

Researching the personal impact of epilepsy

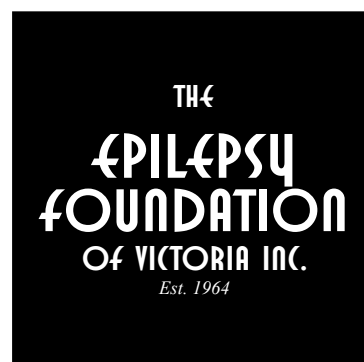
Christine Walker

April 2007



Chronic Illness Alliance

for



Funded by the William Buckland Foundation

Published by Epilepsy Australia
- the national coalition of state and territory epilepsy associations

Acknowledgments

This project was undertaken by Dr Christine Walker of the Chronic Illness Alliance for the Epilepsy Foundation of Victoria, with a grant from the William Buckland Foundation.

It could not have been completed without the assistance of the members, clients and staff of the Epilepsy Foundation of Victoria. We would like to thank the many people living with epilepsy who gave up time, and in some cases drove many kilometres, to join us in our workshops, and whose generosity in sharing their knowledge and insights was invaluable.

Advice and assistance were also received from:

Russell Pollard, CEO of Epilepsy Foundation of Victoria and EO of Epilepsy Australia
Jeremy Maxwell, EFV Development Manager

The Committee of Management of Epilepsy Foundation of Victoria and in particular the members of the EFV Research Working Group:

- Dr Lindsay Vowels (Chairperson)
- Felicity Smith
- Professor Mark Cook
- Pauline Brockett, EFV Librarian

Dr Kevin Brown, Research Officer Epilepsy Foundation of Victoria (2006-2007)

Assistance with recruitment was received from the Services Staff of the Epilepsy Foundation of Victoria:

- Lisa Rath
- Jan Burns
- Jean Ewing
- Emily Adamson
- Sue Stubbs
- Maree Kearton
- Ira Effrett
- Mark Green
- Brendan Moss

Any comments or enquiries about this publication should be directed to:

Dr Christine Walker
Chronic Illness Alliance Inc
818 Burke Rd
Camberwell Victoria 3124
cwalker@chronicillness.org.au
03 9805 9126

Contents

	Acknowledgments	2
	Executive Summary	4
	Recommendations	6
1	Purpose of this project	7
2	Background	8
3	Methodology	10
4	Summary of workshops	12
5	Analysis	15
6	Discussion	22
7	How the workshop participants would like to address the social exclusion of people with epilepsy	27
8	Gaps in applied research	29
9	Conclusion	30
10	References	31
11	Appendix	33

Executive Summary

1. The aims of this project were to:

(i) contribute information on the needs of people with epilepsy to an applied research agenda to ensure future applied social research undertaken by EFV meets the needs of people with epilepsy;

(ii) improve the services currently offered to clients by the Epilepsy Foundation of Victoria;

(iii) develop a better community understanding of the needs and capacities of people with epilepsy.

2. Five workshops were held, a group interview with four people was conducted, as well as telephone interviews with a number of individuals. There were 2 interviews with case workers and a meeting with Italian senior citizens. All workshops included people with epilepsy and the carers of people with epilepsy. Workshops took place across Victoria with men and women and young and older adults.

3. Workshops met with an enthusiastic response from the participants, who clearly appreciated being consulted.

4. The project recognised that some groups of people, namely prisoners with epilepsy; people from other culturally and linguistically diverse groups and indigenous people with epilepsy are rarely consulted, and endeavoured to do so, but it was not possible to achieve this in the time allotted to the project.

5. Workshop participants identified a range of areas important to them where they would like to see more research undertaken. In priority these are community awareness, mobility issues, employment and education, disclosure, quality of life issues, sport, costs and information.

6. A picture of living with epilepsy emerged from workshops where participants felt excluded from participating in the wider community. The concept of social exclusion provides a means to interpret and understand the impact of living with epilepsy. It also provides a conceptual framework to address some of these issues.

7. Workshop participants considered that awareness campaigns would assist the community understand what it was like to live with epilepsy and what people with epilepsy need to improve their situations. Research into attitudes of employers was also strongly supported. Workshop participants also identified that education, sports and mobility issues require greater research. The project identified that because people with epilepsy have a demonstrably poor quality of life, they are likely to live with a high levels of stress.

8. In order to develop effective awareness campaigns and to effectively design research projects around employment issues, it is important to undertake a survey of Australians' attitudes towards people with epilepsy.

9. The aim to inform a research agenda has been met. Improving community understanding is a long-term strategy to which this project's recommendations will contribute.

Recommendations

Researching the Personal Impact of Epilepsy fulfilled its principal aim of providing more information on the needs of people with epilepsy to ensure the applied research agenda of the EFV meets the needs of people with epilepsy.

On the basis of the results the project recommends:

- A survey of Australian community attitudes towards epilepsy be undertaken.
- Based on the results of this survey, a community awareness campaign on the needs of people with epilepsy be developed.
- Research be undertaken into attitudes towards epilepsy among Australian employers to improve employment opportunities and the work environment for people with epilepsy.
- Further applied research be undertaken in those other areas identified by the workshop participants where they experience exclusion, such as sport, education, employment. Applied research projects should address the social exclusion people experience.

The project was not able to reach all groups of people with epilepsy to consult with them. This project recommends that :

- Further projects be undertaken to consult with people with epilepsy from other culturally and linguistically diverse groups; prisoners and ex-prisoners with epilepsy and indigenous people with epilepsy. This will help to meet the needs of these communities as identified by JECA.

The services staff of the EFV contributed to this project because they saw its potential benefits to their clients. This project will consult with them to ensure any outcomes involve them and their clients.

1. Purpose of this Project

1.1 Aims

The Chronic Illness Alliance worked in partnership with The Epilepsy Foundation of Victoria to research the social and emotional issues that impact on the lives of people with epilepsy. The results of the research will be used to:

- (1) contribute information on the needs of people with epilepsy to an applied research agenda that ensures future applied social research undertaken by EFV meets the needs of people with epilepsy;
- (2) improve the services currently offered to clients by the Epilepsy Foundation of Victoria and
- (3) develop a better community understanding of the needs and capacities of people with epilepsy.

1.2 Objectives

The research was conducted throughout Victoria with specific objectives to:

- Identify the areas in which people with epilepsy feel stigmatised and their condition misunderstood
- The cost incurred as people with epilepsy seek to access services
- The issues some face because their condition sometimes means incapacity to work
- Identify the services people with epilepsy require and distinguish the current unmet needs.

2. Background

2.1 Epilepsy in Australia

Epilepsy affects people of all ages, nationalities and social backgrounds.

The World Health Organisation (WHO) has made epilepsy one of its top priorities. It is seen as arguably the most stigmatised, misunderstood and under-resourced of all health conditions (WHO).

In conjunction with the International Bureau for Epilepsy and the International League Against Epilepsy, WHO has initiated a global campaign to bring the condition 'out of the shadows' and to try to deal with the devastating social and economic consequences of epilepsy, particularly in the developing world.

As many as 600,000 Australians may presently, or will at some time in the future suffer from epilepsy. Given access to medication, information and practical support, most people with epilepsy can maintain a healthy and balanced lifestyle (JECA, 2006:9).

Between 30% and 40% of people with epilepsy will not gain full control of their seizures and these people, and those who care for them, need a range of support measures to help them manage their uncertainties and the health and lifestyle compromises that unpredictable and recurring seizures will bring (JECA, 2006:9).

Evidence suggests that people with epilepsy in Australia, despite good health and education systems, experience stigma and discrimination (JECA 2006:2). For this reason the Epilepsy Foundation of Victoria has adopted an applied research strategic plan. This project is part of that plan. The overall aim of any applied research undertaken in this strategic plan is to improve the lives of people with epilepsy, their carers and their families.

2.2 Applied social research and epilepsy in Australia

Research falls broadly into two categories. 'Pure' research is undertaken for its own sake, that is, to increase a knowledge base and perhaps to develop or explain a theory. Applied research takes place in real situations and has the intention of solving problems or improving situations for groups of people. Sometimes, applied research takes the 'discoveries' of 'pure' research and applies them to various relationships between people, or things, where changes are perceived as useful. Applied research should adopt the same rigour in methods as 'pure' research. Broadly methods can be either quantitative or qualitative in applied research.

From this perspective, applied research in epilepsy is generally undertaken by medical practitioners and psychologists. Applied research in medical areas has resulted in improved medications and surgery for people with epilepsy, while psychologists have explored cognitive programs to assist people with epilepsy develop their skills or overcome depression (Farwell et al 1985; Gilliam et al 2004).

There has been little applied research undertaken into the social aspects of living with epilepsy in Australia such as the impact of epilepsy on a person's ability to participate in their community (EFV 2005). The reasons for this are not clear. Public health researchers who could be expected to have an interest in the social impact of illnesses tend to concentrate their research endeavours where most government funding is concentrated, such as the National Health Priorities, so that the lack of government funding to encourage projects in epilepsy is another problem. At best however, these are partial explanations, since social research in epilepsy is undertaken in other countries even though conditions may not encourage it.

3. Methodology

3.1 Data Collection

As an exploratory survey of the broad issues impacting on the life of people with epilepsy and their families, the most suitable method of data collection for the target group was through workshop discussions or interviews. Interviews were offered people when they were not comfortable sharing their experiences with others.

A workshop session was developed where applied social research was explained, followed by examples of applied social research and then by small group discussions around several questions concerning the relevance of those research examples to workshop participants' lives. Issues were chosen on the basis that there had been some research done on them either in Australia or overseas, in order to channel their discussions. Participants in workshops were also encouraged to go beyond these areas and talk about additional issues that concerned them. Participants were not familiar with research to comment on the quality of some of the research projects they read about.

3.2 Workshop content

Based on applied research undertaken in Australia and elsewhere and the advice of the Epilepsy Foundation of Victoria, research themes most likely to concern people participating in workshops were selected. The themes were:

- Driving and mobility issues;
- Quality of life/community awareness;
- Costs.

Workshop participants were encouraged to go beyond these themes if they chose and to introduce their own concerns. The abstracts of the applied research articles appear in the Appendix.

3.3 Recruitment of workshop participants and interviewees.

At the outset it was planned to have 11 workshop sessions with one in Melbourne and 10 in regional Victoria. Each workshop was to have between eight and twenty-five participants. This was abandoned for two reasons. One was that it was likely that ten regional workshops would prove to be repetitive, and would not necessarily result in substantially new information from each group. The other reason was that it was more valuable to think in terms of recruiting from hard to reach populations whose views are not always included in such projects.

Recruiting people for workshops was generally undertaken with the assistance of EFV staff as well as contacting organisations likely to assist in informing their clientele. This method of recruitment was successful as well as maintaining the privacy of people with epilepsy.

3.4 Workshops and interviews

Workshops were planned to target particular populations such as metropolitan, regional, indigenous, people from other culturally and linguistically diverse groups, young adults, families caring for people with epilepsy, people from economically disadvantaged circumstances and prisoners and ex-prisoners. Since many of these groups had no current relationship with EFV recruitment required far more energy and enterprise, than first envisaged. In some instances (prisoners) direct contact was too difficult so other means were used such as speaking with case workers. Rather than asking people about their economic circumstances, a workshop was held in the Western suburbs as a disadvantaged area. Several workshops were held in regional areas on the basis that one single regional area could not be seen as representing all other Victorian regions. Where people did not want to be part of a larger group, individual interviews were also conducted.

Five workshops were held, a group interview with four people was conducted, as well as telephone interviews with a number of individuals. There were 2 interviews with case workers. A presentation was given to the senior citizens groups of the Italian welfare group, CO.AS.IT. Workshop participants were also encouraged to email any further reflections they had on applied research after the workshops. Several people took advantage of this. Most workshops were very interactive with participants enthusiastically engaging in discussion. Recording these sessions would have resulted in poor quality material, so people were encouraged to work in small groups, make notes and to present them back to the larger group. Notes were also made by workshop facilitators so that most responses were very adequately recorded.

Notes were taken from interviews and later transcribed.

Overall, approximately one hundred people attended workshops or were interviewed. While numbers are not important in qualitative work such as this, some of the issues relate to the gender of the participants while others were responses from carers. For this reason alone it is worth noting that approximately one third of the participants were male and ten per cent of the participants were carers.

Ages ranged from 15 years to over 65, with the vast majority falling into an adult age group where tertiary education, employment and planning for later stages of life were important considerations.

3.5 Data analysis

The notes from the workshops and interviews provide the data. The themes were generated from the presentation itself and fell into the broad categories such as quality of life; costs of care; and community attitudes towards epilepsy. Participants however assessed the priority of these issues and provided the substance within the broader issues. This substance constitutes the analytic content of this report.

4. Summary of workshops

4.1 Northern Victorian workshop

Twenty five people attended this workshop in June 2006. They worked in small groups. Group one considered quality of life issues were most important, while group two were divided on whether driving or issues related to discrimination were the most important. Group Three argued quality of life issues were most important. Group Four considered quality of life issues were important, pointing out that sport was an important aspect of country life from which people with epilepsy were often excluded.

Overall findings:

- All agreed sport was important. Some people had stopped engaging in sports because of other people's reactions to their epilepsy, one person had given up tennis because light affected his epilepsy, a couple of others continued despite their epilepsy and seemed to have acceptance from other team members;
- Very few knew about Mobility Allowance;
- Some people were not sure of Centrelink entitlements;
- Community awareness and addressing issues of discrimination were considered important by all;
- Driving issues were considered important by a small but vocal group.

4.2 Central Victorian Workshop

Sixteen people attended this workshop in July 2006.

Privacy emerged as an issue amongst this group, as there was concern that the information participants provided should not be used for purposes other than the research project. A men's group in this workshop argued that driving was the means to having good quality of life. Good quality of life related to employment opportunities which were limited by an inability to drive. Costs of treatment and care were also seen as an important issue, as was the limited income people with epilepsy had because they could not work. A group of women, some of whom were parents of young people with epilepsy considered community awareness was the most important issue especially with regard to schools. Disclosure by the person with epilepsy was discussed as a moral imperative. Both these small groups recognised that access to education played a role in being employed. A group including both men and women considered transport was an issue since it affected their independence but also thought access to support services was important.

4.3 Barwon region workshop

Nine people attended the workshop. There were two young men, three young women and four family members. The workshop divided into two groups, one of carers and the other of young people. Two of the younger people required encouragement to join the conversation.

Members of this group had developed epilepsy early in their lives. All were living with parents though one young woman had had a period of independence and one of the young men was moving

towards this. Neither this group nor the carers group was especially interested in the research side of issues. They discussed issues in terms of the effects on their lives.

The young people gave equal weight to issues of quality of life and costs of their care. Costs were a concern since some were seeking to be independent of their families. Quality of life related to school, university, sports participation and employment. Living a life independent of parents was highly valued by some, while for others it was clearly not an expectation.

Conflicting views about disclosing also emerged in this group of young people where some considered disclosure would result in not getting a job and others thought it a moral imperative to disclose they had epilepsy.

The distinguishing feature of the parents' group was their level of concern for their children. While they admitted to anxiety they were equally aware that it would be nice if their children could attain a level of independence for their own sake.

However they were most concerned with pragmatic issues relating to care. Issues about welfare and its inflexibility were paramount, while negative experiences of schools were also high on the agenda.

4.4 Statewide recreational activity

Twelve people from across Victoria attended the workshop run as part of this recreational activity in September 2006. Some participants were vehement that mobility issues were of paramount importance while others put lack of access to transport in relation to loss of job opportunities, including voluntary work and independence.

This group also discussed treatment issues such as continuity of care, complementary therapies and information about new drugs. Finally the need for greater public awareness was also seen as an issue that required more attention.

4.5 Eastern Metropolitan Melbourne

Eleven people attended the workshop held in April 2006. One was male; one was a carer of another attendee.

Most were young women who were married and had small children.

The discussion fell into the three broad areas of quality of life, costs of treatment, lack of public understanding.

Participants considered that discrimination in workplaces and lack of employment opportunities constituted a quality of life issue, because lack of work led to lack of income as well as a poor quality social life. An important suggestion from this group was that it would be interesting to know why some employers and workplaces could be understanding and accepting while others were intolerant.

Costs of epilepsy care were also an important consideration and included both prescription medications, over the counter drugs and complementary therapies. The cost of transport, and equipment needed to be included.

This group had less concern about transport as many had alternatives to driving themselves. However they recognised the problems that not having the means to travel to a work could lead to a loss of a job.

Lack of public understanding and the need for greater community awareness was discussed at length. The group agreed that lack of understanding was endemic to the whole community. A campaign aimed at the whole community would produce benefits in the workplace and schools.

4.6 Western Metropolitan Melbourne

Interviews were conducted with two people with epilepsy and three carers.

The people with epilepsy were concerned with coping with their current situations than about the research that could be undertaken. However they agreed that issues relating to discrimination in job applications and at schools and the issues of young people with epilepsy/ABI being in nursing homes were areas EFV should consider. Also important were issues relating to health professionals' understanding of the needs of people with epilepsy, with particular regard to people retaining their independence and dignity.

Carers were concerned with the level of information they received to assist them manage better and to optimise the health of the person they cared for. One carer pointed out that they received no training to be the carer of a person with epilepsy and that it was very difficult to get information about support services in the Western suburbs.

Also important to all who were interviewed in this session was the need for greater community awareness, especially with regard to 'normalising' epilepsy, that is, explaining that epilepsy is something that happens to 'normal' people.

4.7 Indigenous groups

Persistent attempts were made to contact agencies representing indigenous people. One contact was through the Victorian Department of Justice and this led to a meeting with Aboriginal Welfare Officers for Victorian Prisons. Discussion took place about the needs of indigenous prisoners with epilepsy but there was little awareness of the condition in the prisons. This is partly because the prison health system ensures medication adherence.

4.8 Culturally and Linguistically Diverse (CALD) communities

Attempts were also made to speak with people from ethnic communities. An information session was held at the Italian welfare agency CO.AS.IT. The largely elderly group was interested in the subject with a number of them reporting they had grandchildren who had epilepsy. Others requested more information on epilepsy. The attendees were invited to participate in a confidential interview with an interpreter. No-one responded.

There were no responses from other ethnic community welfare agencies, despite making contact with some of the community workers.

While ethnic community radio is probably the more successful approach, this will be pursued outside the limits of this project.

4.9 Prisoners with epilepsy

Work has been undertaken to address the needs of prisoners with epilepsy in the United Kingdom. Little is known about the problems faced by Australian people with epilepsy when incarcerated. Discussions with the Dept of Justice and with case workers at the Brosnan Centre in Brunswick suggest that the situation is not well known to those who work in prisons.

5. Analysis

The following themes emerged from the interviews, group discussions and worksheets. Themes are clearly overlapping, such as transport and employment, however participants placed differing significance on the relationships between themes. These are ordered according to the significance placed on them by the participants across all the workshops.

5.1 Community Awareness

All but one of the groups presented information on the need for community awareness campaigns. In those groups all participants were agreed on the importance of this issue.

Community awareness was required to address ignorance relating to what the term ‘epilepsy’ actually encompassed and the stereotypes of epilepsy as a tonic-clonic seizure. “Epilepsy is not a blanket diagnosis” or “not all seizures are alike” surfaced in workshops as examples of community ignorance of the diversity and complexity of epilepsy.

In discussing community awareness, terms such as stigma, discrimination and stereotypes emerged, while at other times these terms were implicit.

Community ignorance was shown in lower expectations of people with epilepsy; expectations that medications were all that was required to control seizures. There were views that communities were not aware of the abilities of people with epilepsy, with stereotypes relating to intellectual deterioration persisting.

Participants suggested that in order for community awareness campaigns to be effective they needed to be seen on television either as part of a drama or advertising campaign, be featured on radio with interviews by experts or consumers, and feature celebrities.

Generally participants implied that awareness campaigns would portray people with epilepsy as ‘normal’ members of the community, or would inform the community of their special needs, and dispel myths about epilepsy.

The benefits of awareness campaigns for people with epilepsy were portrayed as improving the standing of people with epilepsy in the community; reducing discrimination in the workplace and schools and the community; improving the understanding of many health professionals about the experience of living with epilepsy and reducing feelings of isolation. Another benefit of such campaigns would be greater safety for people with epilepsy in public. Community members would recognise a seizure, be comfortable about it and know what to do. One person described the impact of ignorance in his small rural community as “people avoiding him like the plague”.

5.2 Mobility issues.

Mobility was discussed by all groups as an issue that played an important part in people’s lives. Mobility largely related to not being able to drive a motor car because a person could not hold a

driver's licence; not being able to access public transport and being dependent on other people for lifts.

Lack of mobility options meant that many people were not able to work or attend education, either because many positions demanded they hold a driver's licence or because local transport was not available. People living in the Victorian regions felt they were particularly disadvantaged when they could not drive legally, since there was no public transport. Only one person from regional Victoria saw epilepsy and mobility in a positive light. Living in a small country town, everyone knew him and offered him lifts so he was rarely inconvenienced.

Some participants were aware of the Mobility Allowance and 'half price' taxis, whereas others, particularly those from regional Victoria, had never heard of these facilities.

5.2.1 Drivers' licences

There were discussions about the restrictions around people with epilepsy not being able to drive following a seizure. Some people pointed out that this 'blanket ruling' ignored the differences in epilepsy, with one person saying she had only ever had seizures in her sleep, so she thought the restriction should not apply in her case. Others considered the type of epilepsy they had should be taken into consideration. It was evidence of poor community understanding of epilepsy.

There were differing views of the legal requirements: some people thought they could drive if they had been seizure-free for six months while others thought it required a two year duration.

There were clear gender differences in relation to driving. Men were often angry at losing a licence and spoke in terms of 'injustice'. They saw it as the main reason for being unemployed. Other men were just angry that they were not permitted to drive. Men from regional Victoria emphasised that driving was an essential part of country life. Some men hinted they were forced to drive without a licence on occasion. Women on the other hand were less likely to be concerned about driving itself, but concerned about the effects of not being able to drive. One woman found it difficult to work as a nurse since she could not work shift hours as there was no public transport. Participants in the metropolitan focus group were the least concerned with their limitation on driving. This reflected the availability of public transport and that some of them relied on their male partners to give them lifts. No man mentioned relying on a female partner for lifts.

Older women who relied on lifts from friends and relatives spoke of the frustration of having to fit in with others' time frames, such as hanging around when they were already tired and wanted to go home. Younger adults who relied on family to provide transport described themselves as being 'dependent' and 'feeling like a kid'. This was particularly mortifying when going out socially.

5.3 Employment and education

Employment and education presented great challenges for many of the participants. While there were some people who were possibly on 'supported wage' positions and others who had little expectation of working, many saw employment and education as the essential components of social belonging.

Issues arising around employment and education were: that some workplaces and educational facilities were prejudiced against epilepsy to the point of not wanting to associate with it; disclosure was constantly debated.

Participants had varied experiences relating to job applications. Many people felt that excuses were manufactured to avoid employing a person with epilepsy. One example was the strategy of eliminating people's applications on the basis of not having a driver's licence even when it was not an essential aspect of the job. This was a common occurrence. Another means of elimination of an applicant was citing OHS requirements when the person was extremely unlikely to have a seizure at work. Still another person had been told they were not physically fit to undertake the job when no physical fitness test was undertaken. Interviews might be terminated without explanation when the person revealed their diagnosis. Some participants considered that the perception by employers that epilepsy was high risk was never put to the test. When interviewers asked no questions about the person's epilepsy such as the type, the seizure frequency and the effect of seizures on a person's working life, it was a sure sign that the person was not going to be employed.

Those who had worked previously and lost a position (possibly not due to epilepsy) were angry at finding the difficulty of obtaining a new position. Those who had contacted employment agencies for assistance felt they were of no benefit because of their attitudes towards epilepsy. One man who had held a responsible position for many years used an employment agency to assist him find a new position. He felt they had demonstrated prejudice against him by excluding him from interviews on the basis that he did not have a driver's licence. One woman had tested her feeling that she was discriminated against in job applications by no longer disclosing her epilepsy in applications. She found that she went from never getting an interview to nearly always being interviewed.

Some people had been in employment for lengthy periods without incident and generally had not disclosed their epilepsy to work colleagues. Others had differing experiences. One woman had a seizure at work after several years in the same office and the response of one of her colleagues was "I have to work with you, but don't speak to me again". However, another woman had received the response from a colleague, "so what, it's only epilepsy". A woman who had a seizure in the dress shop where she worked was the only one to lose her position in a restructure later that year. Participants in this group compared their experiences and considered that management's attitudes made all the difference to how people were treated.

Education was discussed by most participants in association with employment. The point was made by participants that it was difficult to complete education and lower education meant that people with epilepsy were even more greatly disadvantaged in seeking employment.

There appeared to be gender issues relating to education. Nearly all the mature men (30 years +) said in passing that their education had been interrupted by epilepsy and this contributed heavily to being in casual and/or low paid jobs and having long periods of unemployment. Some mature women were still able to retain good jobs even though they had not completed secondary school education, with one woman having worked in the Information Technology Section of a bank for 25 years.

Young people themselves reported variable school experiences. Some teachers were overprotective; others were uncaring, some had lower expectations of students with epilepsy. One young man said that special consideration at school had allowed him to take a more relaxed attitude to study than perhaps he should have. He had decided to repeat VCE without special consideration to test his abilities. One young woman had been subjected to teasing and bullying as a teenager. Years later on, her mother was still angry at the school and at the other young people.

There were strongly held views by both parents and young people themselves that there was a need for better understanding of epilepsy in schools. Education and information sessions were required in schools regularly. These would improve attitudes of staff and students towards the student with epilepsy. Several participants emphasised that there was no understanding in schools of problems of concentrating and different ways of learning. A majority of young people and their parents considered there was a strong need for better knowledge of first aid in seizures at schools.

Tertiary education was also problematical for young people. In regional Victoria lack of public transport made it very difficult for some people to undertake tertiary study. One young woman from a small town wanted to pursue tertiary studies as otherwise there was nothing to fill her days. "Everyone" she said, "knows I have epilepsy so no-one in town will employ me. If I don't study, there is nothing for me to do all day." Her problem however was that there was no public transport to get to the regional centre.

Several young women were pursuing tertiary studies and said that there was little understanding or acceptance among academics of problems of concentrating or the different ways of learning. One woman thought that obtaining an undergraduate degree might take her several more years than was allowed, but lecturers were not prepared to discuss this with her. A man was interested in pursuing study in electronics but could not find a course that would accept him because of his epilepsy.

Seizures at a university could be frightening because the person was at the mercy of strangers with differing understandings and abilities in first aid.

Several people reported that due to their health or transport problems they had discontinued tertiary studies.

5.4 Disclosure

Debates over disclosure followed discussions of education and employment in all the workshops. There was a range of views and strategies about disclosing epilepsy to employers, teachers, colleagues and peers. Most participants were aware that they did not need to disclose their health status unless there were safety considerations, but everyone took strong positions on the subject, demonstrating they had given it a lot of thought. People's opinions on disclosure fell into two broad areas: the pragmatic or the ethical.

Many people thought that since disclosure was not mandatory it should only be undertaken if absolutely necessary. There were views that disclosure in job applications resulted in people never getting to interviews while openness with employment agencies also resulted in the same thing. One person had tested her hypothesis about employer prejudice. She had written job applications where she had disclosed her health status and job applications where she left this out. She never got interviews when her epilepsy was in the application but had achieved interviews following applications where her epilepsy was not mentioned. Several women had had successful careers over some decades and were strongly of the view that this would not have happened if they had disclosed their health status.

Equally strongly held were opposing views on the need to disclose one's health status on ethical grounds. Some people argued that despite the probability of not getting employment it was 'only right' to tell a prospective employer and workmates of one's condition. This would not leave them unprepared in the event of a seizure. Others argued in addition that it assisted in developing greater understanding of epilepsy which would benefit others with epilepsy in the future. One example of this ethical position was a regional town where two young women were employed at a local supermarket. One has diabetes and the other epilepsy. The manager and the workmates were all informed and responded by wanting to know the first aid requirements for each person.

A smaller number of people may be described as the ‘compromise’ group. They argued that disclosure should only take place once a position had been secured, and then perhaps only to selected colleagues.

5.5 Quality of life issues

The foregoing topics all relate to quality of life issues, but some participants used this term to refer to generally how enjoyable their life was. The point was made more than once that lower education led to fewer job options and lower income. The consequence was that people with epilepsy missed out on many of the good things that other people took for granted, such as owning a home, having friends and personal relationships and leisure activities. Not being able to afford a holiday was mentioned by participants as a big impact on their quality of life. Some participants felt that they were not only unable to enjoy their lives but they were very socially isolated as a result of not being able to participate in the usual life activities related to work and the broader community. One person had felt so socially isolated he had contemplated suicide.

Participants identified different paths to their poor quality of life and social isolation. For some it was the lack of income, while for others it was the inability to drive so they were excluded from social and leisure activities. For others it was side-effects of medication such as fatigue that meant they could not go out as often. Some younger adults considered it was created by their dependency on their parents. Participants in the regional workshops identified there were multiple points at which epilepsy impacted on the enjoyment they were able to derive from life: mobility, social isolation, low incomes led to far less enjoyment.

Epilepsy could also impact on the quality of life for the families of people with epilepsy. Some family members might find friendships were lost or they were not able to enjoy social and leisure activities because of lower family incomes. Carers of people with refractory epilepsy or co-morbidities had many activities curtailed because of their caring duties.

5.6 Sport

For participants in regional workshops, not being able to participate in sporting activities particularly impacted on quality of life. “Sport”, one person said, “is an important part of social life in the country.” Some people had given up team sports because they were not able to meet the expectations of other team members. They related stories where they were not wanted on teams because a seizure might mean losing a game. Others had continued in teams despite having had seizures on the sports field. Two people reported persevering in a team sport despite the attitudes of other team members and having been accepted finally as valued team members. Some young people had given up sports due to poor health, while others were only able to participate when they were accompanied by a carer.

5.7 Costs

Costs received less attention than the preceding matters. There were however individual participants in each group who regarded costs as being onerous. Medications were most often cited as the greatest contributor to high costs. While one participant said his medications amounted to \$100.00 per month out of his pension, another pointed out that co-payments for medications and other allied health services such as massage were additional burdens. People with epilepsy were not told of generic medicines that would save them money. Health insurance, costs of transport to see specialist were all listed as additional burdens.

Some people spoke of the ‘hidden or social’ costs of epilepsy which included not being able to earn decent wages. In some cases this led to a life-time of paying rent and living in substandard housing. One person had lived in shared rental accommodation his whole adult life and had had *to*

shift numerous times. This meant paying for bonds and buying additional household items. One person relied on financial assistance from relatives so he could live with some dignity.

5.8 Information about treatments, complementary therapies, support services

There was some discussion about the lack of information people with epilepsy received from their medical practitioners. Better communication about new treatments and the side-effects of medications were seen as lacking. Some people considered that support groups were necessary to fill this gap.

The need for more information about complementary therapies, new treatments and support services such as Centrelink services and the Mobility Allowance received less attention. However, costs of medications and complementary therapies were mentioned in several of the workshops, suggesting that their affordability was certainly an issue. Some people said they would make greater use of complementary therapies such as massage and relaxation courses if they had the means to do so.

Some parents identified Centrelink as too inflexible where their adolescent children were concerned. Those parents had lost access to healthcare cards when their children were over 16, even though they still required medication and medical care. They considered this inflexibility arose from a poor understanding of epilepsy in Centrelink. There were also indications in some workshops that some people were not fully aware of their Centrelink entitlements.

Support services may have received less attention because some people already had access to these services while others did not mention them because they were ignorant of their existence. This proved to be the case in one of the workshops where a participant mentioned the Mobility Allowance and others had never heard of it.

5.9 Conclusions of analysis

Participants in the workshops placed greatest emphasis on the need for Epilepsy Foundation of Victoria to conduct a large-scale community awareness campaign which it was anticipated would improve attitudes towards epilepsy in the workplace, schools and tertiary institutions, as well as the broader community.

Beyond this, many of the themes were related to gender and age in terms of the emphasis that was put on them. Some of the women participating in the workshops had had positive experiences in employment, while none of the men had. This led some people to suggest that it could be helpful to research why some employers adopted positive approaches to people with epilepsy while others were so negative.

Where motor car driving was concerned men were more likely to think that bans on driving were not only inconvenient but 'unjust' and a principal cause of all their problems. In some cases, men appeared to view their inability to drive as an assault on their manhood. While trying to cope without a licence was clearly a barrier to many forms of employment, this was especially so for men in regional Victoria.

Women never spoke about their inability to drive in such strong terms or in the sense of their personhood. It was 'inconvenient' and it limited their mobility and the work they could do. This was partly due to the women participants having access to 'lifts' and to using public transport in the metropolitan area. Interestingly, only one man spoke of accepting 'lifts'.

While all the participants reflected on problems of employment, access to education and the attitudes of teachers were most emphasised by younger adults or by the parents of younger students. Similarly, access to sport was a younger person's issue and was more important for those in regional Victoria than the metropolitan areas.

Discussions around disclosure were normative and often based on a sense of responsibility towards other people. Many people with epilepsy saw it as their responsibility to disclose their condition to save employers and colleagues embarrassment, rather than portraying the problem as one where organisations had a responsibility towards them. However there were solid opinions expressed by some that disclosure should only be undertaken if absolutely necessary, otherwise there was no need.

6.0 Discussion

6.1 Social exclusion of people with epilepsy

These workshop themes are consistent with previous research undertaken (Collyer 2006; JECA 2006) Like previous research they create a picture of living with epilepsy, where people with epilepsy have lowered abilities to participate fully in their community because of the problems related to mobility, lack of access to sport, education and employment, low incomes and higher costs of healthcare. Participants considered this meant less enjoyable and fulfilling lives. Participants in the workshops argued that greater access to education, employment and better income would alleviate much of the distress they experienced.

Much of this discussion, particularly that relating to having a less enjoyable quality of life, was contingent on participants' perceptions of the quality of life of the broader non-epilepsy affected community. A useful way of exploring the divergent responses in the workshop is through the concept of social exclusion. The concept has merit in this context since in discussing the quality of their lives participants perceived that people who did not have epilepsy were 'socially included' while they were not.

Social exclusion is a term that has come into usage since the 1990s, principally in the United Kingdom and the European Union. Originally it referred to those who were excluded from social insurance programs in France because they were unemployed (Peace 2001: 21). The European Union adopted the term to cover anti-poverty initiatives including those initiatives to combat unemployment. Over the last two decades the term has been applied to larger and less well defined groups of people, such as 'the homeless', people with disabilities, 'the disadvantaged' and people who are 'socio-economically marginalised' (Peace 2001:22).

There are numerous definitions of social exclusion. Some definitions are narrow, largely referring to income poverty or unemployment. Saunders and Adelman (2005) treat social exclusion as an outcome of income poverty, since social exclusion results from material deprivation or not being able to purchase various items. Other definitions are broader and try to capture a view that social exclusion in one facet of a person's life has consequences for other facets. From this point of view, social exclusion is defined as a process. Peace (2001) provides examples of definitions that recognise this complexity:

Social exclusion is a set of processes, including within the labour market and the welfare system, by which individuals, households, communities or even whole social groups are pushed towards or kept to the margins of society. It encompasses not only material deprivation but also more broadly the denial of opportunities to participate fully in social and civil life. (Democratic Dialogue, 1995. Quoted in Peace 2001).

Excluded persons or groups are seen to be in a situation of disadvantage...beyond a narrow definition of poverty as lack of income or material possessions... they are socially isolated in some sense...they have or experience weak social

relatedness...may lack ties to the family, the community, voluntary associations, trade unions or even the nation...they may be disadvantaged in terms of their legal rights...This definition brings together the consumption-related and work-related aspects of disadvantage...it focuses on the dynamics of cumulative causation... (Rodgers et al, 1995. Quoted in Peace 2001)

A useful approach is an institutional perspective in which social exclusion is a property of the basic institutional framework and ongoing institutional arrangements within which individuals and groups (live)...Social exclusion is the property of society if racial, sexual or other forms of discrimination are present, if the markets through which people earn a livelihood are segmented, or if public goods...are semi-public. (Rodgers et al, 1995. Quoted in Peace 2001)

In this report social exclusion will be employed as a process, where exposure to exclusionary practices produces the experiences of exclusion in individuals or groups.

The process of social exclusion of individuals or groups suggests that there is also a process of social inclusion. People may be considered 'included' if they are able to participate in the following activities of a society:

- Consumption, including having an income to consume a range of goods and services.
- Savings, including savings, pensions, home ownership and investments.
- Production activities, which includes paid employment, volunteerism, education or caring for others.
- Political activities ranging from community and neighbourhood involvement to the more formal political engagement.
- Social activities which range from social interactions with family and friends, leisure activities and identifying with cultural, neighbourhood and spiritual groups. (Burchardt et al. cited in Peace 2001).

There are problems with the use of this concept, since it is often applied in a moral sense. People who are 'socially excluded' may be portrayed as being responsible for their own exclusion and expected to make changes. For example, unemployed people must make efforts to be employed. Additionally policies to address social exclusion are implemented in the broader policy context of privatisation and neo-liberalism, which has removed many of the welfare supports vulnerable groups of people relied on, and is aimed to move people towards participating as consumers. Finally, there is an assumption that there is an inclusive society that individuals and groups may join if they are able to overcome the barriers (Levitas, 2003). Most societies however, have layers of inequalities which exclude some people some or all of the time.

Within these limitations, the broadest definitions of social exclusion provide this report with useful means to elaborate and understand the complex experiences of people with epilepsy as they participate in our community.

It is in the latter broad and flexible sense that the concept of social exclusion can be useful for developing a different and more complex understanding of the factors and influences that lead to well-being and relative advantages on the one hand, and disparities, inequalities and relative disadvantage between members of a community on the other hand. (Peace 2001:26)

6.1.1 Social exclusion and internalised experience

Social exclusion may be understood as a process which relates to the means by which people who experience being excluded recognise themselves as excluded. This recognition relies on a view that other people are included. It may imply a level of internalisation where the person recognises themselves as being excluded from a range of social activities.

Internalising exclusion has a relation to Scambler and Hopkins (1986) concept of ‘felt stigma’ where people with epilepsy internalise feelings of shame about having epilepsy and fear knowledge of their epilepsy will subject them to acts of discrimination. Many of the following processes of exclusion may also be analysed as examples of ‘felt stigma’.

This project discusses people’s perception of being excluded and their responses to the perception they are being excluded. It has not collected data on the incidence and prevalence of social exclusion of people with epilepsy. The following section demonstrates that workshop participants were aware that their experiences of social exclusion related to those very activities that were most valued as the means or the process by which people experience social inclusion (Burchardt et al. cited in Peace 2001).

6.2 Workshops and social exclusion

One of the unintended outcomes of the workshops was the clear expression of pleasure from many of the workshop participants on being consulted about these matters. Most people had never been asked to provide their views as part of a formal consultation. This suggests that people with epilepsy may indeed feel excluded from their own healthcare as well as from wider community activities.

If we consider the above activities of consumption, savings, production, social and political engagement as the principal areas where people will experience social inclusion then we may see that these areas were recognised by the workshop participants as precisely those areas from which they experienced exclusion. Workshop participants reported they were not able to participate as fully as they wanted, in consumption, savings and production activities. Access was limited by lack of income, lack of employment opportunities and lower education. Participation in social and political activities was limited by health in some instances, by lack of income in other instances and by specific processes of exclusion in others.

6.2.1 Processes of exclusion

Participants reported being subjected to exclusionary processes. Where employment was concerned these processes related to not being interviewed for positions; not being employed once their health was known or losing a position when their epilepsy became manifest. Colleagues might adopt such exclusionary processes as avoiding the person with epilepsy, silence, not including them in work or recreational activities. Verbal abuse was also reported. While one person reported attempting to start a small business, he had been excluded from government assistance in this endeavour on the basis that he was on welfare payments.

While lack of education was a process in itself that led to exclusion from workforce participation or participation at a low level, processes of exclusion took place within education. Workshop participants reported that they could be stereotyped as ‘poor learners’ or requiring special assistance. Those who had special allowances made for them at school, indicated that this made their ‘difference’ manifest to themselves as well as others. Other exclusionary practices at schools related to peer responses to the person with epilepsy, who might be avoided, bullied or treated as oddities. In tertiary education, processes of exclusion were more likely to operate at the level of

enforcing formal guidelines, such as demanding that students with epilepsy conform to deadlines, attend all coursework and to offer no special consideration or concessions.

There were exclusionary practices related to sporting activities as well. Workshop participants who valued sports reported they might be subjected to a process of exclusion by being asked not to play team sports by either organisers or team members; by having special arrangements made for them such as needing a carer while swimming. Social exclusion is relative to the society in which it takes place. Given the emphasis placed on sports in Australia as well as the centrality it holds in rural social life, exclusion from sports carries great weight.

Lack of public transport to assist people with epilepsy participate in employment, education, social and community activities is a process of exclusion that operates for a broad range of people, including people with a range of illnesses, disabilities and the poor. People at the workshops reported that lack of public transport increased their dependency on family and friends to drive them. As with people from the broad range of disability and illness groups this increased their dependency and contributed to excluding them from independent adult life. Workshop participants recognised that limited transport facilities at least limited their participation in a full range of activities. This recognition meant people from workshops were more likely to identify with other disability groups rather than with groups who were participating fully in the community. For the workshop participants the process of exclusion from a range of activities was augmented by relying on public transport, since having a seizure on public transport meant that they were subjected to abuse as ‘drug addicts’ or open to predatory behaviour.

Many of the workshop participants had close family and family friends and were able to socialise in their family groups. However, some workshop participants expressed levels of isolation outside the family, as they had few opportunities to make friends. From this perspective it is possible to argue that being excluded from a range of activities, such as employment, sports, education contributes to feelings of exclusion and isolation in areas relating to leisure and community engagement, since there are fewer opportunities to develop the relationships in these areas. Some people had experienced more aggressive forms of exclusion, such as being asked to leave hotels. Others were not comfortable in attending large public venues. Other social activities such as outings and holidays received little mention, and it may be inferred that people were excluded from these on a similar basis.

There were few examples from the workshop participants of participation in community activities and none regarding political activities. However this may be because they were not asked directly about these interests. Some people expressed alienation from their community, after having a seizure in public. They thought people began to avoid (‘avoid me like the plague’) them or gossip about them from this point.

6.2.2 Visibility of epilepsy and the process of social exclusion

When epilepsy takes a visible form, people reported being more likely the subject of social exclusion processes. Those who had not disclosed their condition, either verbally or inadvertently by their behaviour, had been employed throughout their adult lives. This had meant they were more likely to enjoy a level of social inclusion across the whole range of activities.

Not holding a current drivers’ licence is a form of visibility. People who were not driving a car were asked the reason by curious people or felt they had to explain when applying for a job.

Other forms of visibility relate to having to use public transport, not being able to participate in a whole range of activities due to lack of income and relying on welfare payments. Not participating

in sports activities in rural areas makes the young person with epilepsy visible in the community. When curious members of the community ask why seemingly fit people behave in ways they see as not conforming to the 'normal' (not driving, not working, not playing sports) this means epilepsy becomes visible to them. It is at this point that a person already excluded from participating in some activities may find the process is extended into other activities. A person with epilepsy may begin to feel his/her life is without dignity or quality.

The issue of disclosure also relates to the visibility of epilepsy. Troster (1997) argues that disclosure or non-disclosure is a means to manage epilepsy in daily social contacts. Following Scambler and Hopkins (1986) work on stigma he argues that strategies consist of concealment of the condition, avoidance of highly stigmatising situations and selective disclosure. He investigates a further strategy of 'preventive telling' which is purposeful mention of the condition (1997:1229). In the workshops it was possible to see all these strategies employed. There were people whose epilepsy was well-controlled, with no need to disclose, there were people who were most often well but with some risk of a seizure in public who needed to disclose selectively and others who felt they had no choice but to disclose. Some people disclosed because they needed to explain why they did not drive or work. This could be dealt with either selectively or purposefully. In this sense, managing disclosure provided a means to manage the level of exclusion a person might experience.

7.0 How the workshop participants would like to address the social exclusion of people with epilepsy

Workshop participants did not phrase their concerns as social exclusion and did not argue that community awareness was the means to address it. Their discussion has been placed within this context as part of the report.

7.1 Community awareness campaigns

There was a strong consensus among the workshop participants that the most important activity the Epilepsy Foundation of Victoria could undertake was a community awareness campaign to remove some of the barriers to participating in education, sport and employment.

While most participants agreed that an awareness campaign would be valuable there was little discussion on what such campaigns could realistically achieve. The assumption behind this call for a campaign was that education of the public would produce the desired outcome of reducing discrimination against people with epilepsy. However, further work is required to explore how effective community awareness campaigns are; whether they are cost-effective and whether better results are achieved by targeting particular population groups. The Joint Epilepsy Council of Australia (2006) has already called for a campaign along these lines and this will receive enthusiastic support as well as offering people with epilepsy an opportunity to participate in an activity that is highly meaningful to them.

7.2 'Normal' or 'special'

Within this broad agreement amongst all the workshop participants, two rationales for conducting an awareness campaign were evident. For some people an aim was to educate the public that people with epilepsy were 'normal'. They had 'normal' abilities and aspirations. If the public were educated they would see beyond the epilepsy to the person who was just like everyone else. Others considered a campaign would educate the public on the special needs of people with epilepsy, by explaining the varied diagnoses that were included under the epilepsy umbrella; by educating the public on first aid measures; by providing educational and working environments compatible with epilepsy. In some responses it is possible to see that a person holds both points of view; in some instances s/he wants to be treated in the same manner as people who do not have epilepsy, while in other circumstances s/he wants to have the special needs of living with epilepsy adequately recognised. These two different motivations may be termed: normalising or non-discriminating and specialist or positive discrimination.

This poses a problem for awareness campaigns. Each view would require quite different campaigns and could result in unanticipated outcomes.

Whether people with epilepsy want to be seen as ‘normal’ or ‘special’ the impetus is to address discriminatory behaviour on the part of the broader community.

7.3 Epilepsy and employment

While there was broad agreement that community awareness campaigns would assist people with epilepsy with discrimination in employment opportunities and their workplace experiences, there were requests to explore workplaces specifically. The research question voiced was: ‘Why is it that some employers have positive attitudes towards people with epilepsy, while other employers don’t?’ This research question has many positive advantages and would result in providing valuable and implementable results.

7.4 Education and sports

Workshop participants did not articulate that research should be undertaken in these areas. However they were important for the younger participants, and it would be possible to conduct similar research in these areas, asking why some educational and sporting bodies adopt positive attitudes towards people with epilepsy and how these can be transferred to others.

7.5 Epilepsy and driving

Driving was an important issue throughout the workshops. Some people felt that the blanket rules against driving with epilepsy were unrealistic, since some forms of epilepsy were not going to impinge on driving abilities. Observations made that some people with epilepsy posed a lesser risk as drivers than people who drank alcohol, had diabetes or engaged in other risky behaviours suggest that research questions could be formulated to explore these matters.

At the same time this project has identified that driving represents more than just the practical issue of mobility. It is an important signifier in people’s lives of their adulthood or independence. Not being able to drive visibly separates an adult from the rest of the community, acting as a means of social exclusion or encompassing the shame and fear of ‘felt stigma’.

Given that some people with epilepsy may still drive, whether for practical reasons or to avoid being excluded and despite restrictions placed on them, more research in this area could lead to greater understanding of risks on the part of people with epilepsy as well as informing authorities related to driving restrictions.

Additionally, workshop participants demonstrated differing understandings of the restrictions on driving and this suggests that further work needs to be undertaken in this area on their behalf.

7.6 Quality of life issues

Though workshop participants did not articulate that they wanted research into these areas undertaken, many were aware that they were more socially isolated and more disadvantaged than those around them. While the workshops did not explore the stress people with epilepsy experienced because of their quality of life, many implied a high level of stress. Research into social disadvantage, including income and costs of healthcare, quality of life, stress and social exclusion could provide directions on the means to improve their situations.

8.0 Gaps in applied research

This project recognised that applied research has neglected to explore and address the needs of people with epilepsy in the community. It recognised at the outset there were specific populations in Victoria and the rest of Australia more neglected by researchers than the broader community. These specific populations were: the indigenous community; people from culturally and linguistically diverse groups and prisoners.

8.1 A call for further research in these neglected areas

The Joint Epilepsy Council of Australia (JECA 2006) 'A National Strategy for Epilepsy in Australia' called for more services for indigenous people with epilepsy in Australia. This paper identified that the most likely problem was inequalities in health services utilisation. A recent article in the Medical Journal of Australia supports this finding. (Archer and Bunby 2006). At the same time there is little research to inform the incidence and prevalence of epilepsy in indigenous communities and little research to inform policy and services on culturally sensitive approaches to implementing programs.

Prisoners with epilepsy also represent an under-researched population. Anecdotal evidence suggests that while many prisoners receive appropriate care for their epilepsy while in prison, because their medication is supervised, they revert to more risky practices when released. Whether there is relationship between epilepsy and imprisonment has not been explored. A survey of some 330 prisoners' health undertaken in 2003 in Victorian prisons explored 'fits' but did not discuss if they were specifically related to epilepsy (Dept of Justice 2003). The same survey identified a high proportion of Aboriginal prisoners in the survey in this category.

There would appear to be no studies of the prevalence and incidence of epilepsy among people from other cultural and linguistically diverse groups in Australia generally. Given research conducted into culture and epilepsy elsewhere (Kleinman, Wang and Li 1995) and the acknowledged relationship between culture and health generally (Kleinman 1988; Ismail et al 2003), this would suggest that the substantial proportion of Australians from other culturally and linguistically diverse groups have their care neglected or are receiving inappropriate care. As with the care of indigenous people, people from other cultures require research to understand culturally sensitive approaches to their care.

8.2 A survey of Australian attitudes

In order to carry out effective community awareness campaigns, to design research projects around employment, education and sport, some knowledge of the beliefs and attitudes held by the broad Australian community about epilepsy and people who have epilepsy is required. This means that campaigns and research projects can be designed to target those beliefs held by the Australian community which most disadvantage people with epilepsy.

A survey of Australian attitudes should be undertaken as a first step in developing campaigns and research that will promote the well-being of people with epilepsy, their carers and families.

9.0 Conclusion

People with epilepsy, their carers and family value being consulted. Their hope is to improve their own quality of life as well as the quality of others living with epilepsy.

In providing their views these Victorians with epilepsy, their carers and families have produced a number of defined areas of research where results would contribute to improving the quality of their lives. Some of this research may be undertaken by the Epilepsy Foundation of Victoria, but there is no reason that other research organisations, including academic institutions and government bodies should not consider undertaking further research. A caveat of the Epilepsy Foundation of Victoria and the Chronic Illness Alliance is that it should provide a benefit to people with epilepsy, their carers and families.

The project set out to:

- (1) contribute information on the needs of people with epilepsy to an applied research agenda to ensure future applied social research undertaken by EFV meets the needs of people with epilepsy;
- (2) improve the services currently offered to clients by the Epilepsy Foundation of Victoria and
- (3) develop a better community understanding of the needs and capacities of people with epilepsy.

The aim to formulate an applied research agenda has been achieved. In the short term, the results of this project will inform future surveys of Victorians with epilepsy who have registered to be part of the Epilepsy Research Register. Research proposals can be developed to research areas of quality of life, costs of healthcare as well as the needs of those who are rarely consulted. Suggestions for research into employers' attitudes and driving may well be the foundation for future research developments with other institutions.

Whether this research will improve the services currently offered by EFV in the short term requires discussion with the services staff and may well require more specific work to meet their needs.

The development of an awareness campaign to improve community understanding requires thought, further consultation and funds. The results of this project may provide directions to develop awareness campaigns in the future. However, in order to target communities effectively, this report strongly recommends a survey of Australian attitudes towards epilepsy.

10. References

Archer J and Bunby R (2006) Epilepsy in indigenous and non-indigenous people in Far North Queensland, *Medical Journal of Australia*, 184 (12): 607-610

Beran R and Beran M (2000) A review of the application of laws to epilepsy and driving, *Journal of Law and Medicine*: 7; 281-285

Collyer L (2006) A content analysis of stigma in epilepsy, unpublished paper. Deakin University, Melbourne, Australia.

Epilepsy Foundation of Victoria (2005) Meeting the research challenge of the world's most misunderstood, stigmatised and under-resourced health condition: epilepsy. EFV. Camberwell Victoria.

Farwell J, Dodrill C, Batzel L (1985) Neuropsychological abilities of children with epilepsy, *Epilepsia* 26 (5); 395-400.

Fisher R, Vickrey B, Gibson P et al (2000) The impact of epilepsy from the patient's perspective 1. Descriptions and subjective perceptions. *Epilepsy Research* 2000: 41; 39-51

Gilliam F, Santos J, Vahle V, Carter J and Brown K (2004) Depression in epilepsy: ignoring clinical expression of neuronal network dysfunction? *Epilepsia* 45 (s2); 28-33.

Government of Victoria (2003) Victorian prisoner health study, Dept of Justice, Melbourne.

ILAE/IBE/WHO (2003) Global campaign against epilepsy: out of the shadows. International Bureau of Epilepsy, Netherlands.

Ismail H, Wright J, Rhodes P and Small N (2003) South Asians and epilepsy: understanding health experiences, needs and beliefs. *Epilepsy Action UK*.

Jacoby A, Snape G and Baker G (2005) Epilepsy and social identity: the stigma of a chronic neurological disorder, *Lancet Neurology* 4(17); 17-18.

Joint Epilepsy Council of Australia (2006) A national strategy for epilepsy in Australia., Epilepsy Foundation of Victoria, Melbourne

Kleinman A (1988) *The illness narratives: suffering, healing and the human condition*. Basic Books New York.

Kleinman A, Wang W, Li S et al (1995) The social course of epilepsy: chronic illness as social experience in interior China, *Social Science and Medicine*, 40 (10): 1319-1330.

Kotsopoulos I, Evers S, Ament A et al The costs of epilepsy in three different populations of patients with epilepsy, *Epilepsy Research*, 2003: 54; 131-140.

Levitas R (2003) The idea of social inclusion. Social Inclusion Research Conference 2003. <http://www.ccsd.ca/events/inclusion/papers/rlevitas.htm> (downloaded 1/3/07)

Peace R (2001) Social exclusion: a concept in need of definition? *Social Policy Journal of New Zealand*, 16: 17-36.

Rahman A (2005) Awareness and knowledge of epilepsy among students in a Malaysian university, *Seizure* 14: 593-596

Saunders P and Adelman L (2005) Income poverty, deprivation and exclusion: a comparative study of Australia and Britain. SPRC Discussion paper No 141.

Scambler G and Hopkins A (1986) 'Being epileptic': coming to terms with stigma, *Sociology of Health and Illness*, 8: 26-43.

Taylor J, Chadwick D, Johnson T (1996) Risk of accidents in drivers with epilepsy *Journal of Neurology, Neurosurgery and Psychiatry*, 60: 621-627

Troster H (1997) Disclose or conceal? Strategies of information management in persons with epilepsy, *Epilepsia*, 38 (11): 1227-1237.

Walker C and Tamlyn J (2004) Costs of chronic illness for rural and regional Victorians, Chronic Illness Alliance
www.chronicillness.org.au

11. Appendix

The descriptions of articles below were used to stimulate conversations at workshops on applied research undertaken both in Australia and overseas, to encourage workshop participants to explore issues they would most like researched for their benefit.

Driving. mobility issues

Risk of accidents in drivers with epilepsy

Joan Taylor, David Chadwick, Tony Johnson

Journal of Neurology, Neurosurgery and Psychiatry 1996; 60: 621-627.

(British research)

Aim of the research

To estimate the risks of road accidents over a period of three years in drivers with a history of single seizures or epilepsy, and to compare them with a cohort of drivers followed up by the Transport Research Laboratory (Britain) .

Research design

A retrospective survey of driving and accident experience by self-completion questionnaire.

16,958 drivers with a previous history of epilepsy responding to the survey and 8888 non-epileptic drivers responding to a TRL survey.

Outcome measures

The risk of any accident, any accident producing an injury and any accident producing serious injury, over a three year period.

Results

After adjusting for differences due to age, sex, driving experience, and mileage between the two populations there was no evidence of any overall increase in the risk of accidents in the population of drivers with a history of epilepsy. However there was evidence of an increased risk of more severe accidents in the population with epilepsy. The risk was increased by about 40% for serious injuries and there was evidence of a two-fold risk of increase in non-driver fatalities. These increases can be explained by the occurrence of seizures in the population during the period of the survey.

Conclusions

The acceptability of driving for people with a history of epilepsy should be determined by an acceptable risk of accidents resulting in injury or serious injury rather than overall accident rates. As people with epilepsy can now drive after a 12 month seizure free period rather than the required two year period when this survey was undertaken, it is important to ascertain whether there is any increased risk of injury associated with accidents with this policy.

A review of the application of laws to epilepsy and driving

Roy Beran and Maureen Beran

Journal of Law and Medicine 2000: 7; 281-285

(Australian research)

Driving by those with epilepsy raises issues of seizure control, duty of care, confidentiality and the reporting of patients to driving authorities. As part of a larger study, patients attending an adult outpatient epilepsy clinic in New South Wales completed a questionnaire including questions about driving. Those who drove had their medical records reviewed to confirm seizure status, therapy and accuracy of data provided. These data demonstrate the need to evaluate critically patients' epilepsy history before assuming those who have seizures and who drive are necessarily driving illegally. They support the need to have flexible road rules and demonstrate an accident rate comparable with those who do not have epilepsy. They further endorse the validity of discretionary reporting to driving authorities.

Quality of life/Community awareness

The impact of epilepsy from the patient's perspective 1. Descriptions and subjective perceptions.

Robert Fisher, Barbara Vickrey, Patricia Gibson et al
Epilepsy Research 2000: 41; 39-51
(US research)

This is a survey of the perceptions and subjective experiences of 1023 people with epilepsy in two community-based samples: one from a national postal survey and the other of callers to the Epilepsy Foundation. Respondents were less likely to be married or employed, had less education and came from lower income households than the norm in the US Census. Complex partial seizures were the most prevalent seizure type, but a convulsion had occurred in 61%. Fifty percent reported incomplete control of their seizure disorder. Respondents listed uncertainty and fear of having a seizure as the worst thing about having epilepsy. Lifestyle, school, driving, and employment limitations were major problems. Cognitive impairment was seen as a potential problem. Even in the sample where there was good control there were social and emotional problems recorded.

Epilepsy and social identity: the stigma of a chronic neurological disorder

Ann Jacoby, Dee Snape, Gus Baker.
Lancet Neurology, 2005: 4: 17-18.

Epilepsy is the most common neurological disorder, affecting about 50 million people worldwide. Because of the stigma, common to many cultures, there can be a negative effect on the social identity of people with epilepsy, particularly those living in poorer countries. This paper presents general theories of stigma as well as those specific to chronic illness. These theories are discussed in relation to epilepsy throughout history and across cultures. There is a discussion on how stigma in epilepsy can be reduced.

Awareness and knowledge of epilepsy among students in a Malaysian university

Ab Fatah Ab Rahman
Seizure 2005;14: 593-596.
(Malaysian research)

University students are better educated and it is important they possess a correct knowledge and attitude towards healthcare issues. This study used a survey which determined the current level of knowledge of epilepsy among 289 students at a Malaysian university. It was found that 86% of the students had heard or read about epilepsy, while 55% had observed a seizure. Only 30.7% said they knew the cause of epilepsy, while 5.3% thought it was caused by evil spirits. Two-thirds

of the students thought it was hereditary and 5% thought it was contagious. Two-thirds did not think it was shameful. This article concludes there is a good understanding of epilepsy among the students at the university.

Costs

Costs of chronic illness for rural and regional Victorians

Christine Walker, Jo-Anne Tamlyn

Chronic Illness Alliance

www.chronicillness.org.au

An extensive survey of all costs associated with caring for people with chronic illnesses was conducted in 2003 across Victoria. More than 450 households responded. It was found that the major costs associated with caring for a family member with a chronic illness was medication, including both PBS and over the counter medications. Having a chronic illness meant that many families had less disposable income and in many instances lived in chronic poverty. Those households where there were single people on low incomes had higher expenses as they had to purchase more assistance and in some instance such households lived well below the poverty threshold. The results of this survey have contributed towards a number of campaigns to make politicians and public servants more aware of the difficulties people with chronic illness face.

The costs of epilepsy in three different populations of patients with epilepsy

Irene Kotsopoulos, Silvia Evers, Andre Ament et al.

Epilepsy Research, 2003: 54; 131-140.

(Dutch research)

This study estimates the costs of care in three different populations of patients with epilepsy; general practice (GP), University Hospital (UH) and Epilepsy Center (EC), and to analyse the distribution of costs by type of services for each patient group. A cost diary was provided to patients to obtain prospective information on epilepsy attributable service use over a period of 3 months. Similar information over the previous 3 months was obtained from a cost questionnaire. Standard cost lists were applied for the valuation of direct cost items. One hundred and sixteen patients with established epilepsy were included and mean costs per patient per month ranged from 52.08 euros to 357.63 euros. Patient from GP appeared to have lower direct costs, spent less time in seeking or undergoing a treatment, and reported lower seizure frequencies and less severe seizure types than the patients from other groups. Patients from EC reported the highest productivity changes and unemployment rates and had lowest quality of life scores. Anti-epileptic drugs, hospital services, unpaid care, and transportation accounted for the majority of total direct costs.

