. Developing the consumer participation model included undertaking a literature review, consultation and interviews with consumer and community groups and community-based workers.

Strategies developed included development of education and training programs, running focus groups and consumer participation workshops, identifying appropriate consultation mechanisms for working with diverse groups of women and developing a process for consumer representation.

Consumers and health service providers were asked separately to define their needs for education and training and then brought together to develop guidelines and principles for education and training. Consumer representatives currently working with the hospital were asked to decide what process should be used to develop the education and training program and all consumer and community groups known to the hospital were invited to participate in this process.

Community and consumer representatives were asked to attend a meeting with the architects responsible for designing the refurbishment of the hospital. A range of issues about access, bed numbers, integration of services, models of care and facilities was raised at this meeting and consumers asked to be kept informed about the way the information they provided was utilised. A survey was undertaken to find out from participants how they would like to have ongoing participation.

Focus groups to identify needs were held with women who lived in a caravan park, Aboriginal and Torres Strait Islander women, young mothers and women from non-English-speaking backgrounds. A range of hospital staff and community health workers were involved in the focus groups. Women living in communities were offered training to run focus groups and offered the opportunity to run a focus group (only one of these women did this). The information from the focus groups was fed back to women in the community.

A consumer participation workshop was held to discuss participation strategies and to develop a model for participation. There was underrepresentation from young women and Indigenous women at this workshop.

Findings

Key recommendations addressed service leadership for consumer participation; vision and mission statements; complaints mechanisms; allocation of time and resources; education and training needs; employment of staff; advisory bodies; issues about consumer representation; evaluation; and involving women from different groups.

Common themes arising from the focus groups were access to information and services, access to primary care and issues around participation.

The model for consumer participation aimed to address the issue of how personal contact with the service can be translated into information which can improve the service. It was recommended that a community participation liaison officer, supported by an advisory body of consumers and service providers, be employed to facilitate this process, which would include facilitating an organisation wide approach to consultation; responsibility for education and training; monitoring of complaints; support for consumer representatives; research; implementation of recommendations; and evaluation.

A range of consultation strategies for different groups of women was identified.

Author: Fitzroy Community Health Centre 1992

Title: How Fitzroy Community Health Centre manages its multicultural clientele

Details: *Multicultural Marketing News*

Purpose

This article is a brief description of how the former Fitzroy Community Health Centre involves consumers from diverse cultural and linguistic backgrounds in its service.

Findings

The service utilises interpreter services, has business and health information translated and employs bilingual staff. Input into service development occurs through representatives from different groups being elected to the management committee, which is also attended by interpreters to assist community representatives. Consumer forums (concurrently translated into six or seven languages) are held quarterly to find out about consumer needs and about what they think of the service. A number of ethno-specific consumer groups are organised from and meet at the Centre.

Author: Fraser, Diane M 1999

Title: Women's perceptions of midwifery care: a longitudinal study to shape curriculum development

Details: *Birth*, 26, Blackwell Science, pp99–107

Purpose

The views of pregnant women were sought to assist in the development of a midwifery curriculum which would reflect the increasing importance of developing a consumer focused system.

Participants

Forty-one pregnant women

Method

A longitudinal study utilising semi-structured and unstructured interviews was undertaken over 12 months. Interviews with women were held during pregnancy, in hospital after delivery and in participants' homes two to three weeks after birth. Women were recruited until no new issues were identified (41 women were interviewed). A diverse range of women were recruited to include women of different ages, numbers of children, ethnicity and socioeconomic status. An interpreter was employed where appropriate.

The researcher told participants that the information they provided would be used to inform program development and would be kept confidential.

Findings

While women reported a number of problems with their care, they often still reported positive experiences of care. Issues important to women included characteristics of carers (attitudes, gender, personal qualities, interprofessional relationships); individualised approach to care (continuity of care, having individual needs and preferences respected, and informed choice); and clinical competence of health care providers (communication skills, knowledge and ability, technical skills, education skills).

Author: Fyffe, Chris and McCubbery, Jeffrey 1996

Title: 'If only we had somewhere to turn...': the service needs of people with acquired brain injury in a rural community

Details: *Australian Journal of Rural Health*, vol 4, pp232–236

Purpose

To identify the needs of rural people with acquired brain injury and their carers

Participants

Sixty-three consumers, under 65 years of age, with acquired brain injury and/or their carers

Method

Consumers and carers were recruited in a number of ways. Sampling was not random, but purposeful. Consumers and carers were identified through public meetings and referral from other carers and consumers. A questionnaire was published in two regional newspapers and 16 carers and consumers completed this. Individual and group interviews were conducted and questionnaires were

completed by all respondents. Questions asked about experiences and needs. With the consumer's consent, carers were considered to be able to speak on their behalf. The study was conducted by researchers working at a regional university.

Findings

Five key themes were identified. These were: inappropriate information and poor communication from professionals (including poor case management and failure to involve consumers and carers in planning); varied service quality and coordination (physical care in the acute setting was good, but there was little communication between acute and rehabilitation services and between rehabilitation and community services); absence of support and services to assist with community reintegration, resulting in isolation; lack of emotional and family support; and rural issues including distance to specialised services, lack of understanding of the issues by local service providers, and cost, time and availability of transport.

Author: Gauntlett, Nick, Ford, Richard, Johnson, Norma and Navarro, Rini 1995

Title: Meeting mental health needs of ethnic minority groups

Details: *Nursing Times*, vol 91, no 42, pp36–37

Purpose

This paper describes a team-based outreach service to work with people with mental health issues who were not accessing mainstream services. Many of these people are homeless or from ethnic minority groups.

Method

Consumers are encouraged to work with case workers in their own care planning in order to develop a high level of independence. This is built into the way the service operates.

Findings

This paper primarily describes a service which aims to work with people who are very marginalised from accessing mainstream mental health services. A key issue is the lack of ethno-specific mental health services and culturally appropriate mainstream mental health services. This paper gives examples of how developing an outreach team with workers from diverse backgrounds can assist in the development of cross-cultural understandings of mental health issues. The success of the approach has been demonstrated by reduction in hospitalisation and potential homelessness.

Author: Gething, Lindsay, Fethney, Judith and Blazely, Angela 1998

Title: The importance of adopting a client focus in assessing outcomes following inpatient rehabilitation treatment of older people

Details: *The Australasian Journal on Ageing*, vol 17, no 4, pp187–192

Purpose

To use a range of quality-of-life measures to examine older people's function, ability and confidence in undertaking daily tasks at the time of discharge from hospital and up to three months post discharge.

Participants

Thirty-seven people over 80 years of age.

Method

People were interviewed by health professionals. The Comprehensive Quality of Life Scale, the Shah Modified Barthel Index, the Elderly Mobility Scale and the Falls Efficacy Scale were all used in the interviews to examine quality of life.

Findings

Consumers' perspectives of their independence and ability may not match functional assessments of these abilities.

Author: Grant, Gordon, Morag, McGrath and Ramcharan, Paul 1994

Title: How family and informal supporters appraise service quality

Details: *International Journal of Disability, Development and Education*, vol 41, no 2, University of Queensland Press, pp127–141

Purpose

To develop an understanding of the way families or informal supporters of people with intellectual disabilities appraise service quality. The authors distinguish between structure, process and outcome dimensions of quality and explore the relationships between these dimensions.

Participants

Seven-hundred-and-fifty-two family members or informal support people

Method

Participants were identified through community support teams in urban and rural areas in Wales. A questionnaire was posted to families by members of community support teams. Participants were asked to return questionnaires to

the researcher in a pre-paid envelope. The researchers provided assistance in completing the questionnaires to those participants who requested it.

The questionnaires included three different types of measures: intermediate service outcome measures (including overall satisfaction measured on a five-point Likert scale and estimates of unmet need calculated by need for more information, advice, help, training, respite, support etc); service process factors (including measures of how empathetic service providers were to carers and to consumers, carer expectations/aspirations for the consumer, access to key workers, involvement in meetings with health professionals about the care of the consumer, involvement in service planning and management, desire for contact with/participation in the service, and estimation of the type and extent of services provided); and personal factors (demographic and behavioural information).

Findings

There was a high correlation between carer satisfaction and professional empathy with carers and consumers. Carers dealing with empathetic health professionals were less likely to report having unmet needs. Having a key worker and involvement in a meeting with health professionals to plan the care for the consumer were also highly correlated with satisfaction. Expectations/aspirations for the consumer and participation in broader service planning could not be correlated with satisfaction. There was a relationship between carers of people with severe behavioural problems and lower satisfaction and higher unmet need.

Participants expressed a range of reasons for not wanting to participate in/have more contact with the service. These included wanting to be self sufficient, bad experiences of participating, lack of resources available to professionals, and insufficient help in the past.

Author: Guendelman, Sylvia and Witt, Sandra 1991–1992

Title: Improving access to prenatal care for Latina immigrants in California: outreach and inreach strategies

Details: *International Quarterly of Community Health Education*, vol 12, no 2, Baywood Publishing Co Inc, pp89–106

Purpose

A large percentage of women giving birth in California were from ethnic minority groups, yet many of these women did not receive prenatal care. This project was undertaken to explore the views and perceptions about barriers to

care for Latina women living on low incomes and to develop outreach strategies to improve prenatal care.

Participants

Sixty-seven consumers and providers

Method

Separate focus groups, run by bilingual health workers, were conducted with consumers and health care providers. Consumer participants were identified through the health workers and were paid for participation. Participants were asked about barriers to care and about how prenatal outreach programs could be improved.

Findings

Barriers to accessing services were related to socioeconomic status, legal issues, being newly arrived, cultural issues and beliefs, poor cross-cultural communication and the constraints of health care institutions.

Some suggestions to improve accessibility to services were: making pregnancy tests free and readily available and linking women into services when they have a test; promotion of Latina women's support groups; and provision of free transport services. The development of an outreach strategy was proposed to overcome these issues and barriers.

In addition, 'inreach' strategies were proposed to change existing practices at health services to make them more appropriate to Latina women. These include reducing bureaucratic barriers by making women's first contact with agencies less cold and unfriendly; reducing the number of forms to be filled in and the number of questions asked of women at their first visit by training staff to prioritise needs rather than trying to identify all needs at one time; increasing employment of bilingual/bicultural staff; reducing long waiting times and provision of culturally relevant information while women are waiting; provision of childcare; and development of better billing systems.

There was a high degree of agreement between providers and consumers about barriers to prenatal care; however, providers were more likely to identify individual characteristics and cultural beliefs as reasons for women not using the service.

Author: Hart, Vicki R, Gallagher-Thompson, Dolores, Davies, Helen D, and DiMinno, Mariaan and Lessin, Phyllis J 1996

Title: Strategies for increasing participation of ethnic minorities in Alzheimer's Disease diagnostic centers: a multifaceted approach in California

Details: *The Gerontologist*, vol 36, no 2, The Gerontological Society of America, pp259–262

Purpose

To develop culturally appropriate services for older people with dementia from ethnic minority groups. Previous work identified a range of barriers including that services were not culturally appropriate and specific needs were not met. In addition, cultural understandings of ageing might mean that help for people with dementia was not sought until there were severe symptoms.

Method

The outreach programs were coordinated across nine centres through a committee of decision-makers from each centre. This facilitated the identification of common problems and solutions which were then fed into policy making and the pooling of information resources relevant to specific ethnic groups. Learnings from each centre were able to be translated to other centres.

Different methods of outreach were utilised by each of the nine participating centres. Some of the key strategies employed include development of links with ethno-specific local agencies; employment and/or collaboration with bicultural workers; establishment of satellite centres in rural communities or in areas with high populations of older people from specific ethnic backgrounds; and development of a culturally appropriate diagnostic dementia program for Spanish-speaking Latin American peoples.

Findings

The participation of older people from ethnic minority groups increased over a two-year period. Centres which focused on developing programs for specific ethnic groups had a greater increase in numbers of people using the service from those groups. When the bilingual staff member of one centre left, the number of consumers from the relevant ethnic group utilising the centre decreased, indicating the importance of employing appropriate staff.

Other key learnings included the importance of leadership support so that appropriate time is allocated to outreach activities and ideas are shared; availability of funds so that appropriate education, training and

diagnostic tools can be developed and implemented; and employment of bicultural staff.

Author: Health Issues Centre 1997

Title: *A woman's work is never done: the impact of shifting care out of hospitals*

Details: Health Issues Centre, p60

Purpose

To explore the impact on women carers of shifting care out of hospitals and into the home. This report examines the changing role of hospitals, the experiences of women as carers and the policy implications of this changing role. This project was a collaboration between the Health Issues Centre and the Department of Urban and Social Policy, Victoria University of Technology.

Participants

Women carers

Method

A reference group was established to guide the project. A review of literature and key policy documents was undertaken and key informants, including representatives from industry, unions, health service providers and consumers, were interviewed.

Findings

The consequences of taking on increased care-giving roles have many impacts on women. These include economic, employment, health and social impacts. The author concludes that as health care is shifted from hospitals to homes a policy framework for supporting women carers should be developed.

Author: Healy, Karen and Walsh, Karyn 1997

Title: Making participatory processes visible: practice issues in the development of a peer support network

Details: *Australian Social Work*, vol 50, no 3, pp45–51

Purpose

A participatory action research project was developed to address violence experienced by young women, especially young mothers. Out of this project a network, 'Young Mothers for Young Women: Peer Support and Advocacy Network' was established. This paper discusses practical and theoretical issues about this kind of participatory process.

Participants

Young mothers up to the age of 25

Method

Initially young women were asked to participate in a participatory action research project about young mothers and violence. The group analysed and developed responses to violence against young women. The establishment of this group was facilitated by two workers who initially played a key role as organisers and meeting facilitators. As young women developed meeting organisation and facilitation skills the workers played an ongoing, but more peripheral role. The process included reflection on changing roles and role development; training and skill development; support; outside mediation; seeking funding and valuing of the knowledge; skills and credibility that each participant brought to the project.

Findings

This paper provides a very useful reflection on process issues in the development of a reflective partnership which is neither client-led or professional-led. This required the development of a process whereby young women could reflect on their experiences of violence and develop a critique of structural and social issues that enhanced their vulnerability to violence (issues included poverty, isolation and stereotypes of young mothers). This critique meant that the group could then be active in developing responses to address these issues. This action includes having input into policy development, undertaking research, running an education campaign, having input into service development, providing peer support and outreach, staffing a telephone information line, and advocacy.

As the initial facilitators of the project the authors identify a range of key issues for professionals. These include that undertaking this work requires considerable skill, but these skills are often invisible and devalued within services; professionals have to be able to give up the role of 'expert' to promote the skills and knowledge of participants; professionals require an ability to negotiate and to work with conflicting views; reflection on the ways young people are involved in management of services is required so that it is not just tokenistic; employing an external mediator is useful to assist in reviewing processes and ensuring professional accountability to consumers; there has to be ongoing negotiation of roles and role development and ongoing reflection on the process; and it is useful in developing relationships if staff other than those participating in the partnership are engaged to provide training and professional support to consumers.

Author: Henenberg, Cathy and Pardy, Maree 1995

Title: It's like we don't have a mouth: women, interpreting, health

Details: Women's Health Victoria, *Healthsharing Women*, April–May, pp8–12

Purpose

This article describes issues for the provision of high quality health care identified by women asked to reflect on their experiences of interpreter-mediated communication.

Participants

Fifty-six immigrant women

Method

Interviews and discussions

Findings

Women had many negative experiences of interpreter services (or lack of them) when utilising hospitals. Interpreter-mediated communication could undermine a woman's capacity to participate in society, in her health care and her exercise of autonomy. Women experienced difficulty in finding out about interpreter services, getting access to interpreters (which was dependent on individual health service providers rather than organisational systems), and in feeling appropriately represented when communication took place through interpreters. The culture of the hospital was intimidating to women and they often experienced anxiety around interpreting issues.

Author: Hickson, Louis, Worrall, Linda, Yiu, Edwin and Barnett, Heather 1996

Title: Planning a communication education program for older people

Details: *Gerontology*, vol 22, Taylor & Francis Educational, pp257–269

Purpose

To involve older people in the development of a communication education program. A second aim was to evaluate the usefulness of nominal group technique as a consultation approach with older people

Participants

Older people living in the community and health professionals

Method

Seven groups were run with older people and two with health professionals. Participants were recruited through newspaper advertisements, posters in neighbourhood centres and churches and by talking with people at senior citizens' centres and shopping centres. Groups were run in community settings and were facilitated by professionals experienced in working with people with communication difficulties. Facilitators made sure that everybody knew what was being said and written throughout the group process.

The nominal group process was followed. Participants were asked to consider questions in silence, then present their answers, discuss, clarify and group the ideas and then individually rank the issues.

Findings

Consumers and health professionals had different perceptions about which communication difficulties were most significant to address. The issues identified by participants included hearing loss, memory loss and difficulties in retrieving words. Participants wanted information about these difficulties to be included in an education program as well as sessions on maintaining communication skills and social networks.

Nominal group technique was found to be useful in seeking the views of older people as all group members could participate.

Author: Huabg X, Butow P, Meiser B and Goldstein D 1999

Title: Attitudes and information needs of Chinese migrant cancer patients and their relatives

Details: *Australia & New Zealand Journal of Medicine*, vol 29, pp207–213

Purpose

To explore the information needs of Chinese-born cancer patients and their relatives to inform the development of culturally appropriate practice.

Participants

Thirty-six people with cancer and 12 relatives of people with cancer. All participants were born in China

Method

Consumers and their relatives were recruited from teaching hospitals and a Chinese cancer support organisation. Four focus groups and 26 telephone interviews were conducted (focus groups and interviews were continued until no new issues arose). Focus groups were run by a Chinese psychiatrist in

Cantonese, Mandarin or English. Participants also completed an 'acculturation scale' and demographic data was collected. The acculturation scale and demographic questions were translated and back-translated to check for validity.

The psychiatrist transcribed all data collected. To ensure accuracy, tapes were also listened to by two independent Chinese-speaking health professionals. Feedback from participants was sought on preliminary findings.

Findings

A qualitative methodology was chosen because there were no existing relevant validated measures or previous research done in this area. One of the limitations of focus groups observed in this study was that some people were less likely to participate and others conformed to the majority view.

While the participants had diverse views about information provision there were some common themes which were utilised to inform the development of recommendations about culturally appropriate information provision. These included that information be provided in a clear and concise manner, that poor diagnosis should not be disclosed to enable maintenance of hope and optimism, the role of the families in liaising between doctors and consumers should be recognised (and advice of families about disclosure of diagnosis followed) and culturally specific treatments should be incorporated into care.

Author: Iutovich, Joyce Miller 1993

Title: Assessing the needs of rural elderly: an empowerment model

Details: *Evaluation and Program Planning*, vol 16, Pergamon Press, pp95–107

Purpose

A key concern was that there was over-utilisation of nursing home beds in the country when compared to national averages, and that a broader range of services should be provided to older people.

In order to inform this service development, a process for undertaking needs assessments which would also empower older people was developed. This process aimed to enable the establishment of shared understandings of the process and the issues as well as ownership of the process by the different stakeholders.

Method

The process was not linear and required 'frequent back-and forth movement' between the different stages. These stages included appointment of a project

director and community organiser, establishment of a community advisory group, identification and training of community volunteers, hiring of a research consultant, finalisation of research design, collection and analysis of data, presentation at a town meeting and development of action plans.

Findings

Critical factors in the success of this model were the recognition of the importance of involving community stakeholders in the planning process; the importance of identifying a highly motivated person to become the community organiser; and that the skills and expertise of all stakeholders were recognised and their capacity to undertake the work accepted.

Difficulties with the process included that some people were sceptical that the results would not be used, and that some of the work was too time consuming for volunteers. In addition, more training was required for volunteers; the town meeting did not result in the information expected and was more a starting point for discussion rather than a forum for developing recommendations.

Author: Jackson, Debra, Teale, Gloria, Bye, Rosalind, McCallum, John and Stein, Irene 1999

Title: Postacute care for older Aboriginal people: an exploratory-descriptive study

Details: *Australian Journal of Rural Health*, vol 7, pp53–59

Purpose

Due to changes in the way hospital care is provided and reduced length of stay, there is an increasing use of community-based alternatives to hospitalisation. These changes can impact on people's health and treatment outcomes. There is little information about the post-acute care follow-up of Aboriginal people, and thus little policy and funding to support post-acute care, lack of understanding of needs, poor case management of people after discharge and 'underlying racist attitudes by the provision of a white based discharge planning service'. This study aimed to explore the post-discharge needs of older Aboriginal people to make recommendations to redress this gap.

Participants

Eight Aboriginal health workers

Method

Aboriginal researchers were employed to undertake the study. Lack of identification of Aboriginality in hospital data meant that it was difficult to identify older Aboriginal people to participate in the study. Instead Aboriginal health workers were interviewed face to face or by telephone. Transcripts of interviews were sent to participants for checking.

Findings

Key findings include that often Aboriginality was not recorded; there was racism and stereotyping by health professionals; poor discharge planning by mainstream health professionals and a reliance on Aboriginal health workers, who were over-stretched; lack of availability of appropriate post-acute care services; lack of information about available services and entitlement to services; and that unlike Aboriginal-controlled services, mainstream services often do not provide appropriate services to Aboriginal people.

Author: Jameson, Anna, Sligo, Frank and Comrie, Margie 1999

Title: Barriers to Pacific women's use of cervical screening services

Details: *Australian and New Zealand Journal of Public Health*, vol 23, no 1 pp89–92

Purpose

To explore barriers to the utilisation of cervical screening services by Pacific women. This study was done because Pacific women have a higher incidence of cervical cancer than European women and little was known about their understanding of cervical cancer or the effectiveness of the information provided about the disease. This information was considered necessary to developing appropriate services.

Participants

Twenty Pacific women (seven Tongas, five Fijians, five Samoans, one Tokelauan, one Cook Islander and one Papua New Guinean).

Method

Preliminary discussions about methodology with Pacific women indicated that neither written surveys nor focus groups would be appropriate due to the sensitivity of the information. Participants were identified through snowball sampling. Semi-structured face-to-face interviews were held. Women who could not speak English were excluded from the study.

Findings

Key findings included that most women knew about the program; most had found out about the program from their doctor; women did not want a specific media campaign about pap smears directed at Pacific Islander women, as they were frustrated that Pacific people were often seen as socially problematic; most preferred information to be provided by a health professional rather than from a brochure; and some had received their information when a Pacific Islander nurse came to speak to their community group. Barriers to service use included lack of cultural appropriateness, lack of language services, issues about confidentiality, embarrassment, and cultural issues.

Author: Janssen CGC and Kars H 1994

Title: Parents' attitudes towards and their satisfaction with care in an institution for mentally handicapped people

Details: *The British Journal of Developmental Disabilities*, vol 40, no 79, pp81–97

Purpose

There has been widespread criticism of large institutions for people with mental retardation. There are many differences between parents of institutionalised people with mental retardation, including the roles they wish to have in the care of the child. In addition, generally high levels of satisfaction are not useful as people may use different reasons for determining satisfaction and very little useful information for organisational change is obtained. The purpose of this research was to identify the roles different parents wished to play, to group parents with similar wishes and then to explore the ways in which different groups of parents evaluated satisfaction. The authors considered that this method might provide them with better information than individual judgements about satisfaction.

The institution has additional mechanisms for parent participation including a strong parent organisation and parent committees which have input into management.

Participants

Parents of institutionalised people with mental retardation.

Method

Parents and professionals participated in developing a questionnaire (with four point scales) about the roles parents wanted to play in their child's care and the things they expected from the care.

Ten parents critical of the service were interviewed and asked about the aspects of care they considered to be important. This information was used to develop the initial satisfaction survey (with five point rating scales), which was then evaluated, commented on and revised by a forum of professionals and parents. The survey was then tested on 22 parents and adjusted appropriately.

Two residents from each of a number of group homes were chosen at random. This resulted in a sample of 69 people, most of whom had profound, severe or moderate mental retardation. The parents of these people were asked to complete both questionnaires.

Findings

Six sub-groups of parents were identified. These groups had different ideas about goals of their child's care, their participation in the care and views about who should have authority for decision-making about care.

There were differences between the six groups about what they were and were not satisfied with. Parents judged care against the things that were important for them. The authors suggest that this methodology produces more meaningful information for the institution than surveys which do not take into account the characteristics of the parents.

Author: Jenkinson, Crispin, Fitzpatrick, Ray, Oeto, Viv, Greenhall, Richard and Hyman, Nigel 1997

Title: The Parkinson's disease questionnaire (PDQ-39): development and validation of a Parkinson's disease summary index score

Details: *Age and Ageing*, 26, pp353–357

Purpose

To develop and evaluate a questionnaire about the impacts of illness on daily living for consumers with Parkinson's disease

Participants

People with Parkinson's disease

Method

Interviews were conducted with participants. A survey based on the issues raised in these interviews was developed and posted to a large number of consumers. Results of this survey were used to develop the final survey questionnaire.

The final survey was either posted to people with Parkinson's disease or administered in a neurology clinic. Those consumers answering the survey in

the clinic were also rated with existing clinical scales to measure functional ability.

Findings

The response rate was higher for the surveys administered at the neurology clinic than for postal surveys. The self-reported survey results corresponded with the clinical assessments, indicating that the questionnaire developed in this study was a reliable and valid instrument for assessing the impacts of Parkinson's disease.

Author: Jylha, Marja 1994

Title: Self-rated health revisited: exploring survey interview episodes with elderly respondents

Details: *Social Science and Medicine*, vol 39, no 7, Elsevier Science, pp983–990

Purpose

To develop an understanding of the factors operating between interviewer and interviewee and an understanding of the meanings associated with self-rated health status.

Participants

Forty older people

Method

Survey interviews

Findings

The way participants conceptualise and discuss their health is different from the assumptions made about the meaning of 'health' by those who developed the questionnaire. To participants the health was something that was relative and could not be discussed outside of the context of their everyday lives. States of health can seem contradictory as people could experience good health and disease at the same time. The authors conclude that health is best evaluated within the context of people's lives.

Author: Kipke, Michele D, Unger, Jennifer B, O'Connor, Susan, Palmer, Raymond F, and LaFrance, Steven R 1997

Title: Street youth, their peer group affiliation and differences according to residential status subsistence patterns, and use of services

Details: *Adolescence*, vol 32, no 27, Libra Publishers, pp655–669

Purpose

To develop an understanding of the diversity of young people living on the streets, of how they live and the services they use. A methodological problem identified by the authors was that while it is estimated that only 40 per cent of street youth use drop-in centres, previous researchers have recruited people only through these centres. This means that issues for a large number of 'street youth' remain invisible.

Participants

Seven hundred and fifty two young people between 12 and 23 years old who had been living on the streets for at least two months.

Method

Young people were recruited from shelters, drop-in settings, the street and locations where youth 'hang out'. The authors purposefully oversampled from the later sites. Numbers of people at each site were estimated and a sampling methodology was developed. Young people were asked to respond to a short questionnaire to determine their eligibility for the study. Those who were eligible were then asked if they would participate in a structured interview (using the AIDS Evaluation of Street Outreach Project Street Intercept). Questions pertained to risk behaviours, contact with outreach workers and use of services and drop-in centres. Young people were given food vouchers for their participation.

Findings

A range of findings about group affiliation, state of homelessness, economic activities and service utilisation are reported. These include that young people identifying with different sub-groups utilise services differently. The authors conclude that the development of a better understanding of how young people live on the streets will enable the development of better and more appropriate interventions and service provision.

Author: Kline, Frank, Acosta, Frank X, Austin, William and Johnson, Richard G 1980

Title: The misunderstood Spanish-speaking patient

Details: *American Journal of Psychiatry*, vol 137, no 12, pp1530–1533

Purpose

To explore the experiences of Spanish-speaking consumers who have an interpreter for psychotherapy sessions with the experiences of those who are bilingual and do not have an interpreter present. The perceptions of the consumer's psychotherapists (none spoke Spanish) were also studied.

Participants

Twenty-one Spanish-speaking consumers, 40 bilingual consumers and 16 psychiatrists

Method

Consumer participants were asked to fill out a questionnaire (available in Spanish or English) after their initial interview with the therapist. Psychiatrists were also asked to complete the questionnaire.

Findings

Consumers interviewed with the assistance of interpreters felt more understood and assisted and were more satisfied than bilingual consumers who did not have an interpreter present. On the other hand, the perception of the psychiatrists was that bilingual consumers whose consultations were in English were more appreciative and felt better understood. The paper recommends that more bilingual and bicultural therapists be trained and that the importance of interpreters be promoted among health professionals.

Author: Lambert, Connie 1998

Title: Removing the mystery: evaluation of a parent manual by adolescent patients

Details: *Adolescence*, vol 33, no 129, Libra Publishers, pp61–72

Purpose

Adolescent mothers may have reduced access to appropriate services, inadequate social support networks, and limited knowledge about child development and child rearing. It is thought that early intervention can assist young parents in overcoming some of the difficulties they experience. In this study a parenting manual was evaluated by young mothers and reviewed in line with their input.

Participants

Thirteen young mothers aged between 14 and 18 years, from a range of cultural backgrounds

Method

Participants were selected from a high school. The director of the school program in which they were enrolled was asked to facilitate the evaluation. The facilitator stressed that the input of the young women was important and would be used to revise the manual. The young mothers were asked to evaluate the content, format and readability of the manual. Participants were asked to fill in a semi-structured questionnaire containing five questions about format; read and comment on sections of the manual (including writing on it if it was not clear or if they did not understand any of the words); and after reading the manual filling out a content evaluation form. This form also included questions about how they would use the manual and how they thought it should be used. There was also group discussion facilitated by the program director. The manual was revised based on this input.

Findings

The manual had a focus on the development of children. The young women wanted more basic child care information and more information about being a parent. In addition, the participants identified that the manual would be best used to facilitate group discussions rather than as a resource for individuals.

Author: Langer, Ana et al 1997

Title: Improving post-abortion care in a public hospital in Oaxaca, Mexico

Details: *Reproductive Health Matters*, 9, pp20–28

Purpose

While much of the research done into abortion in Mexico focuses on its social and epidemiological aspects, little work has been done on the quality of services provided to women. This study sought feedback from patients and staff of an abortion clinic in order to design and implement service improvements. These improvements will be evaluated by comparing a later collection of data with the information obtained in this study. The clinic was located in a poor rural area where many Indigenous groups lived and where very few people spoke Spanish.

Participants

One hundred and thirty-six women

Method

The methodology included questionnaires, clinical record review, in-depth interviews with (nine) women patients and hospital staff, and observation of clinical consultations. The questionnaires and interviews asked women about their social and demographic situations and addressed women's perceptions of quality of care (including technical quality and interpersonal quality) and whether they were counselled about family planning.

Findings

Key findings included that women were treated insensitively and staff had little concern for their emotional issues; there was lack of privacy; poor management of pain; long waiting times; and poor provision of information. In addition the most appropriate method of abortion was not often practised.

Steps for improving services included reviewing hospital procedures to ensure shorter waiting times, increased privacy and pain management; training for staff in communication and information provision; and staff training on abortion procedures.

Author: Lillie-Blanton, Marsha and Hoffman, Sandra C 1995

Title: Conducting an assessment of health needs and resources in a racial/ethnic minority community, Part II

Details: *Health Services Research*, vol 30, no 1, pp225–236

Purpose

This article discusses a range of issues for people wanting to do needs assessments within racial/ethnic minority communities.

Method

Reflection on experience of undertaking needs assessments

Findings

A range of barriers to participation of people from ethnic minority communities in community-based research and needs assessment was discussed. These include that these groups are often sceptical about such research and see it as a way of delaying taking action or as way for researchers to gain knowledge at their expense.

A range of issues were discussed including that researchers should be sensitive to how they are perceived within communities; should develop knowledge about the community and its history and understand the differences within communities; should develop mutually beneficial partnerships; should

communicate throughout the project and develop an agreement about how the research can serve the community. In developing research design consultation with the literature, key informants and community leaders is important, as is understanding why previous research methodologies were inappropriate.

Steps should include development of common goals and understanding of the policy and program implications of the research; clarification of decision-making processes and involvement of communities in these; development of trust and respect; development of community expertise and capacity (for example through transferring knowledge and skills and employing and training community members where possible).

The authors also discuss a range of issues about methodology, including the use of existing data, measurement issues, analytic strategies and interpretation of results. One of the key issues raised about each of these areas is the importance of developing communities in decision-making about each of these methodological questions.

Author: Lisnov, Lisa, Harding, Carol, Gibb, Safer, Arthur L and Kavanagh, Jack 1998

Title: Adolescents' perceptions of substance abuse prevention strategies

Details: *Adolescence*, vol 33, no 130, Libra Publishers, pp301–311

Purpose

To develop an understanding of why specific drug education programs are effective/not effective in prevention of substance use. This was done because previous evaluations had focused on pre-program and post-program evaluation of students' knowledge. These type of evaluations did not provide much information about what aspects of programs were most successful.

Participants

Seven hundred and nineteen students in public schools. Most students were from ethnic minority groups and/or from low income families.

Method

A survey was developed and piloted with 60 students. Students were asked to give each question a grading (A through to F) similar to the gradings they would receive for school work.

Findings

School-based prevention programs were found to be more effective than television or print advertisements, testimonials by famous people and billboards. The most effective program was one in which students participated in a theatre program which was sensitive to their diverse racial and ethnic backgrounds and encouraged them to talk about their feelings about substance use.

Author: Lopez, Rafaela and Fazzalori, Lella 1995

Title: *Immigrant women's health project hospital-based research: report*

Details: Mercy Hospital for Women, p157

Purpose

This was a joint project undertaken by the Mercy Hospital for Women and the Key Centre for Women's Health in Society. The Mercy Hospital had an established Multicultural Services Unit which examined hospital services, policies, structures and attitudes affecting service delivery to women of non-English-speaking backgrounds with the aim of improving access and equity of service provision to these women. A second, community-based part of the study aimed to explore health beliefs of immigrant women and to examine barriers to access from the point of view of women living in the community.

Participants

Women from Vietnamese, Chinese (from Vietnam), Salvadoran, Chilean, Russian, Ukrainian and Lebanese Muslim backgrounds

Method

There was a clear commitment from the hospital management to undertake the project. A steering group including representatives from the two organisations involved in the study, each of the targeted ethnic groups, the hospital-based and community-based research teams and the funding body was established. In addition a hospital-based working group was set up.

A literature review was undertaken on the health beliefs and practices of Lebanese Muslim, Vietnamese and ethnic Chinese women from Vietnam. A survey of women from the five ethnic groups was undertaken. The hospital-based research included a review of hospital policies and protocols, examination of hospital structures and sub-structures, and consultations (unstructured interviews and focus groups) with hospital staff and workers from community-based organisations.

Findings

Key findings from the community-based study included that women experienced lack of access to information about hospital services; difficulty in understanding the health system; language barriers and failure of services to utilise appropriate language services; cultural insensitivity; and experiences of racial discrimination and hostility when attempting to access services.

The hospital-based study identified six key areas requiring change. These were language services; quality management (including policy development, addressing of ethnocentrism and discrimination, discharge practices, food services, gender of medical staff, participation of medical students, complaints processes, and signage); policies, protocols and procedures (informed consent, use of interpreters, patient rights and responsibilities, bilingual staffing); structural participation (that is participation of people of non-English-speaking backgrounds in decision-making within the hospital); education (including cross-cultural training for staff and conduct of appropriate antenatal training for women); and marketing (provision of information about the service to the community). The report also addresses recommendations to national and state policy makers as well as to individual organisations.

Author: McGrath, Morag 1989

Title: Consumer participation in service planning—the AWS experience

Details: *Journal of Social Policy*, vol 18, no 1, pp67–9

Purpose

To explore the reasons why there is a low level of participation of carers in the development of services for people with an intellectual disability in a region of Wales, despite the existence of strategies to promote participation.

Method

Observation at meetings, interviews with service providers and a survey (by face-to-face interview) of carers living in households known by service providers to include a person with an intellectual disability.

Changes were made to the structures for participation based on this study.

Findings

A range of issues impacted on participation. These include lack of knowledge, lack of interest in broader service planning (as opposed to individual care planning), difficulty in attending meetings, negative experiences at meetings, the large size of meetings, delays in progress, the limited representativeness of those who did participate, and not having carer views listened to.

Recommendations to increase participation included development of small informal and local meeting structures; involvement of voluntary advocacy agencies; and ensuring participation is relevant to the experiences of participants. Other factors that needed to be considered were the representativeness of representatives, the structure and size of work groups, development of guidelines for the function and role of groups, practical assistance required by participants, training, development of an effective communication system between different service providers and between service providers and carers, and establishment of direct dialogue between different stakeholders.

Author: McGuinness, Maggie and Wadsworth, Yoland 1992

Title: *Understanding, anytime: a consumer evaluation of an acute psychiatric hospital*

Details: Victorian Mental Illness Awareness Council, p83

Method

The evaluation of the facility was initially planned as a one-off self-administered questionnaire with closed-ended questions. This was developed into a series of individual and group interviews with consumers and staff. Information from these interviews was then swapped so that consumers could see what staff were saying and vice versa. This process was built upon so that further comments were exchanged (this became a 'constructed conversation' or dialogue) and consumers began developing recommendations for change.

Findings

This report provides an in-depth discussion of theoretical and practical issues around developing new ways of evaluating hospital services.

Author: McLean, Cameron and Roberts, Richard 1995

Title: Experiences of gay men whose partners have AIDS: implications for hospital social work

Details: *Australian Social Work*, vol 48, no 2, pp19–26

Purpose

To develop an understanding of issues and needs relevant to carers of gay identified men hospitalised with HIV-related illnesses to inform social work practice.

Participants

Thirteen partners of gay men with AIDS (non-random sample)

Method

Interviews with minimal structure were used to collect information. The interviewer/researcher was a social worker on the AIDS unit, which meant that support and referral could be provided to participants. A software package, Ethnograph, was used to analyse data. The non-random sample was considered to be appropriate as the interviews were used to generate hypotheses and concepts rather than to make valid and reliable conclusions.

Findings

Issues identified by participants included that caring for their partners was a big responsibility and caused participants high levels of stress and impacted on their capacity to fulfil their personal and work obligations; their relationships with each other changed; partners experienced emotional distress and felt isolated from potential sources of support; lack of acknowledgement of their partner status could result in exclusion from decision-making or from relevant support services; social work services often focused on the person with AIDS and not their partners; the health care system did not validate gay relationships; and partners felt isolated. This paper concluded that social work practices needed to be modified in order to adequately meet the needs of partners of gay men with AIDS.

Author: Meehan, Effie and Hanson, Kate 1999

Title: *Three-D: a preliminary report on sexual and occupational health of non-English-speaking background women with disabilities*

Details: Women in Industry and Community Health Inc, p26

Purpose

The purpose of this report was to identify health issues and barriers to accessing services for women of non-English-speaking backgrounds with disabilities and to identify changes that would make the agency and its activities more accessible. The focus was on sexual and reproductive health and occupational health.

Participants

Twenty-one women with a range of disabilities, aged between 18 and 50

Method

A woman with a disability from a non-English-speaking-background undertook the research project. Two questionnaires were developed and tested with the project working party. These contained questions about demographics, factual questions and open-ended questions. Interviews with participants were

conducted over two months. Participants were contacted through ethno-specific agencies.

Findings

Women of non-English-speaking backgrounds with a disability experience a 'triple disadvantage' in society, due to the intersections of gender, ethnicity and disability.

Some of the barriers identified included limitations to physical access to buildings and to some equipment; difficulty in recruiting women for the study as some agencies could not identify whether their clients came from non-English-speaking backgrounds; there is little literature about women of non-English-speaking backgrounds with disabilities; negative and 'handicapping' attitudes to women with disabilities; discrimination resulting in segregation in education and employment and exclusion of some health, social and recreational services; women are seen as not having the same 'hopes, anxieties, fears, expectation and emotions as able-bodied women'; women with disabilities may be considered to be 'genderless and asexual' and are therefore not catered for by women's health services.

The study also found that most women did not know about women's health services and only a few women had utilised any type of women's health service (such as breast screening). Most women saw local doctors for their health issues and were happy with their communication with these doctors. Two women reported that they could not communicate with their doctor because he/she did not take their disability into account. Other issues included the language in which information was presented; the distance of the health service from the woman's home; the gender of the health care provider; the need for appropriate information about sexual and reproductive health; health care providers often focusing on a woman's disability rather than offering a holistic model of care, including preventive health care.

It was noted that this was a pilot study undertaken over a short time on a limited budget and, as such, the results might not be generalisable across Victoria. Suggested strategies to enhance service appropriateness for women with disabilities included disability awareness training and education; establishment of working parties of staff and women with disabilities to investigate available services; developing a disability resource library; ensuring agencies are close to public transport; employment of a woman with a disability from a non-English-speaking background to work on appropriate service development; ensuring there is a place on the management committee for a woman with a disability; provision of attendant care, child care and sign

interpreters for activities involving women with a disability; and ensuring physical accessibility to buildings and emergency exits.

Author: Minicucci, Catherine 1997

Title: Assessing a family-centred neighbourhood service agency: the Del Paso Heights model

Details: *Administration in Social Work*, vol 21, no 3/4, Haworth Press, pp127–143

Purpose

To establish and evaluate a neighbourhood-based, community-governed, multidisciplinary service.

Method

A neighbourhood-based integrated service was established to pilot a new model of service delivery in an area with a high number of people living on low incomes and from African American, Hispanic and Asian backgrounds. This model was based on nine principles with the overall aim of empowering people and providing appropriate family-centred, multidisciplinary services. This required reorganisation of a range of health and welfare services, establishment of a community governance body, establishment of mechanisms for self help and mutual support and development of an outcome evaluation.

Findings

This paper documents a range of issues relevant to the development of neighbourhood-based, community-governed services, especially when the idea for that governance does not come from within the community. For example, many community leaders were suspicious of the country government, which proposed the idea, and this affected participation. In addition, institutional barriers such as accountability, funding priorities and scarce resources needed to be overcome to move from an institutional model to an integrated, multidisciplinary neighbourhood-based model. However, over time a neighbourhood governance structure was developed which now facilitates community problem solving. This model resulted in the development of neighbourhood support groups which could have input into the development of services and social service agencies employing neighbourhood residents.

From a staff perspective a range of issues—about leadership, working in multidisciplinary teams, developing a family-centred approach which enabled consumers to have more control over their lives and be less dependent on welfare—required a lot of work and training in new ways to undertake service delivery and evaluation.

Neighbourhood-based models are useful for overcoming fragmentation of provision of services by individual agencies working in isolation from each other. When services can work together to develop strategies for responding to community identified needs, resource allocation and service development are profoundly affected. Developing these models successfully requires support from the top, vision, commitment over time, patience and resources.

A key lesson from the project was that 'neighbourhood-based information is essential for setting priorities, measuring progress, and mobilising support for action'.

Author: Norton, Ilena M and Schauer, Joan 1997

Title: A hospital-based domestic violence group

Details: *Psychiatric Services*, 48, pp1186–1190

Purpose

To evaluate a hospital-based drop in group for women survivors of domestic violence

Participants

Women survivors of domestic violence

Method

Women attending a group for survivors of domestic violence were asked to fill in a questionnaire exploring demographic details, how they were referred to the group and their satisfaction with the group.

Findings

Women generally reported satisfaction with the group for a range of reasons, including that the leaders were supportive; they heard the stories of other women and were able to tell their stories; they learned about domestic violence and received support from other women; and they received referrals to other services.

Author: O'Brien, Anne and Mahony, Kate 1999

Title: *Automated services: the experience of people with acquired brain injury*

Details: ARBIAS, p64

Purpose

This study was undertaken to research difficulties experienced by people with acquired brain injury when trying to use automated technology such as

automatic teller machines, automated ticketing machines and telephone interactive voice units.

Participants

Service providers and 94 people with acquired brain injury

Method

An extensive literature review was followed by a survey of agencies providing services to people with acquired brain injury to identify the types of automated services people experience difficulty in using. This information was used to develop a questionnaire which explored the awareness and use of automated services by people with acquired brain injuries and the difficulties they experienced. The questions were open ended and were read to the participants by a case worker, and their responses were documented.

In the second phase of the study 26 people who had answered the questionnaire were given three tasks (to access a service which required using voice activated telephone options, to travel on a tram and purchase a ticket utilising the electronic ticket machine and to get money from an ATM machine). The researcher accompanied the participants and observed difficulties they had in undertaking these tasks. Each participant was then asked: 'Did you have any problems with this task?' This methodology allowed the researchers to identify how people's perceptions of their ability to use the technology compared to observations of their use of it. This was done as one of the common consequences of acquired brain injury is that people may lose their capacity to judge their strengths and weaknesses and lose insight into their behaviour.

In the third stage of the project, five participants who had trouble using ATMs were trained in their use and were tested following training and six weeks later.

Findings

Many barriers to participation of people with acquired brain injury were identified in this study. They include that the use of technology often requires people to be able to read and follow written instructions; terms used (such as **validate**) may not be understood; technological devices such as ticketing machines are not accessible from a sitting position, thus people who have difficulties with balance are unable to access them; information about using technology is not often available on an ongoing way in the media (for example on television); there are often no people available to assist those who have difficulty in utilising technology (this means that participants often reported seeking assistance from other people around them—in the case of ATMs this can make people vulnerable to theft); PIN numbers can be difficult to

remember; and physical design of the machine (and different designs for the same type of machine such as ATMs) can cause problems.

Automated telephone services also created difficulties as participants sometimes had difficulty understanding and remembering the instructions (instructions were too complicated and long); could not always respond to the question by pushing the correct button on the phone; and did not have access to an appropriate phone. For people with acquired brain injury, this can mean they do not access services or experience considerable difficulty and anxiety in doing so. The comparison of self reporting of difficulties with the observations of the researcher indicated that people with mild, moderate and severe acquired brain injury were able to accurately report the difficulties they faced in utilising technology, suggesting that those in this study had not lost their insight in this regard. Training, based on positive reinforcement, was successful in improving the capacity of people with acquired brain injury to utilise ATMs.

Author: O'Neal, Paul D 1999

Title: Methodological problems associated with measuring consumer satisfaction in the mental health field

Details: *Australian Social Work*, vol 52, no 3, pp9–15

Purpose

To review the literature on consumer satisfaction, including methodological issues, with a focus on mental health.

Method

Literature review

Findings

The author argues for consumer satisfaction as a tool in evaluating services and suggests that it should only be one part of an overall continuous quality improvement framework. A number of specific issues are discussed including the propensity of consumers to say they are satisfied with services even when they may not be, the use of vicarious measures of consumer satisfaction, factors which may predict patient satisfaction, methodological problems associated with asking consumers to rate the skill of health care professionals, questions raised by high non-response rates, and payment for participants.

Author: Oawar, Manohar S and McClinton, John 1999

Title: Poverty in North-East Victoria: implications for social work practice

Details: *Australian Social Work*, vol 52, no 2, pp19–27

Purpose

To interview rural people living in poverty to find out about their experiences of poverty, their knowledge of local services and their views on those services, and suggestions for how poverty may be alleviated.

Participants

Twelve people with household incomes under \$20 000.

Method

This paper describes a survey which was part of an action research process. A district in Victoria where 40 per cent of households had incomes less than \$20 000 (using ABS data) was selected for the study. Participants were recruited through local workers, articles in local newspapers and leaving leaflets at people's houses.

An interview schedule was developed and reviewed through community consultation and interviews were undertaken by a skilled person.

Findings

Respondents identified a range of structural and personal causes of poverty. Most respondents were aware of some services and programs. Very few of these services were rated as very good.

Respondents were also able to propose a number of ways poverty might be alleviated and expressed a willingness to work with others to do this.

Author: Otto, Di 1990

Title: *Unlocking the system: consumer participation strategies in mental health*

Details: Victorian Mental Illness Awareness Council, p43

Purpose

This project was undertaken to recommend strategies for involving consumers in the mental health system.

Method

A community development approach was utilised. This included discussions with groups of consumers, discussions with individual consumers involved in advocacy and initiation of pilot participation projects.

Findings

A number of themes emerged from this process. These include that consumers thought that they needed to be able to participate and learn from experience, that the framework operating in mental health systems needed to be changed to enable consumers to participate, consumers needed to be informed about decision-making structures, work needed to be done on identifying and overcoming barriers to participation, and resources needed to be available to enable strategies for change to be developed and to assist in dealing with structural inequalities.

Some of the barriers identified from a consumer perspective included consumers not wanting to criticise services they are currently utilising; attitudes of health professionals; the impact of institutionalisation in taking away people's living skills; lack of confidence and dependency on the system. Service providers identified barriers related to attitudes, domination of the medical model and structures of the mental health system. Issues specific for consumers of non-English speaking backgrounds and women consumers were also discussed. A number of strategies were proposed to overcome some of these barriers.

Author: Pardy, Maree 1994

Title: Casemix and cultural diversity: the case of women from non-English-speaking backgrounds

Details: Health Issues Centre, *Health Issues*, vol 38, pp23–7

Purpose

This paper explored the experiences of women of non-English-speaking backgrounds of using language services and the implications of case mix funding on the provision of these services.

Participants

Women of non-English speaking background

Method

Women were asked to talk about their experiences of interpreting services. The method for doing this was not stated.

Findings

Women from non-English-speaking backgrounds have some very traumatic experiences in hospitals as a result of inadequate and inappropriate interpreting services. Examples identified in this paper include undergoing procedures without interpreters; being unable to communicate with health professionals for long periods of time and consequently being confused or in pain for a long time; interpreters often being provided when it was in the hospital's interest (for example when forms had to be filled in for medical records); difficulties in communicating with service providers in the presence of a male interpreter; poor experiences of language services resulting in women no longer asking for an interpreter; and children still being asked to interpret.

The paper also discusses the role of ethnic health policy and ethnic health audits in promoting the development of more culturally appropriate services and the implications of case mix funding on the development of such services.

Author: Pinches, Allan and Dunstone, Nina (Northern Area Consumer Consultants) 1998

Title: *A proposed consumer participation strategy* (revised version)

Details: Northern Area Mental Health Services, p18

Purpose

Written by consumer consultants, this paper explores issues in consumer participation in mental health services from consumer perspectives.

Findings

The authors outline a range of strategies to enhance consumer participation within mental health services. These include establishing networks of consumers; running support and advocacy skills training for consumers who may become consumer consultants in the future; expanding consumer representation on a range of committees with accountability to consumers through consumer gatherings, surveys, questionnaires and newsletters; payment for consumers to be included in service budgets; development of formal and informal participation processes; consumer participation in staff training, development and selection; improved complaints mechanisms; and development of ways consumers can relate with other consumers to provide peer support and participate in a 'therapeutic community'.

In addition, this report makes suggestions for overcoming the barriers of gaps between stated values and actual practice, tokenism, questions about representativeness, role strain of consumer representatives, poor

communication, economic factors, jargon, responsibility for consumer participation, resource allocation, level of formality and consumers becoming ill.

Author: Pritchard, Colin, Cotton, Andrew, Bowen, David and Williams, Richard 1998

Title: A consumer study of young people's views on their educational social worker: engagement as a measure of an effective relationship

Details: *British Journal of Social Work*, 28, pp915–938

Purpose

To explore the views of young people accessing educational social workers.

Participants

One hundred and ten young people and 127 parents

Method

A questionnaire was developed and piloted. Following the pilot, quotes from young people were incorporated into the questionnaire to make it more friendly. The questionnaire was then distributed to young people and parents by educational social workers, who explained that it gave the participants a chance to have their views heard and that answers were anonymous and confidential. Participants were asked to fill in the questionnaire and return it to a university department in a prepaid addressed envelope. There were some questions with five point scales and some open ended questions asking participants to comment on the best and worst aspects of seeing their educational social worker. A confidential coded social history was filled out by the social worker, matched with the questionnaire and posted to the university department to ensure anonymity of the social worker and the client.

Findings

The authors suggested that it was more useful to explore consumer 'engagement/non-engagement' with the service, rather than satisfaction/dissatisfaction.

Key findings were that the young people and their families were experiencing a range of issues and problems; 90 per cent of the participants were 'engaged' with the service providers; most young people had positive views about educational social workers and appreciated the practical help and guidance offered by them.

Author: Quine, Susan and Cameron, Ian 1995

Title: The use of focus groups with the disabled elderly

Details: *Qualitative Health Research*, vol 5, no 4, Sage Publications, pp454–461

Purpose

To examine whether focus groups are a useful method for seeking input from older women with physical disabilities.

Participants

Women over 75 years of age with a physical disability

Method

Focus groups with a maximum of six participants were conducted in the hospital setting.

Findings

Focus groups are effective means of getting feedback from older women with physical disabilities in a hospital setting. Key lessons were to keep the groups small (five or six participants was optimal), ensure the space is adequate for people with mobility aids and keep the time the group meets to approximately half an hour.

Author: Radoslovich, Helen 1998

Title: Putting the focus on women: evaluation of the impact of the HIV/AIDS Women's Project in South Australia

Details: Available online from the Women's Health Statewide web site at < <http://www.whs.sa.gov.au> >

Purpose

To document the work of a project focusing on the needs of women with HIV/AIDS, to evaluate the project, to identify gaps in service delivery and to develop recommendations.

Participants

Consumers and service providers

Method

The project was developed in response to a need identified by HIV positive women for a service to be established to meet their needs. The project was directed by a reference group including the women, service providers and

others with relevant expertise. The women participated in planning and developing the project, employing the project worker on an ongoing basis throughout the project. The project aimed to develop a clinic for HIV positive women, increase the awareness of existing services about their needs, assist agencies to develop appropriate and sustainable strategies, and empower HIV positive women. The project included lobbying, advocacy, information provision, establishment of support groups and later peer support.

Evaluation

A reference group was established to guide the evaluation.

Documents relevant to the project were reviewed and interviews were undertaken with women involved in the project and with staff from relevant agencies.

Findings

Women experience HIV/AIDS differently to men in several ways. For example, many services have focused on the needs of men, and women have felt isolated from those services; unlike many positive men, many positive women have children; women respond differently to HIV treatments than men; many responses to HIV/AIDS have not been developed in women-sensitive ways; and HIV positive women from diverse backgrounds have special needs.

Through this project the experiences and views of HIV positive women formed the basis for action which resulted in more appropriate policy and service provision for them and increased access to these services. In addition, attracting funding was assisted by the visibility given to issues for positive women by the project.

The key reasons for the success of the project include involvement of positive and affected women; development of an appropriate space for positive women; success in promoting issues relevant to positive women and getting these recognised in policy and service delivery; supporting positive women to become advocates; providing high quality services; and working with other agencies. One disadvantage of the project was that some services tended to use the existence of the project as a reason for not developing appropriate services for positive women as they saw that they could refer women to the project.

Author: Ratima MM, Fox C, Te Karu H, Gemmell T, Slater T, D'Souza WJ and Pearce NE 1999

Title: Long-term benefits for Maori of an asthma self-management program in a Maori community which takes a partnership approach

Details: *Australian and New Zealand Journal of Public Health*, vol 23, no 6, pp601–605

Purpose

To explore whether an asthma self-management strategy developed and implemented in partnership with a rural Maori community was successful. This program was developed after a Maori asthma review team recommended that asthma centres based in Maori community centres and with Maori management be established to address the high morbidity and mortality of Maori peoples from asthma. The project was a collaboration between a Maori community centre and a university.

Participants

Forty-seven of the 69 people originally enrolled in the program

Method

A Maori tribal representative and Maori community health workers coordinated the project in collaboration with the community and with university researchers and service providers. Self-management plans were developed based on the needs of the community. The program was discussed at community meetings and participants in the program were identified through community networks. Maori workers supported people participating in the plan. Participants were interviewed throughout the program and asked to keep a diary (with assistance from the workers where appropriate). Follow-up studies were done one, two and six years after the program.

The six-year follow-up was done as a collaboration between a university and a Maori research group. Maori community workers coordinated the work of researchers and the community, recruited participants, and organised clinics and community meetings. As well as questions about their health participants were interviewed about their use of services and asthma self-management (by a university researcher). A member of the Maori research group interviewed participants, in community settings, about other effects of the project and about the benefits of the culturally appropriate approach taken by the project.

Findings

The program was successful in assisting people to manage their asthma over a long time which meant that participants were also more able to participate in

social and recreational activities and everyday life. Other findings included that: participants made stronger links with other Maori people; the program assisted them to take more control over other aspects of their health and to make positive changes; it encouraged people to make changes to assist their family and friends improve their health; there was increased information sharing; people had more confidence in accessing health services and health professionals; and the cultural appropriateness and Maori management of the service (including Maori workers) was critical. Participants also identified that the program needed to include more follow up and should be more widely available.

Author: Rees, Roger J and Hannaford, Meredith 1996

Title: Effects on the primary caregiver when a family member experiences acquired brain injury

Details: *Australian Journal of Social Issues*, vol 31, no 4, pp392–409

Purpose

To undertake a pilot study to explore the experiences of primary carers of people who have acquired brain injury.

Participants

Twenty families

Method

Families were randomly selected from those caring for a person with acquired brain injury (for more than two years) attending a rehabilitation clinic.

Methodology included face-to-face interviews, participant observation, reviewing diaries and correspondence and review of clinical records.

Findings

Most of the carers were women. There was an increased burden on carers after the consumer acquired the brain injury. Carers often felt isolated and there were few appropriate services to support them.

The authors recommend that acquired brain injury needs to be recognised as distinct from developmental disabilities in order for appropriate services to be developed.

Author: Rice, Pranee Liamputtong, and Naksook, Charin 1998

Title: Caesarean or vaginal birth: perceptions and experience of Thai women in Australian hospitals

Details: *Australian and New Zealand Journal of Public Health*, vol 22, no 5, pp604–608

Purpose

To explore the perceptions and experiences of Thai women who have had vaginal or caesarian births in Australia

Participants

Thirty Thai women, some of whom had experienced birth in Thailand only, some in Australia only and some in both countries

Method

Women were recruited from community centres and meeting places, through networks of the researchers (who are both Thai speakers) and through snowball sampling from these initial contacts. The number of women interviewed was determined by saturation of information emerging from interviews.

Women who agreed to participate were contacted by telephone, the study was discussed with them and an interview time arranged. Interviews were undertaken in Thai in the women's homes by the researchers. Interviews were transcribed in Thai and the only translations into English were quotes for the final report. These quotes were translated by one author and checked by the other. During the course of the study the researchers participated in a range of Thai community activities and acted as participant observers.

Findings

The paper identifies women's experience and perceptions of caesarean birth including their experience of anaesthetics, preparation for caesarean birth, and participation in decision-making.

Author: Rogers, Anne and Pilgrim, David 1993

Title: Service users' views of psychiatric treatments

Details: *Sociology of Health & Illness*, vol 15, no 5, Blackwell Publishers, pp612–631

Purpose

To develop an understanding of consumer views of psychiatric treatments using both quantitative and qualitative methods in order to guide the activities

(including campaigns and service provision) of Britain's largest mental health charity (MIND).

Participants

Five hundred and sixteen people who were users of psychiatric services.

Method

A semi-structured questionnaire was developed and piloted with six consumers and amended based on their advice. Face-to-face interviews were conducted using this questionnaire. Consumers who had utilised inpatient psychiatric hospital services were contacted through local MIND associations, social services and mental health groups.

There were 241 questions and the interviews took two to three hours to complete. Questions covered a range of issues from initial contact with services through to returning to the community. There were also questions to find out why people gave positive or negative answers.

Findings

The use of quantitative and qualitative questions enabled the researchers to explore complex and ambivalent consumer responses to psychiatric treatments. By doing this they were able to build up a quite sophisticated understanding of consumer responses to experiences of health care. For example, while most consumers had negative experiences of electroconvulsive therapy (and recommended against its use), they often also reported some positive outcomes. Other issues explored include pharmaceuticals (major tranquillisers and antidepressants), occupational therapy and talking therapies.

Key findings include that negative experiences of a range of treatments are related to side effects incurred, whether consumers were forced to undergo the treatment and the perceived attitudes of psychiatrists.

Author: **Rose, Diana, Ford, Richard, Lindley, Peter, Gawith, Libby, & the KCW Mental Health Monitoring Users' Group (1998)**

Title: *In our experience: user-monitoring of mental health services in Kensington & Chelsea and Westminster Users' Group*

Details: The Sainsbury Centre for Mental Health, pp5–33

Purpose

To involve people with long-term mental health issues in evaluating mental health services

Participants

Fifty-eight people with mental health issues

Method

A group of 12 users of mental health services was established to conduct the project. Members of this group were trained as evaluators to conduct interviews and site visits. The project was coordinated by a user of mental health services. Consumers were randomly selected from a database. The reason for random sampling was to identify people who may not have been included if sampling had only included those who regularly attended services. The consumers' key workers were contacted by letter and were given a letter for the consumers.

The interview questions were developed by staff members and were re-drafted following input from others, including consumers who adapted it to be relevant to an inner urban, multicultural community setting. The questionnaire was tested in pilot interviews by each member of the user group before being finalised. Semi-structured interviews were undertaken with some closed-ended and some open-ended questions. Interviewers were debriefed after each interview and results of interviews were discussed at group meetings.

Findings

There were problems with the database and with contacting a number of consumers due to lack of contact with key workers. Just under half of those contacted refused to participate. The reasons suggested for this were that consumers who are very ill may have little motivation to participate, consumers were 'over-researched', consumers may not have been clear about what they were being asked to do, or key workers may not have been enthusiastic about consumers participating. There were no identifiable demographic or risk profile differences between those who agreed to participate and those who refused.

Key issues identified include: some consumers had little knowledge about services or the help available to them; consumers expressed 'neutral' satisfaction with services and expressed different levels of satisfaction with different types of service providers; many consumers identified that they thought only their problems, and not their strengths and abilities, were evaluated in their assessments; waiting times were sometimes too long; and worry about side effects of medication. In addition, consumers identified a range of issues such as housing and finances which impacted on their health.

There was an association between access to 'talking therapies' and overall satisfaction. The authors reflected that the attitudes and concerns of key workers had a big influence on their preparedness to ask consumers to

participate. Some workers were enthusiastic, while others were fearful of criticism or thought that consumers might have difficulty respecting the confidences of other consumers.

Author: Salisbury, Christine 1998

Title: A health service and Aboriginal & Torres Strait Islander partnership to develop and plan mental health services

Details: *Australian Journal of Primary Health—Interchange*, vol 4, no 4, LaTrobe University, pp18–30

Purpose

To trial a participatory action research approach to establishing partnerships with Indigenous people in the planning and development of a mental health service. The authors state that 'to achieve this type of partnership the health service had to be willing to enter the partnership and to give the authority to the Aboriginal and Torres Strait Islander Health Outcome Council to seek and trial solutions on Aboriginal and Torres Strait Islander mental health matters. This represented a structural change and a sharing of power. 'Outcomes were measured in terms of how acceptable the services were and how they were utilised'.

Method

An Aboriginal owned action research process including cycles of planning, action, analysis and reflection was developed and implemented. A reference group who consulted with the wider Aboriginal and Torres Strait Islander communities was established. Discussion about the project occurred in many settings. Decisions were made by consensus and were always open to review. Themes were identified and fed back to a reference group. Information about utilisation of the service by people of Aboriginal and Torres Strait Islander descent were collected before and throughout the process. The service was evaluated by collecting information from Aboriginal and Torres Strait Islander consumers after changes were implemented.

Findings

The reference group identified a number of barriers to Aboriginal and Torres Strait Islander people accessing services. These included mistrust, fear, racism, discrimination, waiting times and lack of transport. Solutions developed by Aboriginal and Torres Strait Islander communities are discussed in the paper. These changes resulted in a large increase in service utilisation.

Author: Santamaria, Nick and McKenzie, Margaret 1999

Title: *Carers in acute situations: hospital in the home*

Details: Carer Training Centre, The Alfred Hospital, p12

Purpose

To develop an understanding of the impacts on carers of hospital in the home (HITH) programs, including physical and psychological impacts, satisfaction, information needs and impacts on health.

Participants

Seventy-eight carers of HITH patients from two Melbourne teaching hospitals

Method

Participants were randomly selected from HITH databases at two hospitals and letters were sent to their homes inviting them to participate in the study. A structured interview was conducted in the carer's home. This interview covered demographic details, carer needs and satisfaction with the program. Carers were asked to self-report their stress, fatigue, health status and activities.

Findings

Generally carers were satisfied with the HITH program. Key issues included needing more information, especially about the consumer's condition and emergency procedures. Some impacts on the health of carers were identified.

Author: Sen, Rinku 1994

Title: Building community involvement in health care

Details: *Social Policy*, pp32–43

Purpose

This paper discusses a model for activism developed by a small organisation called People United for a Better Oakland working with disenfranchised communities to facilitate effective participation in health system debates.

Participants

Participants were people living on low incomes, people of colour and immigrants. Most were women.

Method

Local residents were approached to join People United by workers, friends and family members. Discussions about health and health care were held in local

meeting places and common issues were identified. These issues formed the basis of activism for People United.

The organisation developed key strategies to enable community participation in health care decision-making. These included building a collective approach to problems and developing common solutions, challenging the practices of health care providers and administrators and developing leaders who had a good knowledge of the health care system.

Findings

While the demands made in each campaign were specific to that campaign, they were often around the following: getting health care professionals and institutions to recognise the issues or health threat; asking that health care professionals take on responsibility for educating themselves and other health care professionals about relevant issues; seeking changes to programs to ensure access and high quality services; trying to get public institutions to recognise the right of people living on low incomes to make demands of them; and changing health providers' view of themselves from being providers to being partners.

Five phases in developing relationships with service providers and administrators were identified. These were conflict, confrontation, negotiation and agreement, monitoring and partnership. The attitudes of professionals determined how quickly these phases could be moved through.

The organisation was successful in improving health services provided to the community and in creating community leaders who have become experts in community health issues and in promoting community action in health.

The author outlines a vision for a coordinated community-based response to national health policy issues.

Author: Shoalhaven Youth Health Service 1996

Title: *Shoalhaven Youth Health Service pizza party program*

Details: Shoalhaven Youth Health Service, p3

Purpose

The program was established to increase awareness about binge drinking, assist young people to develop strategies to avoid binge drinking and assist the development of directions and planning for the service.

Participants

Young men and women between the ages of 15 and 18

Method

The service held gatherings which lasted for three hours, with the first 90 minutes being an informal party in which pizzas and soft drinks were served. During this time staff asked the participants about the service and how it could be improved, and also about their knowledge of drugs and alcohol. During the second half of the party, participants reflected on how many soft drinks they had consumed and what this would mean if the drinks had been alcoholic. This was followed by a discussion about the consequences of binge drinking. In addition to holding the parties the Youth Health Service leaves 'graffiti sheets' around to encourage young people to comment on the service.

Findings

The party program was a useful way of finding out from young people how the service could be improved and for getting some good ideas for service planning. Feedback about the parties showed that young people enjoyed them, liked the format and gathered information.

Author: Small, Rhonda, Lumley, Judith, Yelland, Jane and Rice, Pranee Liamputtong 1997

Title: *Mothers in a new country: Vietnamese, Turkish and Filipino women's views of maternity care*

Details: Centre for the Study of Mothers' and Children's Health, p36

Purpose

This was a companion study to 'A survey of recent mothers'. The study aimed to seek the views of Vietnamese, Turkish and Filipino women on their experience of maternity care, as women from non-English-speaking backgrounds were under-represented in previous studies on women's experiences of birthing services in Victoria.

Participants

Three hundred and eighteen women attending three major metropolitan hospitals

Method

Bicultural interviewers talked with and invited women to participate in the study while they were still in hospital after having given birth. Women wanting to participate were asked to sign translated consent forms. They were interviewed at home in their language of choice, six to nine months after having their baby.

Findings

Many participants reported that they were not very satisfied with care. Issues included lack of information; need for services in which the carers were kind and not rushed; thorough and good communicators; lack of participation in decision-making; lack of continuity of care giver and choice of gender of care giver; lack of interpreting services; and the need for services which could respect customs of different groups of women.

Author: Small, Rhonda, Yelland, Jane, Lumley, Judith and Rice, Pranee Liamputtong 1999

Title: Cross-cultural research: trying to do it better, no 1, issues in study design

Details: *Australian and New Zealand Journal of Public Health*, vol 23, no 4, pp385–389

Purpose

To discuss a range of issues for consideration when undertaking cross cultural health research

Findings

This paper includes discussion of sampling issues (including recruitment, sample size, representativeness of the sample) and employment and training of bilingual workers.

Author: Small, Rhonda, Yelland, Jane, Lumley, Judith, Rice, Pranee Liamputtong, Cotronei, Valerie and Warren, Rosemary 1999

Title: Cross-cultural research: trying to do it better, no 2, enhancing data quality

Details: *Australian and New Zealand Journal of Public Health*, vol 23, no 4, pp390–395

Purpose

This paper explores issues and strategies around translation of study instruments and assessing interview quality in cross cultural research.

Participants

Vietnamese, Filipino and Turkish women who had utilised maternity services in Victoria

Method

Information sheets and consent forms, interview schedules and quality of life measures were translated into Vietnamese, Turkish and Tagalog. The original translations of the questionnaires were done by accredited translators, then each was discussed by a group of people from each community (this group included those working on the project and on the project reference group as well as other community members). The group was asked to discuss the clarity, accuracy, meaning, accessibility and appropriateness of the translation as well as the order of the questions. The groups also discussed the ways women in each culture might talk about the issues being examined. The questionnaires were then modified and both the original and modified versions piloted with at least five women from each community. The original English version and the modified translated version were also completed by three women. The results were then translated back into English and discussed at a reference group meeting.

Semi-structured interviews were carried out by bilingual workers who ticked pre-coded answers or wrote down what women said in their language of choice. This information was transferred to an English version of the questionnaire, with the women's responses translated into English. Where permission was given the interviews were taped, which allowed the interviewers to check the responses. A random sample of 20 taped interviews were translated and transcribed. The quality of the interviews was checked by analysing the transcribed interviews, checking that the English coded versions of the interviews were completed appropriately (and giving feedback to the interviewers about this) and comparing translated interviews with the original survey information collected at the time of interview. In addition, for some of the questions which had been difficult to translate, women were asked to specify what they understood by the question and the response options.

Findings

A range of issues impacted on the meaning and quality of the original translations. For example, some of the terminology was too technical, some of the translations did not give the same meaning as the English version (eg in one, self-harm had been translated as suicide), some of the response options were seen as being too similar to each other and some of the response options had quite different meanings in different cultural contexts. There were also difficulties with the back translations, with some responses differing from their original meanings.

Women reported that the modified translated forms were easier to fill out than the original translated forms. Some problems with the responses were picked up by asking women to talk about how they understood the question and the

responses to difficult-to-translate questions. Comparison of the transcribed interviews with the original questionnaires indicated that there were a few instances when questions were asked differently from how they were written down and occasionally not asked at all. This was then discussed with interviewers to ensure that questions were asked in a consistent way. Review of interview transcripts and coded data enabled the team to identify discrepancies arising throughout the translation, transcription, interview, and back translation process. As a result of this work the authors make six key recommendations about translation issues. Monitoring of interview quality as soon as possible after each interview was undertaken and responses transcribed meant that interviewers could re-contact women to seek information on incomplete questions.

Author: South Australian Community Health Research Unit 1996

Title: *Obtaining and using feedback from service users in women's and community health services*

Details: South Australian Community Health Research Unit, p96

Purpose

To investigate how consumer feedback and evaluation work within community and women's health services in South Australia

Participants

Thirty staff and 30 clients from women's and community health services

Method

A project advisory group was established. Staff and clients from women's health and community health centres were interviewed by telephone.

Findings

Formal feedback was often obtained through written evaluation questionnaires and through newsletters and forums. Feedback was also obtained through letters, complaints and suggestions. This information was fed into service planning and monitoring.

Informal feedback was obtained in a variety of ways, often in conversations. This type of feedback was less likely to be fed into quality improvement processes. Feedback was generally about quality, access and availability of services.

A range of factors affected feedback processes. These included the relationships between clients and workers; the broader relationship between the clients and

the organisation; and the relationship between the worker and the organisation. Organisational culture and practices, including philosophical commitment to involving consumers and having structures in place for processing feedback, were critical for ensuring client feedback was utilised. Barriers to utilising this information include that sometimes informal feedback was not passed on to the organisation, communication and information breakdowns occurred within organisations and there was a lack of time and resources to respond appropriately.

The authors argue that patient satisfaction surveys are not appropriate in a context where service users expect to be active participants in their health care. They also suggest that feedback should create an opportunity for a dialogue between service providers and users and that clients should participate in service decision-making.

Author: Sozomenou, Andrew, Mitchell, Penny, Fitzgerald, Maureen and Malak, Abd

Title: *Innovative strategies for engaging non-English-speaking background mental health consumers, carers and community members in partnership in developing, managing and evaluating mental health services*

Details: Transcultural Mental Health Centre, p58

Purpose

To describe innovative strategies for involving consumers of non-English-speaking backgrounds in developing, managing and evaluating mental health services

Method

A project advisory committee including consumers, carers, health care providers, academics and individuals with relevant expertise was established to guide the project. A literature review was undertaken and relevant State and Commonwealth policies were also reviewed. A broad national survey (with open and closed-ended questions) was undertaken to identify services that were engaging communities of non-English-speaking background and identify a range of strategies being utilised. Nine sites were selected for in-depth case studies based on the survey results. A statewide forum was held to enable consumers, carers, community members and providers to discuss ways they could work together.

Findings

This paper discusses a range of issues relevant to consumer participation, including definitions of consumer, carer, participation and empowerment. Key

findings about barriers to participation include issues of power, control and knowledge; resources; the added complexity created by issues of social diversity and disadvantage; representativeness; structures and forums of participation; and tokenism.

Author: Stewart, Fiona J and Rosenthal, Doreen A 1997

Title: Rural and urban female secondary school students' attitudes towards and use of primary care services

Details: *Australian Journal of Rural Health*, 5, pp126–131

Purpose

To explore sexual health issues and experiences of utilising related health services of young women living in rural and urban areas.

Participants

Two hundred and seventy-two young women aged between 15 and 18 years attending secondary school in areas where many people were living on low incomes. Thirty-seven per cent were from rural areas and 63 per cent were from urban schools. Most of these young women had Australian-born parents and lived at home.

Method

Focus groups were conducted with rural and urban young women to inform the development and wording of a questionnaire which asked about relationships, attitudes to a range of sexual health issues and to use of health services. The questionnaire was then piloted with a small number of young women from urban and rural settings. Young women at school were asked if they would like to participate in the study, and if so, to fill in a consent form. Parents were also asked to fill in a consent form. Those who wanted to participate were asked to fill out the questionnaire.

Findings

Many factors impact on the accessibility of services to young women. These include the atmosphere of the service and the attitude of staff, cost (especially in rural areas where bulk billing is less common), the way doctors treat young women (including being judgemental), gender of doctors, difficulty in asking doctors to prescribe contraceptives, and issues about confidentiality and privacy.

Author: Success Works Pty Ltd 1999

Title: *Improving health outcomes for people experiencing homelessness in Victoria: a framework*

Details: Royal District Nursing Service Homeless Persons Program, p40

Purpose

To develop a framework for the planned provision of services to people experiencing homelessness. Factors considered in developing the framework included issues related to the client group, the types of services required and necessary government and service provider responses. In addition, the report considered issues relevant to specific groups of people including young people, women, men, older people, Koori people and people from culturally and linguistically diverse backgrounds.

Participants

Service providers, consumers, non-government organisations and policy makers

Method

An advisory committee was established to oversee the project. The methodology included a literature review, analysis of health and demographic data, consultation with service users, service providers and other key stakeholders, and a review of existing good practice models.

The methods for consulting service providers included questionnaires, follow-up phone calls, focus groups and interviews. Best practice models were identified through service visits and interviews and published information. In addition, nine case studies were undertaken in a diversity of settings. Consumers were consulted through focus groups and individual interviews.

The consultants doing the project also undertook participant observation at one outreach service.

Findings

People experiencing homelessness have higher rates and severity of a range of health conditions than the general population. There is a range of gaps in service provision, especially in regard to mental health, drug and alcohol abuse and dental health.

Specialist services with a focus on and understanding of homelessness were found to be most useful to homeless people, while hospitals (especially emergency and outpatient departments) were found to be the least helpful.

Issues in accessing services included lack of transport and lack of respect service by providers. Outreach programs decreased these access issues.

A whole-of-government response is necessary for the development of an appropriate health care service for people experiencing homelessness. Key components of an effective service include active outreach, appropriate assessment and referral, specialist health workers, single entry points into the system, the provision of all services at one service point, and multidisciplinary services. It was also identified that the system needs to be able to respond to the diversity of homeless people.

Author: Taylor, Brent and Clarke, Richard 1993

Title: Client feedback—development of an instrument for psychiatric inpatients

Details: *Australian Health Review*, vol 16, no 3, pp231–244

Purpose

To develop a survey tool to seek feedback from consumers utilising psychiatric services

Participants

Consumers, staff and community members

Method

A questionnaire was developed in collaboration with a committee which included staff and community members (including consumer advocates). Interviews with government, non-government and carer organisations were also conducted to inform questionnaire development. The draft questionnaire was reviewed by a group of former patients. One of the things these consumers were asked to comment on was whether they would have been willing to answer the questionnaire.

All patients using an acute facility over a two-month period were given the questionnaire and asked to post it back to an independent address. The questionnaire was also given to a random sample of long-stay patients.

Findings

There was consistency in the results given by the consumers participating in the survey indicating that consumers with mental health issues are able to give competent feedback to health services. Key issues for consumer satisfaction included inter-staff communication and consumer-staff communication.

The authors argue that consumer satisfaction is critical in the development of high quality health services, that consumers are capable of making judgments about technical aspects of care and that perceptions of treatment can influence service utilisation and consequently the health budget. In addition, they also argue for the importance of considering social or contextual aspects of quality in service improvement.

Author: Tidemann, Sonia C, Bohme J, Burnett R, Camphoo J, Cook H, Daniels L, Dixon B, Dixon F, Fernando D, Heffernan K, Huddleston B, Huddleston V, Law M, Lee M, Marika K, Mayanini B, Maxted G, Mununggurr M, Muthamuluwy L, Tidemann K and Yikaniwuy S 1996

Title: *Aboriginal patient survey tools and processes: survey of Aboriginal people's stay in hospital—quality matters: final report*

Details: Batchelor College, p36

Purpose

To develop ways Aboriginal people could provide feedback to acute health services.

Method

Initially the idea of seeking feedback from Aboriginal communities was discussed with Aboriginal health workers participating in a diploma course. Questions were developed in collaboration with these workers. The process was to be jointly owned by all who participated in developing and collecting information.

To increase the number of responses, Aboriginal health workers employed in communities were asked to participate in seeking feedback from Aboriginal people who had utilised hospitals.

Generally Aboriginal health workers interviewed people from communities in their preferred language and then translated the information into English to a non-Aboriginal person who acted as a scribe.

A small trial was done in which Aboriginal and non-Aboriginal interviewers asked the same people the same questions (on different days, but within the same week) to ascertain whether there were differences in the information given to Aboriginal and non-Aboriginal workers.

Findings

The most effective way of seeking feedback from Aboriginal people was for an Aboriginal health worker to organise and undertake interviews with a person in their preferred language.

Open-ended questions resulted in information that was more useful for improving services than closed-ended quantifiable questions. It was important that the interviewers behaved in ways appropriate to communities. A range of issues was identified by Aboriginal people utilising hospitals. Recommendations were developed focusing on communication, admission and discharge, cultural issues, staffing, patient support, outreach and infrastructure and service issues.

Author: Triado, Tony 1998

Title: *Home from hospital: experiences of older people from the community of Moreland, Moreland discharge project*

Details: North Western Health, Aged Care Program, p114

Purpose

The aim of this work was to explore the experiences of older consumers and carers about discharge from hospital and their return to the community. The work was undertaken to identify good practice from a consumer perspective and develop recommendations for service improvement.

Participants

One hundred and fifty-one consumers and carers. Consumers had been recently hospitalised and were over 65 years old.

Method

Participants were selected so that they were representative of the demographic profile of older people in the city of Moreland. This resulted in a sample in which 50 per cent of participants were of non-English-speaking background and 50 per cent were of English-speaking background, and there were approximately equal numbers of participants in the age groups 65–69, 70–74 and over 75.

Questionnaires were developed and piloted. Semi-structured interviews were conducted in people's homes four weeks after their discharge from hospital to collect qualitative information about their experiences and reflections. Quantitative information using existing instruments which measure functionality, quality of life and stress was collected. Satisfaction surveys were also undertaken.

Relevant information was translated into Italian and Greek and qualified interpreters were utilised to explain the project to people from other language groups. All participants were offered interpreters and ethnic health workers assisted at interviews where appropriate. Next of kin were asked to participate if consumers had dementia.

Interviews with service providers were also undertaken to investigate issues affecting discharge planning and continuity of care from their perspective and identify issues they required information about from consumers. Focus groups were run with service providers to discuss the final draft and get input into development of recommendations.

Findings

While participants were generally happy with the quality of care provided in hospitals and by community services, they made many observations about the limitations of this care. Some of the areas identified for improvement in hospital services included responding to the specific needs of carers; communication and information provision; consistency in the level and quality of care; respect for consumers and carers as equal partners in care; more appropriate language services for people of non-English-speaking background; hospitality services; and length of stay. Areas of improvement relevant to community services included that the role of general practitioners could be strengthened; some groups of non-English-speaking background consumers were receiving fewer services than other groups; there had been reductions in home help provided by local councils; and in some cases cost was a factor.

Author: Trollor, John 1997

Title: A survey of carers in the north-west district of New South Wales

Details: *Australian Social Work*, vol 50, no 1, pp51–55

Purpose

The views of carers of people receiving home-based palliative care were sought to examine satisfaction with the service and inform planning of new specialist home-based services in a rural area. This study also aimed to contribute to the development of the literature as not much previous work has been done in this area.

Participants

Twenty-six carers of people receiving home-based palliative care

Method

Questionnaires were developed in consultation with researchers and palliative care and community nurses. Potential participants were identified by community nurses and were then contacted by telephone to ascertain whether they would like to take part in the study. Questionnaires were posted to participants with reply paid envelopes.

Findings

The majority of carers were women over 60 who were married to, or daughters of, the patients. Key issues identified by carers were need for respite, difficulty with feeding the patient and 'feeling alone in their worry and concern'. A high level of satisfaction with general practitioner and community nursing services was expressed.

Author: Velasco, Maria-Jesus 1999

Title: *Medicine information project (MIP): annual report July 1998–June 1999*

Details: Combined Pensioners and Superannuants Association of NSW

Purpose

The project aims to train and support older people to be peer educators on the use of medicines (Medicine Information Persons or MIPs), run community education programs and promote consumer perspectives to service providers.

Its overall objective is to reduce inappropriate use of medicines and empower older people.

Participants

Sixty older people (36 from non-English-speaking backgrounds) participate in the program.

Method

The MIPs Project has a steering committee. Older people are recruited through community organisations including ethno-specific groups. Training on the safe use of medicines is run in eight languages. MIPs then undertake presentations to the community, work with older people on a one-to-one basis, distribute written information, and become systemic advocates.

Findings

This approach has been successful and the MIPs contribute to public policy, service development and increasing the awareness of health professionals and older people.

Author: Wadsworth, Yoland and Epstein, Merinda 1996

Title: *Understanding and involvement (U & I): consumer evaluation of acute psychiatric hospital practice: a project concludes*

Details: Victorian Mental Illness Awareness Council Inc, p216

Purpose

This is the third volume of the Understanding and Involvement series. It describes a model for building consumer participation into evaluation and service development in an acute psychiatric service.

Participants

Consumers, staff and 'researchers'.

Method

This process was based on principles of participatory action research. This included facilitating the exchange of views and understandings between staff and consumers to develop the types of knowledge that could inform systems and cultural change.

Findings

The model which evolved included 12 critical aspects. These included a quality improvement framework; a commitment to consumer feedback and staff-consumer communication; the development of a range of comprehensive and systematic processes for consumer input; building these processes into service development so that they are 'do-able' and routine; achieving culture shift; developing multiple feedback mechanisms; establishing consumer-only, staff-only and consumer-staff sites for dialogue, discussion and decision-making; incorporation of consumer participation into all levels of organisations; payment of consumers for their expertise and participation; support for consumers working as systems advocates; and supports for staff.

Author: Washington, Valora 1985

Title: Head Start: how appropriate for minority families in the 1980s?

Details: *American Journal of Orthopsychiatry*, vol 55, no 4, pp577–590

Purpose

The Head Start Program was implemented to enhance education provided to pre-school children from minority groups living in poverty. Key aspects of the program discussed in this paper are community control, parent participation, service development and cultural diversity.

Participants

Mostly children and community members from ethnic minority groups living in poverty

Method

N/A

Findings

Head Start was designed to enhance community participation in developing solutions to poverty. Education was seen as a key vehicle for reducing transgenerational poverty. Key aspects of the program discussed in this paper are community control, parent participation, service development and cultural diversity.

Author: Woodruff, Ian W 1993

Title: *Client satisfaction with HIV/AIDS services in Victorian hospitals: a research report submitted in partial fulfilment of the requirements for the Master of Public Health Degree*

Details: Department of Social and Preventive Medicine, Monash University

Purpose

To explore the satisfaction of clients of HIV services in Victoria. In particular the project focused on communication, discrimination, accessibility and quality of care.

Method

The project was carried out under the auspices of the People Living With HIV/AIDS (PLWHA) Program of the Victorian AIDS Council (VAC) to facilitate recognition of the project among the target group.

The survey questionnaire was based on a previously developed questionnaire. It was piloted with 10 health professionals and 10 service users. In-depth interviews were undertaken with these 20 people to determine what they understood each question to mean. Following these interviews the questionnaire was re-drafted.

The questionnaire included one question asked in two different ways to provide an internal validity check. It also included a question about the reputation of the different services to identify if there was a correlation between reputation (expectation) and satisfaction.

To preserve confidentiality and anonymity, the survey was mailed to participants randomly selected from the PLWHA's mailing list. All surveys were

given a coded number and the codes were held by the VAC. Survey responses were mailed to the researcher, who was not located at VAC and did not have access to the codes. The surveys had closed-ended questions (with a Likert scale and neutral midpoint) and a section for comments.

Findings

There were high levels of satisfaction with medical and nursing care. Lower levels of satisfaction were recorded for some services in the areas of access, communication and courtesy. In particular, dissatisfaction was expressed with pharmacy waiting time; explanation of test results, procedures and treatments; and information on home care and preventive measures.

There was not necessarily a correlation between reputation and satisfaction. One service had a high reputation and high levels of satisfaction, one had a low reputation and high levels of satisfaction, while a third was low on both scores.

There was a high response rate to the survey which the author attributed to the high sense of 'ownership' of the issues among gay men. Possible reasons for non-response suggested by the researcher include illness, fear that dissatisfaction will result in reprisal, language barriers, HIV-related disability such as dementia, and that the participant may have died.

Author: Yates BD, McEwan C and Eadie D 1997

Title: How to involve hard-to-reach groups: a consumer-led project with lay carers of people with advanced HIV infection

Details: *Public Health*, 111, The Society of Public Health, pp297–303

Purpose

To use qualitative research methods to find out about the needs of carers of people with advanced HIV disease and to involve these consumers in the development of a video to address a paucity of information in this area.

Participants

Lay carers, relatives or partners of people with advanced HIV disease

Method

The project involved carers from three centres in Scotland and three centres in England and was directed by a steering group of health professionals from a number of disciplines. The medically qualified steering group members visited doctors working in the area to explain the project and ask them to identify

carers who might like to participate in the project. A member of the health care team was nominated to liaise with the carer.

There were a number of barriers to carer participation, including concerns about anonymity and confidentiality and ensuring a representative sample of carers. Strategies to overcome these included that steering group members talked with carers and carer support groups, developed good relationships with doctors working in the area and identified a key liaison person at each of the centres.

The video was made in four stages. The first stage included finding out whether there was support for the idea of a video and identifying issues of concern through focus groups, paired groups and interviews with carers and service providers. The second stage was development of a pilot video. The issues presented in the video were identified through a review of the information collected in stage one and collaboration with the steering group and health professionals. Time was spent with carers participating in the video to determine what they would like to say and to tell them about how the material would be used. The pilot video was then tested on carers and health care providers and adapted before final production.

Findings

Development of relationships between the researchers and carers and between the liaison officers and carers was critical to the success of the project, as was meeting the needs of carers in relation to venue, time, provision of respite and whether they wanted to participate in a focus group or an individual interview.

The concept of a video was most supported by the carers, who saw that it might assist in reducing discrimination through raising public awareness, help professionals understand their needs, reduce their feelings of isolation, show how others had coped, identify emotional problems and indicate sources of help. Specialist medical practitioners were more interested in providing 'factual' information and were less supportive of a video, while community-based workers were reasonably supportive of the idea.

Key issues identified by carers included mental and physical exhaustion, social isolation, stress on relationships and the difficulty of seeing the person with HIV-related illness deteriorate.

The authors conclude that the success of the video demonstrated the importance of involving carers throughout the process. In addition they reflect on the importance of asking open-ended questions so that carers can have scope to identify their own issues.

Author: Zarcadoolas, Christina, Ahern, David K, Blanco, Mercedes S, and Christner, Anne Marshall 1999

Title: *How to evaluate information from providers: tools for non-mainstream populations, final report, phase 2*

Details: Agency for Health Care Policy and Research, Department of Health and Human Services; prepared by The Abacus Management Group, p68

Purpose

This project develops ways to coach people living on low incomes, with low literacy and/or from ethnic minority groups, to communicate effectively with doctors. The project builds on previous work in which tools were developed to assist people from these groups to participate in consultations with their doctors.

Participants

People living on low incomes, with low literacy and/or from ethnic minority groups and health service providers

Method

A tool kit consisting of coaching cards, brochures, a poster, a video, an interactive voice response phone system and an English as a second language (ESL) curriculum was developed (with English and Spanish versions) and field tested.

Filed tests were conducted in clinics, work sites and at social service agencies. Information for field testing was collected through qualitative methods including focus groups and observation and from teaching the curriculum in an ESL class. Quantitative information was collected on the interactive voice response phone system. Consumer and provider responses to the field test were used to refine the products.

Findings

Along with communication strategies, a key message promoted in the coaching kit was that it was desirable for consumers to actively participate in their care. Participants in the project indicated that the strategy was successful.

Another key finding was that all stakeholders in the health system supported good information provision and communication, but that there was little practical and functional support for it.

Author: Zarcadoolas, Christina, Ahern, David K, Follick, Michael J, Blanco, Mercedes S, Evans, Joann M and Getting, James P 1997

Title: *How to evaluate information from providers: tools for non-mainstream populations, final report, phase 1*

Details: Agency for Health Care Policy and Research, Department of Health and Human Services; prepared by The Abacus Management Group, p61

Purpose

To identify consumer information needs and develop educational materials about treatment options for people on low incomes, with low literacy levels and from ethnic minority groups. Other objectives of the project were to improve the quality of care and patient satisfaction, to increase appropriate use of health services, to reduce the burden on physicians through creating more informed consumers, and to impact on health care costs through enhancing compliance and improving health outcomes.

Participants

Consumers on low incomes, with low literacy levels and/or from ethnic minority groups, and health service providers

Method

The methodology included establishing information panels of health professionals; focus groups with consumers and project staff; and reviews of literature, web sites and consumer materials. Calls to a multilingual health line were also monitored. Focus groups were held at a clinic, two manufacturing sites and in an adult literacy centre. Participants were reimbursed for attending.

Information was collected about how consumers perceive and process information from doctors; decision-making processes; relevant cultural, ethnic and linguistic issues; and the types of tools that would assist consumers interact with providers and make informed decisions. Consumer focus groups were held to develop and revise tools to assist them in interacting with their doctor.

Findings

Many barriers to good communication were identified. Consumers reported difficulty in talking with doctors and that doctors didn't care about them. Many had lost faith in doctors and were sceptical about medicine more generally. While consumers thought that doctors should have primary responsibility for

providing information, they often sought information from other health workers. Many consumers want to participate in decision-making but do not know what type of information they need to get from doctors or how to go about getting it, and consider that it is the doctor's responsibility to ask questions. Barriers to consumers asking questions include language barriers, lack of time and not knowing what to ask.

Doctors said that consumers did not communicate well with them, making it difficult to make diagnoses and recommend treatments. A number of tools were developed to assist people in asking questions of their doctors. These included booklets and flip charts entitled 'How to talk to your doctor', a poster, a video (produced in Spanish and English) and an interactive voice response system.