

Human Rights Commission

'A badge of exclusion ...

EPILEPSY AND HUMAN RIGHTS

Occasional Paper No. 7

October 1984

Australian Government Publishing Service
Canberra 1985

Commonwealth of Australia 1985

ISSN 0810-0314

ISBN 0 644 03846 2

- Occasional Paper No. 1 Incitement to Racial Hatred: Issues and Analysis, October 1982.
- Occasional Paper Nb. 2 Incitement to Racial Hatred: The International Experience, October 1982.
- Occasional Paper Nb. 3 Words that Wound: Proceedings of the Conference on Freedom of Expression and Racist Propaganda, February 1983.
- Occasional Paper Nb. 4 Compendium of Human Rights Courses in Australian Tertiary Institutions, August 1983.
- Occasional Paper Nb. 5 Aboriginal Reserves By-Laws and Human Rights, October 1983.
- Occasional Paper Nb. 6 The Teaching of Human Rights, August 1984

This is the seventh of the Human Rights Commission's Occasional Papers Series.

Occasional Papers are used by the Commission from time to time to deal in depth with a particular problem or subject.

A late stage draft of the report was prepared for the Commission by NC Rob Sheehan on behalf of ACROD to enable presentation to the "Epilepsy '84" National Symposium. At all stages, Ms Joan Jardine, a member of the Commission's Project Group and currently Acting Director, has contributed substantially to the project. This is the final version of the Report.

None of the views that may be expressed or implied in the Report are necessarily those of the Human Rights Commission or its members, and should not be identified with it or them.

PREFACE

The idea for this project arose from the Commission's direct interest in human rights problems faced by persons with disabilities. While the Commission presently has a number of research projects which deal with the rights of disabled people, these projects tend to focus on those with disabilities which are apparent to others. Epilepsy, on the other hand, is a condition which, in most cases, presents no external features; except at the time of a seizure. Yet epilepsy is often experienced as a severe social handicap because of the stigma which is attached to it. The old superstitions and misconceptions about it persist to such an extent that associated social problems - fear, prejudice and rejection - are sometimes more difficult for the individual to bear than the condition itself.

When a person has a "hidden" disability such as epilepsy, the very fact that it is hidden gives rise to misconceptions about its true nature. This leaves the way open for discrimination to take place when the disability is discovered. Discrimination occurs because it is the label "epileptic", or whatever other label it is, that people react to rather than the individual person. In other words, it is to a stereotype that people respond rather than to the qualities and capabilities of the particular individual. It means an uphill battle for individuals to whom the label has been attached, trying to get employment, acceptance in the community, or fair recognition of their rights.

In embarking on this project, the Commission was particularly anxious not only to help people with epilepsy, but also to see their problems as part of the problems experienced by all those who have "hidden" disabilities. It is hoped that by working through the specific human rights problems associated with epilepsy, the study will provide a model for studies dealing with other such disabilities.

Indeed, in recent weeks the Commission has approved a project that will focus on multiple sclerosis, a disability that, at least in its early stages, is 'hidden' but includes the further complication that it can be progressive in its incidence.

Peter Bailey
Deputy Chairman
Human Rights Commission

23 October 1984

Undertaking this Project has been a rewarding and enlightening experience, frustrations notwithstanding. Many of the rewards have come through the opportunity to work with many people from so many backgrounds. I thank them all for their time and interest. There are too many to identify individually, but I will tread dangerously and name several people without whom I, and this Report, surely would have foundered.

For their friendship, personal support, practical assistance in completing many of the tedious tasks, and their preparedness to give their time to discussion of many of the issues involved in the area of epilepsy and human rights, I am particularly grateful to the following people: Janit Gardner, Robert Gourley, Edith Gourley, Denys Correll, Cathy Sheehan, Mark Sheehan, John Breen and Hagan Nolan.

The Committee of Management and staff of the Epilepsy Foundation of Victoria have always been ready to help. The success of the epilepsy phone-in was due in large part to their commitment. Staff members of the Australian Council for Rehabilitation of Disabled have always been ready to assist and special thanks must go to Sally King.

The Project Advisory Committee have been outstanding in its managements of the project. The Committee consisted of:

Denys Correll, Chairman
John Foley, representing ACROD, Victorian Division
Robert Gourley, representing NEAA
Joan Jardine, . representing Human Rights Commission
Libby Kinross, representing Epilepsy Foundation of Victoria
Billy Pitman, representing Disabled Peoples' International (Aust)

Finally, I wish to thank all those who have epilepsy and their relatives who contacted me and who shared their views and so much of their lives so openly. It is my hope, and was my aim, that the Report adequately reflects the concerns they identified.

Rob Sheehan

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1. Throughout this Report "the Declaration" means the United Nations Declaration on the Rights of Disabled Persons. The Declaration appears as Appendix 1.
2. Throughout this Report "the NEAA" means the National Epilepsy Association of Australia. "Epilepsy Associations" means the State and Territory Epilepsy Associations. Associations exist in the Australian Capital Territory, New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia.
3. The words "contact" and "contacts", except where the sense determines otherwise, refer to persons who have epilepsy and their relatives who have directly contacted the Project Officer during the course of the Project, or who participated in the phone-in.
4. Section 2.6 contains an outline of a classification of seizure types. The words used in that classification to describe different seizure types have been preferred to older terms such as petit mal (absence in Section 2.6), grand mal (tonic-clonic), and psychomotor and temporal lobe (partial). "Seizure" has been preferred to "fit". "Intellectually disadvantaged person" has been preferred to "mentally retarded person". The word "epileptic" has been avoided and words like "the person who has epilepsy" have been used instead.
5. Percentages have been rounded to the nearest whole number, except where to do so would cause them to represent inadequately the position to which they refer.

CHAPTER ONE

INTRODUCTION

Taking everything together, epilepsy has made for a harder life than I might have had. The hardest thing has been, and still is, knowing that any time you might have to wear your epilepsy like a badge of exclusion or exile. It is a badge I usually keep well hidden.

(32 year old female - country Queensland)

I get angry when people respond out of ignorance. Why should it be necessary to grab hold of their prejudice and keep it down long enough for than to realise I am a person, not an alien with some mysterious affliction?... It is hard going living in the 20th century alongside attitudes that make you feel it's the middle of the 19th century.

(Male " Melbourne)

1.1 BACK.GROUND TO THE EPILEPSY AND HUMAN RIGHTS PROJECT

1.1.1 In April, 1983, the Human Rights Commission (HRC) contracted with the Australian Council for Rehabilitation of Disabled (ACROD) to carry out a Project on Epilepsy and Human Rights. ACROD appointed a Project Officer in May, 1983, and work began late in that month-

1.1.2 **A**, Project Advisory Committee (PAC) was appointed by ACROD and met on three occasions to monitor the progress of the Project. The **PAC** members were: Mt Denys Correll, Executive Director of ACROD, who acted as chairperson and was also the Project Administrator and Supervisor; Nk: John Foley, Executive Director of the Multiple Sclerosis Society of Victoria who represented the Victorian Division of ACROD; Mt Robert Gourley, President of the National Epilepsy Association of Australia (NEW); Me Joan Jardine who represented the HRC; Mrs Libby Kinross Who represented the Epilepsy Foundation **of** Victoria; and Mrs Billy Pitman who represented Disabled Persons International (Australia).

1.1.3 The Project's terms of reference were wide-ranging, as the chapter headings indicate. They were arrived at after consultation between the HRC, ACROD and the NFAA. The United Nations Declaration on the Rights of Disabled Persons provided the main framework within which the terms of reference were explored.

- 1.1.4 The HRC has responsibility for protecting and promoting the observance of human rights within the limits of Commonwealth power. In consequence the Report focuses on areas that relate to Commonwealth responsibilities. Other matters were introduced only where required for clarity or completeness.
- 1.1.5 There are many important issues which are not canvassed in the Report, or which receive passing reference. Constraints of time and resources precluded detailed investigation of matters such as the particular difficulties epilepsy poses for aged and overseas-born Australians and their families; the adequacy of service provision within public hospitals; the operation and efficacy of Employment Discrimination Committees; the appropriateness of eligibility criteria and the adequacy of a number of Commonwealth Government benefits, pensions and Allowances.
- 1.1.6 Despite these gaps, the Report represents the first such Australian study on epilepsy. One of the challenges it poses is the need to fill these gaps. The Report incorporates the views of persons who have epilepsy. Because of the inclusion of these views, the issues and problems discussed have been enlivened and many challenges and needs have been put more directly and forcefully than the formal language of report writing ordinarily allows.

1,2 METHODOLOGY

- 1.241⁻ So that the views of persons who have epilepsy and their families could form an integral part of the Report, five principal strategies were employed to elicit their responses. Once collected those views acted as a guiding influence, both in the selection of matters for investigation and in the determination of the emphasis and prominence given to them. Wherever possible their statements were written into the Report - usually without editing.
- 1.2.2 The first of the strategies employed was to conduct a phone-in in Melbourne on Saturday, September 10th, 1983. It was publicised mainly through suburban newspapers and metropolitan radio stations in the week prior to the phone-in. Volunteers (the majority of them final-year-student nurses at the Lincoln Institute of Health Sciences) were recruited - several weeks prior to the phone-in. They acted as telephone interviewers and all attended a training session conducted by staff members of the Epilepsy Foundation of Victoria (EFV) and the Project Officer.

- 1.2.3 The phone-in was conducted between 8.00 am and 8.00 pm at the EFV's Kintore Centre. Two volunteers, working four hour shifts, were stationed at each of the four telephones used. Each caller was invited to respond to a series of open-ended questions contained in a prepared questionnaire. At the end of each call the caller was offered further information about epilepsy in the form of pamphlets and, if necessary, the offer of follow-up contact with a counsellor.
- 1.2.4 There were just over 100 calls; the average call lasted 17 minutes. Of the calls, 97 yielded useful information. The offer of further information was accepted by 65-callers and 16 requested follow-up contact which was carried out by EFV social workers.
- 1.2.5 The advantages of a phone-in are anonymity for callers and the widespread availability of telephones. However, there are people, those living in institutions particularly, who do not have ready or private access to telephones. Only four callers indicated they were born overseas. This low level of contact with overseas-born Australians was not improved upon during the Project-. Despite these drawbacks, the phone-in was a successful strategy.
- 1.2.6 The second strategy employed was to 'approach' newspapers in country areas, requesting them to run an article on the Epilepsy and Human Rights Project. The article included an invitation to write to the Project Officer outlining any difficulties faced due to epilepsy and to make suggestions about ways in which problem areas could be tackled. In all, 8 newspapers in rural Queensland, South Australia and Victoria ran articles. Some published the request for views as a letter to the editor. The newspapers approached had circulations of between 2,500 and 60,000.
- 1.2.7 This proved a successful way in which to collect the views of country residents. It is not possible to say precisely how many letters were received in response to these articles; but the figure is probably between 90 and 110.
- 1.2.8 A third strategy was to run similar articles in the newsletters of all Epilepsy Associations, and the newsletters and journals of a variety of groups and organisations involved with disabled persons and self-help groups. As many as 90 letters were received from throughout Australia by these means.

- 1.2.9 A fourth strategy involved the Project Officer attending meetings of epilepsy self-help groups and other self-help groups to alert people to the Project and to invite their views. Six such meetings were attended and while most views were expressed during or immediately after meetings, many people took up the invitation to write or ring.
- 1.2.10 A fifth strategy involved writing directly to epilepsy self-help groups throughout Australia and to general self-help groups of disabled people (mainly in Victoria and New South Wales). As many as 50 letters and 30 to 40 telephone calls were received in response to these letters.
- 1.2.11 Table 1.1 below shows that about 463 persons who have epilepsy or their family members were contacted during the Project. This figure does not include contacts made through self-help group meetings. The remaining tables provide further information on contacts. The total numbers in each table vary because records are incomplete. In the case of Table 1.2, in almost all instances the contacting parent was a mother.
- 1.2.12 The five strategies outlined also generated contacts indirectly or in unforeseen ways. Letters and newspaper clippings were passed to others, for example. About 25 people, mostly from Melbourne, came directly to the address listed for the Project on letters and in articles,
- 1.2.13 Articles and letters also prompted letters and telephone calls from professionals working with people who have epilepsy, and from members of the community who were usually seeking information about epilepsy. Nearly all letters received had been answered individually at the time of writing. It is intended that replies will be sent to all contacts as soon as time permits.
- 1.2.14 The information used in Chapter 5, Professional Education, was gained through the distribution of a questionnaire which is attached as Appendix 3. Section 5.2 outlines the methodology employed and its results. Unfortunately insufficient time was available to make a thorough analysis of the information received and a general picture only is presented.
- 1.2.15 Formal literature research was undertaken for all terms of reference. The library of the EFV was an especially valuable resource for literature on the psycho-social aspects of epilepsy. Contact was also made with Epilepsy Associations, professionals and academics where appropriate.

TABLE 1.1 Number of all contacts by type of contact.

TYPE OF CONTACT	.NUMBER CONTACTED
Personal interview	41
Telephone	85
Phone-in	96
Letter	224
Not recorded	17
TOTAL	463

TABLE 1.2 Contacts by .number who had epilepsy, number who were parents and number who were relatives of persons who had epilepsy.

PERSONS CONTACTING	NUMBER OF CONTACTS
Person who had epilepsy	365 (81%)
Parent	68 (15%)
Other relative	17 (4%)
TOTAL	450

TABLE 1.3 Contacts who had epilepsy by sex.

SEX OF CONTACT	NUMBER OF CONTACTS
Male	136 (39%)
Female	213 (61%)
TOTAL	349

TABLE 1.4 All contacts by area of residence.

AREA	NUMBER OF CONTACTS
Capital cities	259 (56%)
Other areas	200 (44%)
TOTAL	459

- 1.2.16 Chapter 2, Description of Epilepsy, was drafted on the basis of available literature. Six medical practitioners were asked to comment on the draft (four neurologists, one paediatric neurologist and one general practitioner). Their comments and suggested amendments were incorporated wherever possible. There were a number of conflicting comments and amendments. Where these occurred reliance was placed on available literature relating to the points of conflict.
- 1.2.17 In Chapter 8, which deals with Employment, Section 8.2.3 makes mention of a small telephone survey of employers which was conducted in late October, 1983. The survey was designed to gain a broad indication of several matters - possible reservations or objections employers might have about employing workers who have epilepsy; whether or not they would use specialist services provided by the Epilepsy Associations and the Commonwealth Employment Service; and the level of knowledge held by employers about epilepsy. The survey was very small (only 49 employers participated) and the information gained only general. It would be inappropriate to place heavy emphasis upon the survey results. They did, however, confirm the perceptions of many persons who have epilepsy and professionals, involved with them about the information needs of employers.
- 1.2.18 As in the case of any limited survey it could be suggested that persons who have epilepsy and their family members contacted during the course of this Project constitute a biased sample. Such a suggestion could be based on two propositions. Firstly, that the people most likely to express their Views by letter or telephone would be people who have experienced particular difficulties. In other words, their experience is likely to be atypical. Secondly, the experience conveyed by contacts cannot be authenticated. That is, what people have written or said, for whatever reason, may be exaggerated, inaccurate or may not even have occurred.
- 1.2.19 There may be some measure of truth in such observations. However, the views expressed and the experiences conveyed do accord (though with variations in degree and frequency of occurrence) with findings on many points contained in the available literature. Secondly, they do not deviate to any marked degree from the perceptions formed by professionals and volunteers closely connected with Epilepsy Associations. Thirdly, contacts were made throughout Australia and there is a remarkable consistency in the views expressed and the experiences conveyed. Even if the contacts made do represent a biased sample, it must be accepted that there is a very substantial group of people, represented by these contacts, who do have real reasons for their concern and dissatisfaction. They cannot be ignored.

1.3 GENERAL ISSUES

- 1.3.1 This section deals with some of the major issues which run through the Report. What becomes clear is that prejudice and discrimination regularly intrude into the lives of persons who have epilepsy. Their outlook and lifestyles can be influenced significantly by the ignorance and lack of Understanding in those around them.

People by their ignorance have held me back. There is a lack of knowledge on other people's behalf.

(Female - Melbourne)

- 1.3.2 Contacts mentioned misinformation and lack of understanding more often than any other factors Which disrupted their lives. The need most often expressed was for information to be available to three broad groups: those Who have epilepsy and their families; professionals involved with then ; and the community at large, especially employers.

Another thing that would have made it much easier for me would have been if I had known a lot more about the complaint. I had never seen anyone take any type of fit and I knew very little about it. My doctor didn't explain much - just kept telling me she would probably soon grow' out of it, though she never did.

(Parent - country Queensland)

It is appalling that the ones who really need to have an idea of what epilepsy is - teachers, nurses, social welfare workers, etcetera - can't get information that helps them in their work.

(45 year old female - Hobart)

- 1.3.3 It is difficult to assess just how widespread are prejudice and misinformation. Two studies may provide some insights. Vinson (1973), carried out a survey of 602 Sydney adults during 1972. From responses to a series of questions he was able to present the following findings: 13% of respondents objected to their children playing with children who had epilepsy; 9% objected to their children associating at school with children who had epilepsy; 14% believed people who had epilepsy should not work in jobs in the community mainstream; one in three believed persons who had epilepsy should not go out unescorted; two in five advocated some sort of separate schooling; and over half said some limitations on sport should apply. The mesh of attitudes, prejudices, fears and misinformation which produced these responses in 1972 is still in existence, according to contacts, a dozen years later.

- 1.3.4 In another study, reported by Carr (1981), Wills and More conducted a survey of 301 Australian men holding lower or middle management positions in large commercial organisations. The men involved were asked to rank their acceptance of 30 community sub-groups. Overall, those who had epilepsy were ranked 24th out-of 30. Of those surveyed, 37% accepted those who have epilepsy, 61% had reservations about or a reluctance to socialise with them, and 2% rejected them. Clearly, the large middle group needs to be more widely informed about epilepsy.
- 1.3.5 Providing information to a variety of groups on a range of issues, in a manner which is relevant and accessible, is a clear priority; but it is only part of the task. Information is not the same as education. Professionals, -employers and community members, must learn to understand and use the information with which they are provided.
- 1.3.6 In the lives of persons who have epilepsy there is a chance factor which causes confusion and frustration. It is impossible for a person who has epilepsy to predict a stranger's response to his or her condition. Responses may range from rejection to ambivalence - which in effect is close to rejection - through to acceptance. As responses are unpredictable so are the effects on an individual's life. Uncertainty and insecurity can become familiar companions in all aspects of his or her community life, or be present to such an extent that he or she does not participate at all.

Who can you trust to be sensible about it? It isn't written in people's faces so you always wonder what they will do once they hear someone has epilepsy. That makes her very anxious. It makes us anxious too.

(Parent - Adelaide)

- 1.3.7 Most disabled people have to deal with unpredictable responses. For those who have epilepsy there are additional complications. Epilepsy is a hidden disability. It is not apparent that a person has epilepsy unless he or she is seen to have a seizure. The person who has epilepsy is constantly confronted with a choice, and for many it can be agonising or unnerving. The choice is whether to disclose her or his epilepsy to others or to withhold the information. It is a decision based upon acknowledging the possibility that some form of discrimination may follow disclosure. It involves measuring one's capacity to withstand abrasions and lacerations to dignity and self-esteem and often to economic security. The threat of pain and disadvantage is sufficient reason for many to opt for concealment.

- 1.3.8 Schneider and Conrad (1980) p.32, have written that "sometimes people conceal their epilepsy, sometimes they do not, and the same persons can be "open" and "closed" during the same period of their lives. In short, both concealment and disclosure proved to be quite complex and selective [as] strategies of information management". Some people conceal their epilepsy as completely as possible; others take a middle course and conceal their epilepsy according to their perceptions about the potential for damage that disclosure carries in any situation. There are others who deal with the choice by refusing to conceal their epilepsy from anyone. Ekemo (1976) p.96, noted that "those with high degrees of self-esteem are better-equipped to withstand the attitudes of persons in their surroundings... The person with epilepsy with a high degree of self-esteem is furthermore not ashamed of this handicap, and is quite open among other persons about his epilepsy".

My husband has had epilepsy for forty years but only his parents and I know about it. We have kept it confidential from the children and friends.

(Spouse of 58 year old male - Melbourne)

In fact I don't tell many people [that I have epilepsy]. There is a stigma to it and it makes me pretty careful about letting anyone know - a few good friends, that's all.

(Male - country South Australia)

"Don't tell" is the message from my mother and father and the doctors. I don't take much notice though... because I would rather know where someone stands. I don't need people who can't see past their own stupidity.

(25 year old female - country Victoria)

- 1.3.9 Just as disclosure has its burdens, so does concealment. Concealment is chosen to avert potential discrimination. Fear, bitter experience, a desire to be accepted for oneself, all have an influence. Yet when concealment is chosen, paradoxes arise. In order to preserve self-esteem, self-esteem can be compromised as feelings of deceitfulness spring up. In order to protect one's right to participation in society, or to economic security through employment, participation and employment can be endangered.

People didn't actually say they weren't interested in being friendly because I was epileptic. They just stopped seeing me and including me in things. So now I don't say anything. I don't know what's worse - getting it off my chest or being dishonest because it really is part of me.

(33 year old female - Melbourne)

I get along pretty well with the bloke who owns the place but I'm pretty sure if I told him I'd be out the door. I shut up about it and hope like buggery I don't have a fit at work... You never know, he might be the sort who wouldn't care one way or another but I can't afford to find out.

(26 year old male 7. country Victoria)

- 1,3.10 Concealment and the chance factor arise because of misinformation and prejudice. The provision of information and educational programmes which seek to inform and change attitudes are critical if those with epilepsy are to enjoy their basic human rights. People cannot be fairly asked to disclose their epilepsy in what is or may be a hostile environment. Nor can they be fairly judged as dishonest and deceitful if they choose concealment. Such judgements ignore the social reality of the world in which they live.
- 1.3.11 There is a need for agencies and groups which are able to play an advocacy role for people who have epilepsy. The Epilepsy Associations and epilepsy self-help groups would appear to be the most appropriate bodies to bear the greater burden of that role.
- 1.3.12 There are three other issues which frequently present difficulties. The first is that of the application of medical standards to epilepsy, especially for employment purposes and which act as criteria for programmes and services. Too often standards are based on outdated knowledge about epilepsy and are not relevant to their purpose or to assessing the needs of people who have epilepsy and their families for services, benefits and programmes.
- 1.3.13 The second issue is the need for services. Many contacts stated that they, or their family members who have epilepsy, are not catered for by the services available. To some extent this is related to the lack of information about epilepsy possessed by service providers, and the lack of awareness amongst service providers and those who have epilepsy about the existence and resources of Epilepsy Associations. But there are those who require assistance which can be provided only through specialist services. However, overcoming these problems would not exclude the need for specialist services.

These services have at their disposal specialist knowledge about epilepsy and expertise in dealing with both the medical and psycho-social dimensions of the condition. None of the Epilepsy Associations currently is able, due to lack of funds, to fill the gaps.

Very handicapped people get some help but my son is not very handicapped and we still need some help.

(Parent - country New South Wales)

People don't appreciate the effects of epilepsy because outwardly there are no problems until you have a spell which only happens every now and then at home. They don't really understand the help I need. I - have talked to other people with this illness but they can only help so much.

(Male - country Tasmania)

- 1.3.14 The third issue is once again related to services. The need for access to specialised services is especially acute in country areas. Available specialist services are concentrated in capital cities with the exception of part-time community workers employed by the EFV in two country areas of Victoria. The EFV Country Outreach Programme provides one model for service provision to country residents. Rehabilitation and counselling services are often out of reach for reasons of distance, availability of suitable accommodation and lack of transport amongst other reasons. When people who have epilepsy are eligible for programmes and benefits - the Commonwealth Mobility Allowance, for example - country people often cannot make use of them. In the case of the Mobility Allowance there is often no form of transport they can hire to make use of the money available.

CHAPTER TWO

DESCRIPTION OF EPILEPSY

2.1 INTRODUCTION

2.1.1 Some understanding of epilepsy is necessary in order to appreciate both the nature of the difficulties it presents to those who have it and the associated human rights issues. The purpose of this chapter is to provide an introduction to epilepsy for those unfamiliar with it.

2.1.2 Epilepsy is not well served by generalisation. The description below attempts to avoid broad statements, but space is a constraint. Finer details may be desirable; but the broad picture is, nevertheless, sufficient to the purpose.

2.2 SEIZURE THRESHOLD

2.2.1 There is no certain explanation of why some people contract epilepsy while others do not, though genetic pre-disposition is often implicated. The concept of seizure threshold is an aid to grasping this relationship.

2.2.2 Everyone inherits a seizure threshold, therefore everybody may have seizures. The higher the threshold the lower the potential for seizures. A high threshold may be passed, for example, due to severe brain trauma, a low threshold passed without any, or minimal, trauma.

2.3 DEFINITION OF EPILEPSY

2.3.1 The nervous system functions by way of minute electrical impulses. In epilepsy there is a persistent liability to recurrent, sudden surges of electrical activity within the brain. Seizures are the manifestations of such surges.

2.3.2 Recurrence is a central element of the definition. One seizure alone is not indicative of epilepsy.

2.4 PREVALENCE AND INCIDENCE

2.4.1 Prevalence is the number of people with a condition in a given population at one time. Methodological problems beset prevalence studies of epilepsy. The problems may be definitional (should seizures caused by high temperatures in infants be included?); related to sample variables (age and socio-economic status may yield divergent results); or bound up with the survey method (self-disclosure, for example, can be considered unreliable as people do choose to conceal their epilepsy).

- 2.4.2 For such reasons prevalence studies vary markedly. Wajsbort (1967) found epilepsy prevalence was 0.23 per 100 population. Cooper (1965) found 2.27 per 100 population.
- 2.4.3 The commonly stated rate for Australia and the USA is 1 per 100, reflecting an approximate average of studies undertaken. Beran (1983) found a rate of 2 per 100 in Sydney. This figure accords with that favoured by the Epilepsy Foundation of America's (ERA) Professional Advisory Board.
- 2.4.4 The practical way out of this confusion is to say epilepsy affects at least 1% of the population and as much as 2%.
- 2.4.5 The Australian Bureau of Statistics (1983) estimates Australia's population at March 31st, 1983, to be 15,336,100. If the prevalence rate of 1 in 100 is used there are 153,361 Australians who have epilepsy. The rate of 2 in 100 gives a figure of 306,722.
- 2.4.6 An incidence rate is the number of new instances of a condition occurring in a given population during a given time. Again, methodological problems abound in determining an incidence rate- for epilepsy in Australia. However, assuming the prevalence rates of 1 and 2 in 100 hold constant, annual incidence rates of 0.1 and 0.2 can be derived from them. A rate of 0.1 gives 1,552 new instances per year; a rate of 0.2 gives 3,045. Incidence rates may be rising due to the nature of modern environments and lifestyles (Caveness, 1976).
- 2.4.7, Few studies have explored the influence of socio-economic factors on epilepsy prevalence. Shamansky and Glaser (1979) did so. They state that "For 1960-1970 there was a significant association between epilepsy and economic area...ie, children from lower socio-economic areas had an increased risk of epilepsy." A US National Centre for Health Statistics survey, quoted in Whitman (1980) found significantly higher prevalence rates of epilepsy in members of low-income families. There is clearly a need for research on this issue to be undertaken in Australia.
- 2.4.8 Usually epilepsy occurs alone, although prevalence is higher when certain other impairments co-exist. This is notably so with brain damage, intellectual disadvantage and cerebral palsy, as well as with rarer conditions like tuberous sclerosis.
- 2.4.9 Epilepsy can begin at any time in any person. But as Table 2.1 - adapted from an EFA publication (1975) - shows, some age groups are at greater risk than others. An emphasis on services and programmes for use by those under twenty years of age is clearly warranted where epilepsy is concerned.

Age groups	First seizures occurring -
0- 9	47
10 - 19	30
20 - 29	13
³⁰ - 39	6
40+	4

Table 2.1 Age group by percentage
all first seizures occurring in
each age group.

2.5 CAUSES

2.5.1 In many instances (estimates vary from one quarter to one half of the total) the cause of epilepsy is unknown. In the remainder there is a variety of causes, some preventible (rubella, head injuries, and some birth injuries). Other familiar causes are brain tumours, hardening of the arteries, and fevers in infants.

2.6 SEIZURE TYPES

2.6.1 The following seizure classification is drawn from that of the Commission on Classification and Terminology (1981) appointed by the International League Against Epilepsy. The classification is based on clinical observation and readings of electrical activity in the brain. There are in excess of 20 seizure types, falling into two broad categories: partial and generalised seizures.

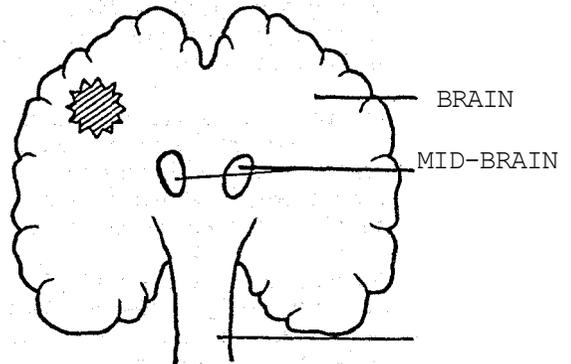
2.6.2 Partial seizures can be divided into three groups:

- (a) simple partial seizures
(consciousness not impaired);
- (b) complex partial seizures -
 - (i) simple partial onset followed by impairment of consciousness,
 - (ii) impairment of consciousness at outset;
- (c) partial seizures (simple and complex) becoming generalised.

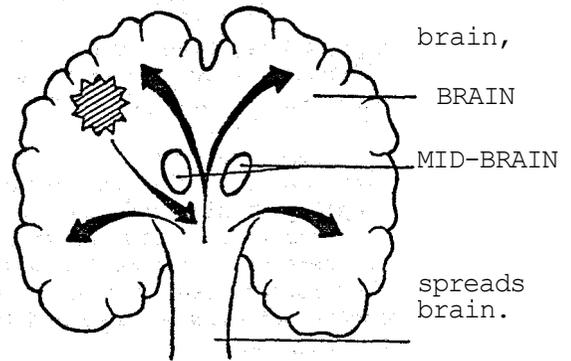
2.6.3 In partial seizures increased discharges originate in one brain area and remain localised (see figure 2.1). Since each area controls different functions, functions located at the site of increased activity will be impaired. Simple partial seizures may involve movement which cannot be halted at will, or perhaps tingling, light flashes, buzzing, smells, nausea, sweating, de ja-vu or visual hallucinations.

These illustrations are intended to give a general impression of what occurs in the brain during different kinds of seizures.

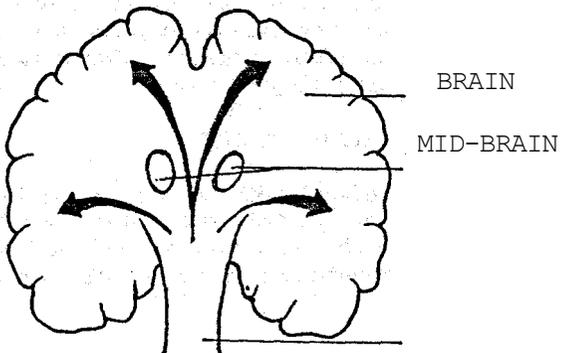
FIGURE 2.1 Partial seizure. Electric activity increases in one part of the brain only and does not spread. Only those brain functions located at the site of the increased electrical activity are affected.



BRAIN STEM
FIGURE 2.2 Partial seizures which generalise. Increased electrical activity remains localised for a time before spreading to the centre of the brain after which it rapidly spreads to other parts of the brain.



BRAIN STEM
FIGURE 2.3 Generalised seizure Increased electrical activity arises in the centre of the brain and spontaneously to involve other parts of the



BRAIN STEM

- 2.6.4 During a complex partial seizure a person may remain still or engage in incongruous behaviour (tugging at clothing, mumbling or wandering) while unconscious.
- 2.6.5 In partial seizures becoming generalised, increased activity is localised for a time before spreading through the brain (see figure 2.2). The common terms "aura" and "warning" describe the initial sensations (like those mentioned in section 2.6.3) associated with a partial seizure which later spreads.
- 2.6.6 Generalised seizures involve increased electrical activity simultaneously arising in both sides of the brain (see figure 2.3). Consciousness is lost, except in brief myoclonic seizures which consist of short jerks. Generalised seizures take many forms: the absence seizures (cessation of activity without falling or convulsions); atonic seizures (loss of muscle tone resulting in a slump or fall); tonic-clonic seizures (stiffening of the body followed by jerking), amongst others.
- 2.6.7 A person may have one or several types of seizure. Seizures span differing time periods: a few seconds (absences or simple partial seizures) to several minutes (tonic-clonic or complex partial).
- 2.6.8 Different seizure types occurring in any situation will affect performance in that situation in different ways (or not at all in some simple partial seizures). Performance problems, though often related to them, are different from problems arising through low self-esteem or personal distress caused by the attitudes of others to epilepsy. The latter can far outweigh performance problems posed by the occurrence of a seizure and are often more debilitating to individual functioning.
- 2.6.9 A precipitating factor, while it is not itself the actual cause of epilepsy, triggers increased discharges in a brain already susceptible to them. Precipitating factors are many (fatigue, certain phases of the menstrual cycle or poor diet, for example). They are recognised through experience, but are often difficult to identify, especially in children. Seizures also begin spontaneously and not in response to any provoking factor.

2.7 SEIZURE CONTROL

- 2.7.1 Seizures can be controlled using medication. Rodin (1972) estimated that 85% of people who have epilepsy achieve total or partial control with medication. He emphasised, though, that diligent medical management is essential to control maintenance.

- 2.7.2 For those whose epilepsy has been completely controlled there is no disability related to the condition itself, although the taking of medication may pose its own problems (see for example, section 4.2.5). Personal, family and community attitudes may impose limitations of a social nature.
- 2.7.3 Changes to lifestyle or to the physical environment which diminish the influence of precipitating factors can be effective in establishing control over epilepsy. Improved or complete control may occur through attention to trigger factors which operate in the inter-personal or intra-personal spheres (over-protective family relationships or low self-esteem for example).
- 2.7.4 Obviously, obtaining a diagnosis early is crucial in establishing seizure control through drug therapy. Much epilepsy goes undetected for long periods because, generally, neither parents nor professionals know enough about the condition to recognise grounds for concern and investigation. Misdiagnosis, say, the imputation of misbehaviour or clumsiness leave many with seizures which are potentially controllable. Other conditions - breath-holding spells or fainting - are often diagnosed as epilepsy and inappropriate treatment and discrimination have to be dealt with unnecessarily. On the other hand, no doubt there are undiagnosed occurrences due to concealment of seizure conditions from medical practitioners.
- 2.7.5 Epilepsy has no cure, though surgery may halt it in perhaps 3% of cases. Appropriate management strategies may help epilepsy to remit entirely or for long periods. After a seizure-free period (usually two to five years) medication may be withdrawn under medical direction and seizures may not recur. Should they recur, medication is reinstated. Juul-Jensen (1964) found 64% of his sample were seizure-free three years after medication was withdrawn. Annegers (1980) calculated, on the basis of a longitudinal study, a net probability of remission to be 70% 20 years after diagnosis.

2.8 RECOMMENDATIONS

- 2.8.1 Australian research should be undertaken to as to 'determine the correlation, if any, between socio-economic background and the incidence of epilepsy (Section 2.4.7).
- 2.8.2 An emphasis should be placed on the provision of services and programmes for those people under twenty years of age with epilepsy (Section 2.4.9).

CHAPTER THREE

PUBLIC EDUCATION

I am still afraid of the stigma - believe me it's real.

(37 year old male - country Victoria)

3.1 INTRODUCTION

3.1.1 Over 80% of contacts voiced a concern that the community generally has little knowledge about epilepsy. A similar proportion urged increased efforts to promote awareness of epilepsy, with many underlining the importance of media exposure. Ignorance and misinformation frequently force those who have epilepsy and their families to endure or combat rejection and exclusion.

People should just give epileptics a fair go. There is no understanding generally. People think it's a horrible disease even now.

(Female - Melbourne)

People by their ignorance have held me back. There is a lack of knowledge on other people's behalf.

(36 year old female - Melbourne)

3.1.2 The existence of ignorance and misinformation is a critical issue. Without adequate information and understanding available to the community many rights will go unheeded. Self-reliance, social integration or re-integration, securing and maintaining employment, and participation in social, creative and recreational activities cannot be achieved while judgements about epilepsy and those who have it are based on false suppositions.

3.1.3 The emphasis, in this Report, on information and educational resources and programmes, both of a general and specialist kind, reflects their importance. Their availability is essential to the protection and promotion of the rights of persons who have epilepsy.

It is only my opinion that not much will change for epileptics unless people are educated about what epileptics are. Normal everyday people.

(58 year old male - Adelaide)

- 3.1.4 The decision to conceal epilepsy can be a response to fears of discrimination. Public education can do much to reduce that fear and alleviate the necessity to choose concealment and its burdens.
- 3.1.5 The chance factor is pervasive and could be minimised by the provision of programmes and resources. It is, however, simplistic to expect that provision of educational resources and programmes will quickly alter discriminatory attitudes. Some of those exposed will change quickly; for many, change will take longer. It may not occur until they meet someone who has epilepsy and their pre-conceptions are challenged by that meeting and the information to which they have been exposed.
- 3.1.6 Epilepsy can begin in anyone at any time. If it is diagnosed people should know through general community awareness where to find the information and support they want. Indicative of this is the fact that at least 30 contacts were made, where diagnosis was relatively recent, primarily to seek information. Raising awareness of the existence of Epilepsy Associations is a prime consideration,
- My son who is three was diagnosed epileptic about eight months ago...I would be interested to have any information you can send as nobody knows very much about it.
(Parent - country Queensland)
 - My first attack was (in 1982)...I am told heavy exercise will cause seizures.. .I would be interested in your comments about (this) as information is hard to come by.
(24 year old female - country South Australia)

3.2 RESOURCE NEEDS

- 3.2.1 The constant call to Epilepsy Associations for educational materials is evidence of the community's need to learn and interest in learning about epilepsy.
- 3.2.2 Two pamphlets for public distribution are produced by the NEW. These cover first aid, information for parents and teachers and a general overview of epilepsy. State Associations produce pamphlets on their services and activities. However, associations express concern that their materials are often inadequate to meet the many and varied requests they receive.

3.2.3 The need for a pamphlet for workers was regularly mentioned. It should be designed to cater for those currently working with people who have epilepsy, although it should also be appropriate for general distribution through the workforce as any worker might at some time work beside a person who has epilepsy.

Education of employers through the workforce may prove, I believe will prove, in the long run a most effective means of raising the awareness of the general public.

(Male - country NSW)

3.2.4 No printed material is available in languages other than English - an obvious deficiency. While firm figures are unavailable, several Epilepsy Associations confirmed that contact with overseas-born Australians seemed markedly lower than their proportion of the population, even though immigration policies restrict the entry of persons with epilepsy.

3.2.5 The need for printed materials about appropriate treatment, treatment procedures and medication side-effects was stressed.

For years I went to GPs who didn't know what they were doing. I could have saved a lot of time and money and upset if I knew about the tests they can do and about specialists.

(Female - Brisbane)

:People ask me about EEG and brain scans and I can't really explain about them properly.

(Parent - Northern Territory)

It would assist me...to have to hand an information sheet outlining Medication "do's and don'ts".

(Medical practitioner - Melbourne)

3.2.6 Other printed materials are required, notably on recreation and driving. Any printed materials that were available could be used by persons who have epilepsy as well as by professionals and other community members.

3.2.7 accept for a Short videotape produced through the Australian Capital Territory Epilepsy Association, there are no Australian-produced audio-visual materials specifically on epilepsy. Film resources produced in either Britain or North America are in constant demand from Epilepsy Associations even though they are sometimes inappropriate.

An Australian-made film or video would make so much more sense to the groups we speak to.

(Epilepsy Association Committee member)

The films shown by the Epilepsy Association are relevant enough but are American rather than Australian which means they are not as relevant as they might be. -

(Lecturer in Education)

- 3.2.8 With NEPA involvement, the professional production of Australian films could usefully be undertaken. At least two groups must be catered for: children of late primary or early post-primary school age and adults. Films for adults should be suitable for general audiences and for use in professional pre-service and in-service education.
- 3.2.9 The development and production of educational materials, and the funds to ensure that they are used effectively, are key requirements. The NEAA should be responsible for resource development. State Epilepsy Associations should be responsible for effective utilisation and dissemination of such resources. These responsibilities cannot be assumed without Government financial assistance as the Epilepsy Associations generally lack sufficient funds to proceed alone.
- 3.3 RECOMMENDATIONS
- 3.3.1 Public education programmes aimed at raising general community awareness of the real nature of epilepsy should be implemented (Section 3.1.4).
- 3.3.2 Materials providing basic information on epilepsy should be produced in different languages (Section 3.2.4).
- 3.3.3 Australian films on epilepsy suitable for children of late primary and early post primary school age and adults should be , produced with NEAA input. Films for adults should be suitable for general audiences and for use in professional pre-service and in-service education (Section 3.2.9).
- 3.3.4 Public education programmes should include the provision of well researched and presented material for wide distribution. Funding for the programmes should be adequate to ensure the effective use of such materials (Section 3.2.10).
- 3.3.5 Adequate government financial assistance should be given to the HEM to enable it to take responsibility for resource development. State Epilepsy Associations should be funded so as to enable them to facilitate educational programmes including the distribution of suitable material (Section 3.2.10).

CHAPTER FOUR

SCHOOL EDUCATION

School was hard for me because I am not a good student and the teachers and other kids were sometimes very hurtful about the epilepsy.

(Female - country South Australia)

4.1 INTRODUCTION

- 4.1.1 In any discussion of epilepsy it is important to consider schooling including pre-school services. Table 2.1 shows that epilepsy most commonly begins before the age of twenty. In addition, epilepsy is more prevalent amongst children than it is in the total population (O'Donohoe (1979) p5). The incidence of new diagnoses is greatest in the 0-4, 15-19 and 10-14 age groups (Epilepsy Foundation of America (1975) p4). Childhood epilepsy does not always persist into adulthood.
- 4.1.2 A diagnosis of epilepsy can have a great impact on a child. Parental attitudes and expectations often develop through an emphasis on the child's epilepsy and disabilities which may be actual, though sometimes exaggerated or imagined entirely. These attitudes and expectations might impose unnecessary and often excessively severe, limitations on the gathering of experience and skills through participation in a range of activities.
- 4.1.3 In many instances, however, parental attitudes and expectations do stem from an emphasis on ability. Some schools are receptive to these positive attitudes and the special needs of the child which they strive to meet, others have to be pushed by parents into accepting children with epilepsy and making such provision.

All along we have had marvellous support from his teachers, who have gone out of their way to help him in his studies.

(Parent - Hobart)

At one school they told us she was hopeless as a student and advised us to put her into a special School. We took her to another school...she is now doing very well.

(Parent - Melbourne)

4.1.4 On the other hand, schools often mirror inappropriate parental attitudes. Little attempt is made to assist parents in overcoming over-protective responses which seek to lessen the demands of schooling and the school environment on the child, rather they reinforce those responses. The limitations such responses impose on a child's academic, social, emotional and physical development are a matter for concern.

My parents mollycoddled her through school. They kept her home at the drop of a hat and she was never allowed to do physical education. What still makes me wild is that the teachers went along with it. They just believed everything Hun told them.

(Sister of 17 year old female who has epilepsy - country South Australia)

I missed out on every school excursion from the day of my first fit. my parents didn't want me to go and teachers were nervous about my epilepsy anyway.

(25 year old female - country Victoria)

4.1.5 A lack of understanding can also result in rejection of enrolment applications, at least initially. Contacts and Epilepsy Associations have reported at least 7 such instances (3 in 1983).

My child has just started secondary school. At first they refused to take her because she had epilepsy. Then they said they would take her if she was under a specialist.

(Parent - Melbourne)

The boy was turned away quite stupidly. Fortunately his mother rang ire and I was able to sort it out with the headmaster.

(Epilepsy Association Committee Member)

4.1.6 While some Children have behaviour problems linked to epilepsy itself, attitudes or expectations reliant upon an over-emphasis on epilepsy or disability also produce behavioural patterns which present schools with behaviour management difficulties (Verduyn, 1980). Where schools adopt inappropriate attitudes and expectations, those patterns are encouraged.

4.1.7 Comments about schooling fell into three groups. The first is negative and exhibits dissatisfaction, disappointment and anger. The second is positive. The third is mixed, showing that the chance factor is to be contended with in schools as elsewhere.

My son was teased a lot at his primary school. We transferred him to another school and they have been great - kids and staff. I can't explain the difference. Luck of the draw.

(Parent - Melbourne)

4.2 EPILEPSY AND LEARNING

- 4.2.1 Where the special needs of children are not taken into account their learning abilities or academic performance might compare poorly with that of their peers. It is not a question of inability to learn or achieve - given, the right attention they can. As Hackney and Taylor (1976) put it, children who have epilepsy "do not, on the whole, need special education in its narrow sense but we would argue that they do need special attention and consideration within the normal school system if they are not to be at a disadvantage". As is illustrated in the previous section, the adoption of positive attitudes and expectations, along with proper medical treatment and management of medication, the identification of learning problems, and the development of strategies to deal with them, must all receive due emphasis.
- 4.2.2 Sorting out the social environment must be a high priority if a child is to learn and perform to capacity academically. Attitudes and expectations which initiate or exacerbate unrewarding behaviour patterns handicap learning and performance. A child subject to unnecessary limitations will tend to operate within them. Beyond very few physical restrictions - rockclimbing for example - the child who has epilepsy should be encouraged to participate in all aspects of school life and should deal with the same demands as her or his peers.
- 4.2.3 To do this effectively, teachers must be confident in their interaction with children who have epilepsy. They must know how to take account of and assess the special needs of those children or be able to call on assistance to do so as placing unnecessary limits or concessions in regard to discipline, learning or other school activities is not in the child's best interests. The school is responsible for the child's learning and plays a central part in his or her overall development and must be able to assist parents to set aside any impulses to unnecessarily insulate or protect the child.
- 4.2.4 The attitudes of other students must be changed if they are disrupting a child's social environment. The confidence and leadership of teachers can markedly affect students' attitudes, as can teaching about rights, disability and epilepsy in particular.

- 4.2.5 There is growing evidence that medications used to treat epilepsy can adversely affect cognitive functioning. Trimble and others (1980) found that different medications can cause a reduction in the ability to retain new information, a significant increase in errors occurring on word recall tests and a significant increase in time taken to make simple decisions requiring either perceptual or semantic processing. The same research found that high levels in the bloodstream of one drug in particular correlated with poorer performance in all areas. The same research found that IQ levels fell or deteriorated over a period of time.
- 4.2.6 These findings are not pertinent in all cases as some children are not affected. Holdsworth and Whitmore (1974) found only 16% of their sample of children who were attending mainstream schools were falling seriously behind. The point is, as Poche (1978) states: "All epileptic children should be viewed as extremely likely to have educational problems". The role of medication in producing educational problems should be assessed in each child who may be struggling in class and action taken to eliminate or reduce its impact.
- 4.2.7 Stores and Bennet-Levy (1983) found children who have epilepsy to be less alert than other students, irrespective of factors such as medication. Holdsworth and Whitmore (1974) noted inattentiveness in a majority of children in their sample. Buffery (1981) demonstrated that learning can be affected in different ways, depending upon the part of the brain in which electrical activity builds up at the outset of a seizure.
- 4.2.8 Once again, this does not mean that children who have epilepsy cannot do as well as their peers. Learning and teaching strategies can be developed to enable them to achieve academically. There is not a question of deficit but one of special difference.

4.3 RESOURCES IN THE SCHOOL SYSTEM

- 4.3.1 Classroom teachers are the most important resource within the system. They have a part to play in most matters already raised, such as promoting the social and physical development of children who have epilepsy, liaising closely with their families and conveying information to other professionals about behaviour and learning which will assist in determining whether medication is producing unwanted side-effects.

- 4.3.2 As has already been mentioned, teachers can play a role in bringing a child's fellow students to an understanding of individual rights and special needs. The importance of this role is udder than its effect in relation to a particular child. Progress along the path to social integration is slower where people have little appreciation of the rights of disabled persons generally. Schools could take a leading part in that progress through teaching about rights. That most have not done so is due in part to the scarcity of curriculum materials on rights, and in particular, on the rights of disabled persons.
- 4.3.3 As part of its role in this area, the Human Rights Commission has prepared some comprehensive curriculum materials which are soon to be published. A booklet entitled Human Rights: a Handbook for use with younger children has already been published.
- 4.3.4 A role also exists for Epilepsy Associations to play where epilepsy arises in a rights context, or where teachers need resources on epilepsy to assist their teaching. At present, however, associations are not in a position to promote education about epilepsy because resources at their disposal are not suitable for teachers and students to use in classrooms.
- 4.3.5 Teachers can be the first to identify that something is amiss in a child and that he or she should be referred to medical services in the school or elsewhere. Diagnosis of epilepsy rests primarily upon description of observed activity. Parents, for whatever reason, do not always notice that something unusual is occurring and teachers, by describing what they have seen can assist in diagnosis. The earlier epilepsy is diagnosed the better, and teachers must know what constitutes cause for concern. If they do not, they may, as is commonly reported, simply tag a child who is, for example, having absence or simple partial seizures as inattentive, lazy, disruptive or easily distracted.
- 4.3.6 After epilepsy is diagnosed, a teacher can be the first to inform parents of resources like Epilepsy Associations. Several contacts stated that this had been the case.

His preschool teacher felt he was phasing out a lot and thought something could be wrong. That was when we first picked it up...we should have realised ourselves but I think we got used to the idea he was a bit of a dreamer.

(Parent - country South Australia)

Why it had to be a teacher and not the doctor who put us on to the Epilepsy Association I will never know.

(Parent - Perth)

- 4.3.7 More common was the observation that teachers knew very little about epilepsy and did not know of Epilepsy Associations. They cannot fulfil the roles mentioned if this is so. Many contacts made the point that teachers acted on imprecise or incorrect knowledge.

I was banned from woodwork because the principal decided it was dangerous to me and the other kids. It was a bloody silly decision because we explained my fits only happened at night.

(22 year male - country Victoria)

Teachers would have helped more I suppose if they knew more but they didn't. I must have had absences for years before the doctor realised it (when I was about fifteen).

(Female - country Queensland)

- 4.3.8 Epilepsy appears to be covered to varying degrees in special education and physical education courses in teacher training. Most general teacher education courses do not offer core instruction about it. Every teacher should receive core instruction in special education, during which some discussion of epilepsy should take place. A general introduction to disability, like that discussed in Section 5-3, does not answer the need.
- 4.3.9 The Australian Capital Territory (ACT) Schools Authority has begun a process of installing a resource teacher in all schools'. Selected teachers, via a time release scheme, undertake one-year full-time studies leading to a Graduate Diploma in Special Education. These teachers return to their schools to act as resources for classroom teachers teaching children who have special needs. The programme is only in its initial stages and present arrangements in most schools do not appear to be satisfactory. Whether one resource teacher is sufficient is probably doubtful in large schools, but at least the need for specially trained staff has been recognised in a practical fashion.
- 4.3.10 Andrews and others (1979) found that 77% of Australian primary schools and 66% of post-primary schools had no staff with academic qualifications in special education (these figures exclude special education schools). Even where such staff are present there is no guarantee that their teaching duties will be centred on resourcing classroom teachers. This is a depressing picture for those children with learning difficulties who have epilepsy and who are attending, as most of them do, mainstream schools. Time release schemes for experienced teachers to undertake special education training should be promoted throughout Australia. The establishment of such schemes would necessitate the establishment of courses at Bachelor of Education and Graduate Diploma levels.

- 4.3.11 In the *ACT*, special education schools have nurses on staff. That mainstream schools do not is unsatisfactory as Children in these schools are no less in need of health services than their counterparts in special education schools. Visiting medical services do have a place but a school-based health professional could provide an important health resource which would provide a focus for health education and health service needs currently lacking. That focus would benefit all Children, including those who have epilepsy. Visiting school medical services by their nature are less able to provide that focus, though their contribution cannot be doubted.
- 4.3.12 Children- who have epilepsy must have access through schools to vocational counselling and careers education. High levels of unemployment amongst disabled persons, their susceptibility to long-term unemployment, the importance of choosing occupations (or studies leading to them) appropriate to their Abilities, and the necessity for those who have epilepsy to confront the issue of concealment in relation to employment emphasise the importance of vocational counselling.
- 4.3.13 Careers education must cover issues such as coping with discrimination and knowing what resources are available to combat it and how to present oneself and one's epilepsy to a potential employer. The . inadequacy of vocational counselling services and career education was 'raised by a number of contacts. Most complained about the lack of such services or about the low level of knowledge possessed by those providing them where they do exist.

There was no guidance at school as to employment that was suited to me. I could have used more help than the general careers stuff they teach to everybody.

(29 year old female - Melbourne)

I applied for the police force after I went over it with the careers teacher. He didn't even know that epilepsy cancels you out from the police. It was a blow to find that out because that's What I wanted to do since I was a kid.

(22 year old male - country Victoria)

- 4.3..14 Epilepsy alone will, only in the rarest of instances, prevent a child from attending mainstream schools. Where epilepsy is linked with - other disabilities, with unrewarding behaviour patterns or with the .. effects of ill-managed medication, a Child may be placed in special education settings.

- 4.3.15 Mainstreaming, the integration of children from these settings into ordinary schools, has been pursued in the ACT for some time and in other States to varying degrees. It is a process which has great potential for the realisation of the right to social integration. However, mainstreaming will disadvantage children from special education settings, and, to some extent, those in the schools they attend unless consideration is given to important elements in the process and the provision of sufficient resources.
- 4.3.16 Integration should be taken to mean not only the integration of individual children but the integration of the special education and mainstream education systems. To keep them separate is to limit the possibilities for integration for all children. System integration allows for flexibility in the use of teaching skills and for the easy movement of children between special and mainstream settings.
- 4.3.17 Special settings must be retained for children who have not developed the survival skills :necessary to benefit from the open social environment of the mainstream school. Once possessed of survival skills the child can learn social skills directly, through contact in mainstream schools, rather than learn about them in a sheltered social environment. Some children in 'special education settings benefit most from small class learning situations which increase the possibility of individual attention. Special education settings can do this more easily than mainstream settings'.
- 4.3.18 Integration should not occur until the disabled child is ready for it and the special and mainstream systems are themselves integrated. The integration process underlines the need for adequate 'specialist staff resources based in mainstream schools.. Mainstream schools must be ready to receive disabled Children in a social sense and careful preparation of the school community must occur. Finally, parents of disabled children must be closely involved in the integration process.

I am very worried that if he goes to the high school they will not cope with what he needs. He needs one-to-one teaching.
(Parent - Melbourne)

She will be nothing but the victim of a vogue idea if they don't put their resources where their mouth is.
(Parent - Canberra) -

4.4 - A ROLE FOR SCHOOL ADMINISTRATORS

4.4.1 It is essential that teachers have information about epilepsy and the - particular problems of children in their care. Confidentiality must be balanced against a child's right to receive an education most suited to her or his needs.

4.4.2 Gadow (1982) and Holdsworth and Whitmore (1974) found that relevant information regularly failed to be passed to teachers and from teachers to others. A standardised system of recording health or treatment information would overcome many of the problems encountered. Its virtue would be that all teachers would know of it and how to use

Every year Mum would go up (to the school) and reel off the some information about me and my epilepsy. It should not have been necessary.

(32 year old female - country Queensland)

We asked the doctor to ring the school...but the whole story stayed with the principal.

(Parent - country Tasmania)

I moved around from school to school following Dad's job. Every school had to be given my medical history which believe you me was a very complicated (history).

(47 year old male -Northern Territory)

4.4.3 A system of recording health information must operate in recognition of the right to privacy. Information should be recorded only on the clearance of the child and her or his parents. The benefits and disadvantages of the system must be explained clearly. Access to information must be governed by safeguards which balance the right of privacy with the need for access. Information recorded must be Objective and relevant to the child's schooling. Parents and child must have the right to view information held and to change it or withdraw it from the system. They must also have the right to veto the transfer of information from one school to another.

4.4.4 School administrators would be responsible for administering such a system. If a standardised system is not introduced, schools should design and administer their own systems. Information received about the ways in which health and treatment information IS currently recorded shows that, with notable exceptions, they are ad hoc, inconsistent, reliant upon memory and fail almost completely upon a child's transition from pre-school to primary and primary to post-primary levels or when a child moves to a new school within a level.

4.5 RECOMMENDATIONS

- 4.5.1 Educational authorities and Epilepsy Associations should develop curriculum materials on epilepsy (Section 4.3.4).
- 4.5.2 Teacher training courses should include A core unit in special education in which informed discussion of epilepsy should take place .(Section 4.3.8).
- 4.5A :The *ACT* time release scheme in which teachers undertake one-year full-time studies leading to a Graduate Diploma in Special Education and then return to their schools to act as resources for teachers of children with special needs should be improved and implemented in all States and Territories. In order to promote this scheme, appropriate courses should be included at Bachelor of Education and Graduate Diploma levels (Sections 4.3.9 and 4.3.10).
- 4.5.4 Vocational counselling and careers education should give consideration to the disadvantages a person with epilepsy may encounter in seeking employment. In particular, information on how to cope with discrimination and how people with epilepsy should present themselves and their epilepsy to potential employers must be included (Section 4.3.13).
- 4.5.5 The integration of Children from special :education settings into mainstream education must be accomplished in such a way as to provide for flexibility in the use of teaching skills and the easy movement of children between special and mainstream settings. This would require integration of the special and mainstream settings themselves (Section
- 4.5,6- Integration should only take place when the disabled child is ready and the special and mainstream schools are integrated. Mainstream schools should be socially ready to receive disabled children and the school community must be carefully prepared (Section 4.3.18).
- 4.5.7 A standardised system of recording health or treatment information should be introduced in schools (Section 4.4.2).
- 4.5.8 Such a system should operate in recognition of the right to privacy. Therefore it should be subject to clearance by the child and her or his parents; should be objective and relevant to the child's schooling and should be subject to review by the parents and child who should also retain the right over transfer from one school to another (Section 4.4.3).

CHAPTER FIVE

PROFESSIONAL EDUCATION

I don't mind explaining about epilepsy to the social worker or a teacher who doesn't know much although I'm sure I don't know as much myself as I should....What hurts is they have prejudices sometimes against epilepsy even for all their extra education.

(Woman who has epilepsy and mother of 9 year old child who has epilepsy - Melbourne)

5.1 INTRODUCTION

5.1.1 Many people who have epilepsy know little about it. However, there is an expectation that members of professional groups will possess a basic understanding of epilepsy and a knowledge of the resources available to assist them and their clients.

The infant welfare sister told me there was no books on epilepsy and I would have to ask my doctor. . She said it was a complicated disease. Of all people [infant welfare sisters] would have to know of the Epilepsy Foundation.

(Parent - country Victoria)

Surely it would have been no effort for the doctors and nurses at the hospital to tell me the Epilepsy Society existed. [Four years after diagnosis] my mother rang to say she noticed it was listed in the telephone directory.

(35 year old female - Brisbane)

5.1.2 While some professional groups are not expected to have detailed information about epilepsy, inadequate knowledge about epilepsy or resources amongst health care professionals brought strong criticism from contacts.

The doctor said it was nothing to worry about, that she would grow out of it. The twitching got worse so we took her to another doctor. He said it was epilepsy... It's a joke. If my husband hadn't decided to see another doctor nothing would have happened.

(Parent - Melbourne)

Some of the nurses had the completely wrong idea about first aid.: I rang up the Epilepsy Association to ask them to send booklets to my ward. I hope you agree that shouldn't be my job.

(Male - country Victoria)

- 5.1.3 It must be acknowledged that professionals are as prone to ignorance and misinformation as other people. What is completely unacceptable is rejection or "moments of discrimination".

Little moments of discrimination come up from time to time to get me angry... Once I was extremely annoyed at a chemist who had the cheek to ask me to come in at quiet times. I asked him why. He said it would be an embarrassment for me to fit with a lot of people around. -

(45 year old female - Sydney)

You need thick skin when a teacher says you will not get anywhere because epileptics are bad students. This happened to me from memory when I was eleven or twelve I have never forgiven that teacher.

(Male - country Tasmania)

5.2 PRE-SERVICE EDUCATION - QUESTIONNAIRE RESULTS

- 5.2.1 In November, 1983, questionnaires were forwarded to 141 Faculties and Departments in 55 post-secondary educational institutions. Helpful information was contained in 102 (72%) responses, Courses Offered in the following areas are included in the responses: -

- (a) education - 40 responses (including courses in general teacher training, early childhood, physical and special education);
- (b) health - 22 (chiropractic, medicine, nursing, occupational therapy and speech therapy);
- (c) generalist - 16 (Arts and General Studies);
- (d) welfare - 14 (child care, social work, welfare work and youth work);
- (e) business (where personnel units offered) - 6; and
- (f) recreation - 4.

- 5.2.2 There was insufficient time to thoroughly analyse the data in the responses to the questionnaires, so the picture presented is not comprehensive. Nevertheless a general account of the current situation can be constructed with several important issues emerging.
- 5.2.3 Precise information on time allotted to instruction about epilepsy and its social impact appeared in 82 responses. No instruction was offered in 25 instances. In 57 instances instruction varying from twenty minutes to five hours or more was offered. But, in 28 of these instances instruction formed part of elective rather than core studies. Health and special education courses accounted for 24 of the 29 instances of core instruction.
- 5.2.4 Precise information on time allotted to instruction about the social impact of the disability was received in 76 responses. In 16 instances no instruction was offered. Instruction varying from one hour lectures to whole units of study was offered in 60 instances. It was elective in 22 instances.
- 5.2.5 Most instruction occurred in lectures. Epilepsy Associations were significant in delivery of services. Their representatives delivered lectures in 6 instances and in 19 instances Associations provided pamphlets or films. Other formats included seminars, student placement in Epilepsy Association services or other agencies where epilepsy is encountered and visits by student groups to such services or agencies.
- 5.2.6 Shortcomings in dealing with epilepsy in courses were identified by 31 respondents. They were
 insufficient course time available (mentioned by 17);
 inability to ensure student contact with persons who have epilepsy (9);
 insufficient teaching staff - meaning that lecturers not necessarily acquainted with epilepsy must teach about it (4);
 and
 insufficient funding for new courses within which emphasis could be given to epilepsy and disability, and to research (3)
- 5.2.7 Strengths were identified by 49 respondents. Some were:
 emphasis in teaching given to social aspects of epilepsy, rather than a simplistic introduction to the condition, first aid and treatment (mentioned by 15);
 amount of time given to consideration of epilepsy (12);
 learning formats used: for example, lectures given by Epilepsy Association representatives; and possibility for students to elect to undertake detailed work on epilepsy as part of a course (12);

use of printed or audio-visual materials provided by Epilepsy Associations (11); and teaching undertaken by staff professionally experienced in dealing with people who have epilepsy or who have close knowledge of epilepsy (5).

5.2.8 Some 58 respondents suggested roles that could be adopted, or in some instances maintained, by Epilepsy Associations which would assist in the presentation of epilepsy in their courses. Most suggestions made relate to the role of resources. They are:

- provision of printed and audio-visual materials: (26);
- provision of guest lecturers (19);
- provision of teaching materials such as case studies and instructional packages (8);
- regular up-dating of staff on information and programmes relating to epilepsy (7);
- student placement in Epilepsy Association services (5);
- student visits to Epilepsy Associations (5);
- assistance in designing course content on epilepsy (5);
- production and provision of Australian audio-visual materials **(4)**; and
- participation in seminars (3).

Five respondents suggested that the Epilepsy Associations should lobby Governments to fund teaching positions or new courses.

5.3 PROBLEMS AND NEEDS IN PRE-SERVICE EDUCATION

5.3.1 The availability of professionals with informed attitudes about epilepsy or disability generally, and with a knowledge of resources available, is dependent on the exposure that professional groups have had to these issues during their training.

5.3.2 Pre-service training is essential as it is insufficient simply to hope that public education programmes will reach professionals, challenging any inappropriate attitudes. The chance factor is increased when instruction about epilepsy or disability is elective or not offered.

5.3.3 Provision of instruction by itself cannot guarantee positive attitudes and responses to needs. Difficulties encountered with medical practitioners (to cite an example discussed in Section 7.2) who do receive instruction supports this. What matters is the kind of instruction given and the emphasis.

Al]. students who might be employed in positions involving service provision (teachers and nurses, for example) or decision-making (say personnel officers or social planners) relevant to persons who have epilepsy, must learn something of the social perspectives of disability. Issues particular to hidden disability should form part of that learning. In addition they must learn the usefulness, and appropriateness, of consulting with or referring to organisations like Epilepsy Associations.

- 5.3.5 Epilepsy is one of many disabilities (Epilepsy Associations are few of many organisations in the disability field). It is unreasonable to expect every one will be dealt with in detail in every course. With a general approach to disability and use of resources as basic minima the degree of knowledge about epilepsy needed by each student group can be evaluated separately, as can the resources needed to facilitate that teaching.
- 5.3.6 Intensive instruction about epilepsy, its treatment, social impact and the availability of resources should be part of all courses for health care professionals. The emphasis on social impact and available resources should be regarded as integral, rather than peripheral or distracting as is the attitude in some health courses.
- 5.3.7 Section 4.3 looks at training needs of teachers. Those undertaking welfare, social administration or business courses, for example, may simply need to be aware of resources available to them should they need to extend their understanding of epilepsy or to seek support in dealing with the needs of persons who have epilepsy. Printed material currently available through Epilepsy Associations can only partly fill this need. In regard to welfare training, Learner (1979), argues that: "...the relevance of particular disorders as they affect ability to meet needs, must be recognised and understood". (p 52). This position suggests that more detailed instruction on particular disabilities is desirable and goes further than the position just proposed.
- 5.3.8 The argument often raised by course supervisors: that there is insufficient time during courses to devote to these issues must be set in perspective. Given the prevalence of disability and the level of service use by disabled persons, graduates cannot be said to have received adequate training unless these issues are addressed. The extra time involved would not exceed a few hours in some courses.
- 5.3.9 Disabled persons are served by, and have their lives affected through decisions made by, professionals in many disciplines. Pre-service training ought to be alert and responsive to their needs and their views must be accorded due weight. At present they have no official base from which to comment upon the training of professionals.

.....

Establishment of disability advisory groups within the official structure of tertiary institutions to advise on the appropriateness, shortcomings and strengths of pre-service training in areas relevant to them, may be one way of recognising the pertinence of their views.

- 5.3.10 Limited investigation of hospital-based training for nurses and nurses aides was undertaken. Nurse educators in 12 training hospitals were contacted. While this is a very small sample, it appears that these courses fit the general picture described above. In several instances teaching about epilepsy appeared to be inconsistent with current knowledge. This is apparent in other courses.
- 5.3.11 Conversations with nurse educators indicated that there are insufficient post-basic nursing courses in neurology offered in Australia, one at least having been discontinued in recent years. The position deserves evaluation and, if a need is demonstrated, a course or courses should be established.

5.4 IN-SERVICE EDUCATION

- 5.4.1 This is an easier task with which to grapple. In-service education can be directed at identifiable groups of professionals. Attendances at seminars organised by Epilepsy Associations for teachers, health and welfare professionals in Victoria and Tasmania demonstrate that a high demand exists. The experience of participants indicates that although a great deal of energy must be expended in their organisation the programmes are worthwhile. The conduct of programmes in all States would be an important advance though, again, Associations are without the resources to take up this role.
- 5.4.2 Epilepsy Associations have conducted seminars in association with post-secondary institutions and amongst others, the Family Medicine Program. However, although several Departments in post-secondary institutions indicated an interest in the notion, the full potential for conducting joint seminars does not appear to have been explored thoroughly.

ADMISSION INTO PRESERVICE EDUCATION -

- 5.5.1 The questionnaire asked whether there were any conditions attached to the admission into courses of persons who have epilepsy. All respondents said epilepsy was no bar to admission and many did not ask for medical information from intending students. But 23 of 102 respondents indicated that a medical assessment had to be carried out on intending students who have epilepsy. Its purpose was to determine if a person's epilepsy would be liable to affect his or her eventual employment or professional practice. This is effectively a condition of entry.

- 5.5.2 Informed vocational counselling is essential for disabled persons. Issues such as ability to carry out the functions of professional employment, or the difficulties of gaining employment due to discrimination, must be addressed. But the condition to admission noted above is unacceptable if it is linked to perceived resistance to the employment of disabled persons - a resistance such conditions reinforce.
- 5.5.3 If performance of functions related to professional practice is likely to be affected by a person's disability, this ought not to disqualify him or her from admission in every instance. The proposition first assumes that an individual will practise after completion of the course. It also emphasises disability, notability, and ignores the broad work options within most disciplines.
- 5.5.4 If such conditions are to apply, they should operate under uniform criteria so that people approaching different institutions to undertake similar courses are treated equally. Medical and vocational assessment of persons who have epilepsy must be well-informed. There is evidence that such assessments are not infrequently based on an inadequate understanding of the situation.

I wanted to do nursing...Two hospitals told me because I was epileptic I could not train with them. I was persistent and (a third hospital) accepted me.
(29 year old female - country Victoria)

5.5 RECOMMENDATIONS

- 5.5.1 Pre-service training for professionals who might come into contact with people who have epilepsy should include instruction on epilepsy or, at least, disability (Section 5.3.2.).
- 5.5.2 All students who might be employed in positions involving service provision or decision making relevant to persons who have epilepsy must learn something of the social perspectives of disability. Issues specific to hidden disability should form part of that learning as should the usefulness and appropriateness of consulting with or referring to organisations like Epilepsy Associations (Section 5.3.4).
- 5.5.3 Intensive instruction about epilepsy, its treatment, social impact and the availability of resources should be part of all courses for health care professionals (Section 5.3.6).
- 5.5.4 Professionals in many disciplines serve and affect the lives of disabled persons. Therefore, professional's pre-service training should be alert and responsible to the needs of disabled people (Section 5.3.9).

- 5.5.5 NEAA should be supported by the Government to co-ordinate specialist resource development for pre-service training (Section 5.3.10).
- 5.5.6 In-service education programmes should be implemented for health and welfare and related professional groups (Section 5.4.1).
- 5.5.7 Epilepsy Associations and other organisations with an interest in dealing with epilepsy as well as institutions which may have contact with people with epilepsy should investigate the possibility of conducting joint seminars and other relevant programmes for in-service education purposes (Section 5.4.2).
- 5.5.8 Medical assessments prior to entry to post secondary professional education courses could eliminate some persons who have epilepsy, thus denying them access to employment or practice in the field of their choice on the basis of their epilepsy alone.- This places the emphasis on disability rather than ability and ignores the broad work options in most disciplines. Informed vocational counselling should take the place of medical assessment (Sections 5,5.2 - 5.5.4).

CHAPTER SIX

MOBILITY

Looking back, the car was a lifeline for me. Since my licence was suspended I have not been able to get around as much as I used to.

(Female - Canberra)

6.1 INTRODUCTION

6.1.1 Participation in social life, cultural, recreational and voluntary activities and the use of services, is significantly affected by mobility. Aspects of family life - shopping, transporting children, visiting family members - can be upset without access to appropriate transport.

6.1.2 People who have epilepsy are not granted driver's licences if they fail to meet certain medical standards.

With two littlies it's very hard without a licence. Shopping, school functions, just getting there sometimes. I miss out on school things and I feel a bit guilty. But it's a case of no car, no time.

(27 year old female - Melbourne)

Not having a car and getting to doctors, chemists and work causes a lot of problems.

(48 year old male - Melbourne)

The major problem for me which I think is unfair is being cut off without transport...I use the telephone to keep in touch but it is a poor substitute.

(60 year old female - Adelaide)

6.1.3 Public transport is often inaccessible in metropolitan and larger provincial centres. When it is accessible, travelling time can be considerable where radial transport systems serve sprawling cities. On weekends, some services do not run or cease operation early. Using public transport at night has its worries.

I have to leave parties about 10.00 if I have to catch a train. I don't usually go because it's too risky on trains at night.

(24 year old female - Melbourne)

I had to turn down a good job because it was twenty miles away across town from home.

(Male - Melbourne)

I get annoyed, by things like trains taking me two hours to travel to cricket games when it would not take 45 minutes by car.

(26 year old male - Melbourne)

- 6.1.4 Many people with epilepsy must use taxi services. Some use than if public transport is inconvenient, some because they have not learned to use, or worry about using, public transport. Taxi fares are perceived as expensive and several people said they had to use taxis sparingly, with the result that participation in outside activities decreased.

Taxis are too expensive. They should be subsidised. I have cut out some outings...My husband goes through the roof at the expense.

(Female - Adelaide)

She cannot use public transport and taxis are the only way she can get from place to place. Fares are expensive as I myself am only on a pension.

(Parent country Queensland)

- 6.1.5 Many contacts depended on others for transport. This dependency can cause unease.

I am sorry for my parents. They drive me everywhere.

(23 year old male - country Victoria)

My friends help me. I tell them I am epileptic-It is awful to always be asking for lifts and the like.

(37 year old female - country SA)

- 6.1.6 Negative experiences deter some people with epilepsy from using public transport. There is a clear need for public transport personnel to be educated as to how to deal with a person who is having a seizure.

I do not use public transport these days in case of a fit. I had a fit once and when I came to the driver Was slapping my face. People were pushing for a look.

(45 year old female - Sydney)

- 6.1.7 Country people have particular problems.

I'm isolated from the community because I live on a farm. my licence has been taken from me and I have to depend on my husband.

(Female - country Victoria)

Around here not having a car is like being in Brisbane without legs. You can't go anywhere unless someone drives you.

(Male - country Queensland)

He is at home (on the farm) nearly all the time. He can't go into (town); not that it's much but it would be a break. He goes everywhere with me or my husband.. .(and) we do find it restricting.

(Parent - country Victoria)

- 6.1.8** Isolation, decreased participation in outside activities or service use, hamper the social integration or re-integration of persons who have epilepsy. Their partial or total exclusion must be overcome. "Mobility should not act as a bridge for some sections of the community and a wall for others." Gilmore (1978), p10.

6:2 DRIVING LICENCES

- 6.2.1 Caution must be exercised in granting licences to persons who have epilepsy but the dangers should not be exaggerated. Parsonage and others (1982), quote a study (p77) by Van der Lugt (1975), which found ..Accidents attributable to epilepsy were approximately 1 in 100,000. Bladin and others (1982), quote (p1) Herner (1965), and a Tasmanian study by Mallingen (1975), which both found 0.3% of all accidents. They also quote a study by Hafstram (1963), which found none of 300 consecutive fatal accidents attributable to epilepsy. Each study is, of course, biased by the inclusion of drivers who may not have declared their epilepsy, a not uncommon practice.
- 6.2.2 In the light of these findings it would be overcautious to propose that all people who have epilepsy should not drive. Such a regulation would compound existing problems of isolation and restricted participation. It would be a dangerous proposition because increased incidences of concealment from licencing authorities would pose an increased risk to public safety.
- 6.2.3 Concealment is usually a response to fears of reduced mobility particularly if it is likely to affect employment. The House of Representatives Standing Committee on Road Safety (1982), recommended that medical practitioners should be compulsorily required to notify licencing authorities of persons who have conditions such as epilepsy. Bladin and others (1982) have reservations because it would compromise confidentiality and the doctor-patient relationship. While it may seem an appropriate response on grounds of public safety, against it must be measured the right of privacy. There is also the possibility that people would conceal their epilepsy from medical practitioners, thereby increasing any risk to public safety.

If I said I had epilepsy I wouldn't have my licence... If I didn't drive I couldn't run my family.

(Female - country Victoria)

How would I get to work or bawls without a car? I wouldn't have work without it so why should I give it in?

(53 year old male - Hobart)

- 6.2.4 Seizures are controllable for most persons who have epilepsy (see Section 2.7). Some seizures occur only during sleep or upon waking. Isolated seizures may occur in response to unusual circumstances.
- 6.2.5 Assessments can be made with considerable accuracy given the array of prognostic aids and indicators. But as Parsonage and others (1982), make plain: "Physicians concerned in assessing fitness to drive need to be well-informed and experienced in virtually all clinical and social aspects of epilepsy" (p78).
- 6.2.6 Regulations covering epilepsy usually give broad discretion to medical practitioners in advising on fitness to drive. An Uninformed and inexperienced practitioner may not exercise wise or fair discretion and although involvement of neurologists in clinical assessment is critical, their expertise and awareness cannot always include familiarity with social aspects of epilepsy (See Section 7.2). As it stands the assessment process includes no recognition of social indicators, such as the likelihood that an individual might comply strictly with a medical regime.
- 6.2.7 Regulations governing the issue of licences vary. Generally a two-year seizure-free period must be proven, though this can be waived under certain circumstances - in ACT, by the Commonwealth Medical Officer. All licensing authorities require medical examinations to be undergone. In the ACT, examinations are required annually; but there are notable variations in other jurisdictions. This lack of uniformity, as is noted by the Standing Committee on Road Safety (1982), disadvantages some citizens
- 6.2.8 At one time medical examinations for licensing purposes were not covered by medical benefits, and this was the cause of some criticism. However, this no longer is the case. The Minister for Health has announced that under Medicare medical examinations for licensing purposes will be covered, on the grounds that compulsory tests are directed towards the welfare of the whole community and that there is no direct financial benefit to those undergoing them (Fry, 1983).

- 6.2.9 Appeals can be made against withdrawal or non-issue of licences. In the ACT, as in most places, courts offer the final avenue of appeal. Appeal mechanisms are an important safeguard. But it is inappropriate that legal representation and argument should settle such matters. Fitness to drive should be assessed by a neurologist and a person familiar with social aspects of epilepsy, in consultation with the licensing authority. An Advisory Board, similar to that suggested by Bladin and others (1982), offers greater certainty as regards public safety and fairness to individuals concerned. However, - decisions by such a Board would need to be subject to some form of review in order to avoid the possibility of injustice resulting from any arbitrary decisions.
- 6.2.10 Public safety is as serious a matter as the effect of restricted mobility. A balance between public safety and isolation and exclusion of person with epilepsy must be sought. A mobility allowance offers the possibility of minimising mobility restrictions for those failing to meet medical standards and for others who have epilepsy.

6.3 THE COMMONWEALTH MOBILITY ALLOWANCE

- 6.3.1 The Mobility Allowance administered by the Department of Social Security is payable to a substantially disabled person aged 16 or above who is permanently, or in the long term, unable to use public transport by reason of her or his disabilities. The person must be employed or undertaking vocational training for at least 20 hours per week. It is currently paid at \$20.00 per fortnight.
- 6.3.2 These criteria exclude many individuals with mobility problems. A person who has one seizure per year is not substantially disabled by epilepsy but still cannot drive. Those not in the workforce or those under 16 cannot qualify, yet public transport is often unsuitable to their needs. In rural areas it may not exist. Some form of mobility allowance should be available to people who have epilepsy and are assessed as unfit to drive, or to any person who voluntarily chooses not to drive because he or she has epilepsy.
- 6.3.3 Clearly eligibility criteria for the allowance should be reviewed. It would be more appropriate in any case to focus eligibility criteria on the degree to which mobility is restricted due to disability, rather than on the degree of disability as is the current situation. It is possible that public safety would be enhanced as concealment would be less frequent under conditions where mobility is less likely to be reduced. Country people are further disadvantaged compared with those with access to public transport.

6.3.4 Some State Governments have introduced mobility allowances. Eligibility criteria, the purposes for which the allowance may be used, and rates of payment, vary therefore eligibility for the allowances is not comparable between States.

6.4 RECOMMENDATIONS

6.4.1 Public transport personnel need to be educated on how to deal with a person who is having a seizure .(Section 6.1.6).

6.4.2 The particular transport problems experienced by country people with epilepsy need to be addressed (Section 6.1.7).

6.4.3 Uniform regulations governing the issue of licences to people with epilepsy should be introduced (Section 6.2.7).

6.4.4 A Licensing Advisory Board should be set up. Members should include those with a broad social perspective as well as neurologists and medical practitioners who should be familiar with all aspects of epilepsy. Decisions made by the Board should be subject to review (Section 6.2.9).

6.4.5 Eligibility criteria for the Mobility Allowance should be reviewed (Section 6.3.3).

CHAPTER SEVEN

PROVISION CR SERVICES

Epileptics don't get much in the way of services.. .they don't fit the groups services are for or the people who run- them don't understand epilepsy. These situations need some looking into.

(Female - country Victoria)

7.1 INTRODUCTION

7.1.1 People who have epilepsy have the right to services that "will enable them-to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration". (Paragraph 6 of the Declaration). Those services must be developed in response to a number of factors.

7.1-.2 Access is a primary consideration. Population distribution. and distance present a number of problems to planners and service providers.

Country folk are very used to hearing promises that all the marvellous services we need will soon be given to us. Where are they? Mostly we have to go to bigger cities.

(Female - country Victoria)

7.1.3 Services must reflect an understanding of consumer needs. Consultation with consumers and their involvement in service planning and evaluation is central to the development of relevant, responsive services. The involvement of consumers in service delivery itself should be facilitated wherever possible. Their personal experiences with the problems at issue constitute a valuable resource.

7.1.4 Control over decisions affecting services and service delivery must rest as far as possible with consumers. The achievement of self-reliance and self-determination is less likely where control over services intended to implement those goals is assigned, wholly or substantially, to others. Bryson (1979) makes the observation that "we cannot take [the] seeking of clients' views at face value to mean a genuine concern to know and act on them...it remains to be seen whether clients' views will be treated seriously or merely collected because it has become methodologically and politically fashionable to do so" (p 2). The participation of consumers in decision-making and in planning and evaluation will help to ensure that their views are treated seriously.

It seems to me we are not as important as the doctors and social workers. We've got a right to say what we want - we need the service and they should give it to us.'

(Female - Canberra)

7.1.5 In this chapter and throughout the Report terms like "consumer", "user", "service provider" and "service delivery" are used. On the surface at least, these terms place the people so specified into business or economic relationships. Such terminology should not obscure what is in fact the essential point of these relationships - that individuals with needs are seeking support and assistance from others with the skills to help. "Services should be supports provided by a society through community structures of various sorts to ensure that all citizens can comfortably manage their own lives in accordance with the prevailing standards and expectations of the culture within which they live out their lives". (Stevenson and Chew, 1979, p 85). Behind the right to services of various kinds is the right, in the words of the Declaration (**Paragraph 7**), to "a decent level of living".

7.2 MEDICAL PRACTITIONER SERVICES

7.2.1 People who have epilepsy routinely use services provided by general practitioners and neurologists. These services were mentioned, more frequently by contacts than any others. Significantly, 'the majority of contacts thought that services provided by medical practitioners were unsatisfactory. Beran (1983) in his Sydney study also found dissatisfaction with such services, though it was not as pronounced as that encountered during this Project. Beran states that "there are a considerable number of patients for whom the medical profession fails to offer an adequate service and [this] reinforces the need to evaluate management in epilepsy" (p 147).

7.2.2 Of those who participated in the Phone-in, 67% commented on medical practitioners. Of that group, 69% was dissatisfied.. This level of dissatisfaction was sustained throughout the Project as a whole. There appear to be five main causes of dissatisfaction:

- a) a lack of communication about medication and Side-effects;
- b) a lack of understanding of the social impact of epilepsy and the sometimes adverse impact of its treatment;
- c) a lack of communication to patients and families about epilepsy itself;
- d) the failure of medical practitioners to refer their patients to helping agencies;
- e) the inadequate understanding of epilepsy by some medical practitioners.

7.2.3 Before each item is considered separately, two general observations should be made. First, dissatisfaction applies to both neurologists and general practitioners', though less to neurologists. Secondly, while negative comments predominated, many made positive comments about service they received. It is inevitable that individual doctor-patient relationships will colour the broad statistical picture. Many people unhappy with such relationships feel unable to sever them for a variety of reasons. Others are more pragmatic.

I've never had any trouble with my doctor. In fact his support and interest has all along been terrific.

(55 year old female - Melbourne)

I have wanted to change the GP for a couple of years but better the devil you know than one you don't.

(Parent - country SA)

Out of six doctors in three years the one I go to now is the best. She was hard to find.

(21 year old female - country Tasmania)

7.2.4 The first specific cause of dissatisfaction was lack of communication about medication and its side-effects. With few exceptions, medication is a continuing necessity for people who have epilepsy. It is not surprising that they and their families should want information about the purposes and possible effects of drug therapy. Medication used in the treatment of epilepsy can have side-effects giving rise to disruptive behaviour, reducing learning capacities and impairing levels of physical performance. Clearly, every aspect of the life of a person with epilepsy can be affected by the medication which it requires.

I haven't had any support from medical people. Drug side-effects have had a serious effect on my life but I've been given no information about drugs.

(41 year old female - Melbourne)

My son (9 years old) says his problem is taking "a million tablets"... He could be right. I've been given no information about drugs or side-effects.

(Parent - Melbourne)

- 7.2.5 The second cause of dissatisfaction noted above was the failure to comprehend the social impact of epilepsy and its treatment. Many contacts felt that doctors ignored their views and concern about medication, and also that doctors failed to respond to the sometimes debilitating effects of attitudes to epilepsy. Practitioners lack of understanding has undermined their patients' self-confidence and respect for them. Disturbing, and occasionally absurd, situations have arisen as a result.

My outlook was completely changed by becoming epileptic. I turned in on myself a great deal... The doctor was the only one who knew. I did not know how to talk about it to anyone else but he would not listen. I was a nuisance holding up his next patient.

(43 year old male - country Queensland).

I have given doctors away... I have a seizure every now and then and knock myself around but that's better than being ignored [by doctors].

(Male - Sydney)

I go to two GPs. I listen to the new one and I go to the old one and screw up his prescription when I get home.

(Female - Melbourne)

- 7.2.6 The third cause of dissatisfaction was the failure on the part of medical practitioners to give adequate, if any, information about epilepsy to patients or their families. Feelings of frustration and resentment were common.

Thank you for the leaflet [about epilepsy] you sent me. I have been asking doctors for fifteen years to explain epilepsy to me. Five minutes [with the leaflet] has filled in for all those years of absolutely nothing.

(36 year old male - Queensland)

- 7.2.7 A fourth factor contributing to dissatisfaction was medical practitioners' failure to direct patients and their families to services relevant to their needs. The period immediately following diagnosis is a critical time for conveying information and providing support.

Doctors need to give parents some resources. I should have been told about the Epilepsy Foundation in the beginning.

(Parent, - Melbourne)

- 7.2.8 Some doctors attempt to contain discussion about epilepsy in their surgeries or within their patients' families on the assumption that this will benefit their patients. Others appear to believe that support services are necessary only if seizure control cannot be established: This belief is based on the assumption that the social problems epilepsy often entails are related to the degree of seizure control.

I was advised not to tell anyone about being epileptic by the doctor. He said that once he got the fits under control I could get by as if I was normal.

(Male - country Victoria)

- 7.2.9 The reluctance to refer patients to other services - especially Epilepsy Associations - may sometimes be related to doctors' perceptions of the expertise of volunteers or staff as threatening to themselves, rather than as helpful to their patients. Alternatively, 'reluctance to refer patients to relevant services may stem from a lack of awareness of the roles of different agencies. Medical practitioners may simply be unaware of what services are available.

At my next visit [to the doctor] I told him I had been to the Epilepsy Foundation and before I had time to enthuse about interrupted me to say something along the lines of if I went there my daughter's epilepsy was out of his hands.

(Parent - Melbourne)

- 7.2.10 Finally, dissatisfaction arises when doctors are perceived to be inadequately informed about epilepsy and its treatment.

I had to explain to my new doctor about my type of fits. Sometimes I wonder what would have happened if I had gone to him first.

(Female - country Queensland)

I was packed off to a psychiatrist who was the one who diagnosed me as a temporal lobe epileptic. He packed me off to my doctor.

(19 year old female - Melbourne)

- 7.2.11 There is one further cause of dissatisfaction which should be considered separately from the five outlined above. While many people are dissatisfied with medical practitioners themselves, there is also a group which expresses dissatisfaction with the methods and outcomes of treatment. This group is unhappy about poor seizure control, about taking medication and about living with side-effects or with the possibility of side-effects.

- 7.2.12 One outcome of dissatisfaction is an interest in natural therapies. About 10% of all contacts were seeking, or were interested in seeking, treatment from chiropractors, naturopaths or acupuncturists. All indicated they were interested in doing so because of dissatisfaction with the methods or outcomes of conventional treatment or because of dissatisfaction with practitioners of conventional medicine.
- 7.2.13 A study appended to the 1977 Report of the Committee of Inquiry into Natural Therapies (the Webb Report) found an estimated new patient population for natural therapists in Australia would lie between 250,000 and 315,000 per year (p349). Another study appended to the Webb Report found that 27% of people attending natural therapists did so because other forms of treatment had proved ineffective. A small Western Australian study (James and others, 1983) concluded that "the growing importance of natural therapy represents both patients' dissatisfaction with what they see as inadequacies of orthodox medicine and their satisfaction with alternative treatments" Op 386).
- 7.2.14 There were, however, some who expressed reservations about natural therapy. Some individuals receiving such treatment perceived it as costly. Some who were interested in going to natural therapists were hesitant to do so because they could not procure independent and reliable comparative information about conventional and natural therapies. This lack of information made it difficult to arrive at decisions which could be fully justified to themselves.

Drugs and doctors' fees are subsidised but alternative treatments aren't. Our treatment choices are limited because of that. We go to a doctor but we'd like to take him off drugs and try a naturopath.

(Parent - Melbourne)

People seem to take sides with doctors or chiropractors or whatever. It is extremely difficult to find an unbiased... assessment of their different merits.

(Male - country Victoria)

7.3 ACCESSIBILITY OF MEDICAL SERVICES

- 7 3.1 People in non-metropolitan areas were often concerned about access to specialist care. Access to general practitioners was occasionally difficult; but the main problem was with neurologists, who with few exceptions, practise in large cities although in some instances they hold clinics in country areas - it is worth noting that there is no paediatric neurologist practising in Tasmania.. This is a serious service deficiency. The greatest disincentive to seeking specialist care was time spent away from home and work, particularly for those dependent on public transport.

With three children it is virtually impossible to make time to go to Adelaide or Melbourne to see a neurologist.... Three or four days away for an appointment I can't manage.

(26 year old female - country Victoria)

Before I moved here [from Sydney] I saw the neurologist twice every year but now I haven't been for six years. It is a long trip and a long time from the family.

(46 year old female - Queensland)

- 7.1.2 Cost was also a disincentive to seeking specialist care. Assistance available under the Isolated Patients Travel and Accommodation Scheme (IPTAS) was felt to be inadequate and some people appeared to be unaware of IPTAS.

Money would make a lot of difference. It would give me the chance to take my daughter to Brisbane for a few good doctors.

(Parent - Queensland)

- 7:3.3 IPTAS serves the convenience of service providers, not service users. Some consultations must occur near medical technology which is usually located in larger cities, but this is not always essential. In addition, IPTAS only provides assistance for people to go to the nearest available specialist. Some people who have epilepsy require specialist services which are not necessarily available through the nearest specialist. If eligibility criteria were amended to provide for attendance at the nearest appropriate specialist service a number of people would be better served.
- 7.3.4 The importance of access to specialist care is underlined by the fact that persons who have epilepsy have different perceptions about who is the more important therapist - the general practitioner or the neurologist. Beran (1983) found that in terms of importance "those with seizures beginning between the ages of 10 and 20 [the commonest age of onset of epilepsy] opted for the neurologist... [there was] no identifiable 'differentiation for those with major seizures although, when minor seizures were difficult to control, there seemed a preference for the neurologist as prime therapist" (p147).

7.4 SPECIAL CENTRES FOR EPILEPSY

7.4.1 There are some for whom epilepsy is associated with significant social problems that make necessary access to various kinds of expertise. Others must undergo diagnostic and treatment procedures dependent upon lengthy periods of observation and sophisticated medical technology. General practitioners, neurologists, Epilepsy Associations, and community-based agencies can meet competently the needs of the great majority of persons who have epilepsy. However, there are a number who need highly specialised services.

7.4.2 In North America and Europe special centres for epilepsy have been developed. By concentrating in one location skilled professional staff from a range of disciplines, these centres provide the best service option to those who have significant social problems relating to epilepsy, or who have a form of epilepsy which is difficult to diagnose and treat effectively. The primary functions of these centres are personal and family assistance and diagnosis and treatment. In addition, some research is undertaken.

7.4.3 Such centres have been recognised overseas as essential in the overall provision of services for people who have epilepsy. However, Australia has no centre of this kind, the need for establishing special centres here should be investigated. There are several matters which should be addressed in the course of such an investigation: the role of research in such centres; the need to ensure accessibility for all Australians requiring such services; the degree to which management control should rest with persons who have epilepsy; and the option of siting special centres within existing hospital structures or establishing them as independent entities.

7.5 REHABILITATION CENTRES

7.5.1 A range of rehabilitation services is provided in both government and non-government facilities. These facilities focus on medical and social rehabilitation. The Department of Employment and Industrial Relations, for example, funds work preparation programmes. (These are discussed in Section 7.6). The Department of Social Security is, however, the main government provider acting through the Commonwealth Rehabilitation Service (CRS). The relationship between sheltered workshops and rehabilitation is discussed in section 8.4.

7.5.2 Most people who have epilepsy will not need to use rehabilitation services. Those who do may have disabilities in addition to epilepsy. They may have missed opportunities to develop social or vocational skills or they may have developed epilepsy at 'a time in their lives Which made it appropriate to undertake a reappraisal of their social and vocational circumstances..

7,5.3 Securing. employment is the usual point of participation in rehabilitation programmes. With high unemployment, particularly amongst disabled persons, that intention is commonly frustrated.

It was six months of trying very hard. He was full of confidence when he finished at the Centre but he hasn't found work and now he just mopes. around.

(Parent - Sydney)

7.5.4 Learning independent living skills is - another motive behind undertaking rehabilitation programmes. This hope, too, can be foiled (see also Section 9.1), since an often critical factor in achieving independence is having employment. What happens after participation in a rehabilitation programme is therefore often as important as what happens during that programme. Many programmes lack the necessary touch of reality because participants often cannot attain the employment and independence for which the programmes train them.

7.5.5 The demand for places outstrips the number of places available in rehabilitation programmes. Consequently, waiting lists and eligibility criteria are premised as much on the need to exclude as the need, to include. CRS Work Preparation Centres (WPC) are open to intellectually disadvantaged persons. Some people who have epilepsy, and who are not intellectually disadvantaged, could benefit from WPC programmes. Service expansion, particularly in country areas, appears to be unavoidable if services are to be comprehensive.

One client we had from the country just could not cope with Melbourne. She had to go back home.

(Rehabilitation worker - Victoria)

[The rehabilitation unit is] in Sydney which is over 200 miles from here. We are always left out of places like that.

(Parent - country New South Wales) -

7.5.6 While it is necessary to consider expanding services it is also necessary to tackle the problems often experienced when those programmes are completed - the difficulty of achieving employment and independence cannot continue to be regarded as unavoidable.

- 7,5.7 Due to a lack of staff and the transfer of information to a new computer system the CRS was unable to provide specific information on epilepsy and on several other issues in time for inclusion in this report. Accordingly, the position of people who have epilepsy in relation to CRS programmes is not clear. However, CRS statistics do bring attention, however, to one matter the imbalance between males and females in rehabilitation programmes. As of 5th August, 1983, only 28% of the people participating in CRS programmes were women. This is despite a 1977 amendment to CRS criteria which enabled women at ^hare to participate in non-vocational programmes. Women constituted only 25% of CRS referrals in the quarter to 30th June, 1983.
- 7.5.8 Funding under the Handicapped Persons Assistance Act (HPAA) has emphasised the provision and maintenance of buildings within which to run rehabilitation, training and activity therapy programmes. The HPAA has thus worked against options like those provided by the CRS, such as work stations, and job placement and work therapy programmes.
- 7.5.9 The need for information, both general and specialist in kind, is apparent amongst rehabilitation professionals. The nature of their information needs and how best to meet those needs requires investigation.
- 7.6 DEIR WORK PREPARATION PROGRAMMES
- 7.6.1 The Department of Employment and Industrial Relations (DEIR) currently funds thirteen work preparation programmes. While, at present, only one is in a country area, further programmes will be located in the Country. The programmes were first funded in 1981 on a three-year pilot basis. They emphasise work preparation rather than rehabilitation and draw from persons already in the labour market who need further training to increase their competitiveness. Independent living skills receive attention in recognition of the relationship between such skills, independence and income.
- 7.6.2 DEIR figures show an employment placement rate of 74% across all programmes. This is impressive given general unemployment levels for disabled persons (see Table 8.4). An important factor in this success is the involvement of local employers, who are represented on the managing body of each programme. Because of their involvement, they are very likely to accept participants on work trials and job placement,

Work preparation programmes have an employment and business orientation, not a rehabilitation and welfare one. They are funded in a job creation context. The Epilepsy Association of South Australia has been funded for a programme called Training and Placement Services (TAPS). TAPS is in the early stages of development, but it promises to make an important contribution to the employment prospects of persons who have epilepsy. Through the opportunity it provides to put before the community - and employers in particular - the true employment potential of people who have epilepsy, the South Australian programme benefits not only direct participants but also others in the Community.

7.6.4 The approach to employment generation which the DEIR programmes take is innovative and obviously successful. These programmes have particular value for persons who have epilepsy because they provide the opportunity for local employers to have direct contact with workers who have epilepsy. The experience of TAPS will hold important lessons for those concerned with epilepsy and employment in other States.

7.7 RECREATION

7.7.1 Persons who have epilepsy have varied recreation experiences. Concealment, discrimination, the presence of the chance factor - all come into play again in the case of recreation. Of phone-in callers, 27% mentioned recreation. Of these, 54% said they had encountered difficulties because of misinformed attitudes.

7.7.2 Choice is viewed as crucially important in the pursuit of recreation and leisure. In order to maintain their access to choice people may conceal their epilepsy since such concealment may enable them to make choices unimpeded by attitudes based on misinformation.

I play bowls. I'm supposed to tell them if there's something wrong but I'm not prepared to tell them because they would react badly They'd leave me out of the pennant games.

(68 year old female - Melbourne)

7.7.3 The chance factor is at play in recreation. Some people with epilepsy choose concealment because participation in sport was denied them in the past when the fact of their epilepsy was disclosed. There can of course be a bitter-sweet reaction if an individual has the reserves to go on from a setback.

I was told not to bother going back to one football club after I mentioned I had epilepsy. I went to another club and we beat my old club in the Grand Final.

(31 year old male - Melbourne)

As a kid I told the footy coach I had epilepsy and I never got a game. Since then. I've never told anyone I play a lot of sport now.

(31 year old male - Melbourne)

- 7.7.4. Some people with epilepsy learn through rejection not to participate at all Others assume that because they have epilepsy, or epilepsy and other disabilities, recreation is closed to them.

I went to basketball when I was growing up but they told my parents that I couldn't play and I haven't since. I would like to play tennis now the children are older but I always think back to that experience.

(41 year old female - New South Wales)

I'm, also slightly paralysed down one side so I can't play any sport.

(Female - Melbourne)

- 7.7.5 A further difficulty is that many parents prevent their children from engaging in recreational activities. In responding to their children's epilepsy, they set boundaries beyond need; they become over-protective. . A lack of experience, an instilled over-cautiousness and sometimes fear, leave many without the confidence or . skills to participate in recreational activities.

- 7.7.6 Recreation is an important avenue for advancing integration since much social interaction is mediated through recreational activities. The right to respect for human dignity, the right to live a life as normal and full as possible, involves the right to take risks. The risk for most disabled people in recreation is not variable and can be assessed by them with certainty but as seizures are intermittent and involve loss or impairment of consciousness people who have epilepsy are often unable to assess risk with certainty. They may need assistance in order to do so.

I enrolled to do an evening course in carpentry. I realise that carpentry could be dangerous in the remote possibility that I might have a seizure. I was excluded on that possibility. I expected to be guided as to what was dangerous and what was safe .

(36 year old male 7 country Queensland)

- 7.7.7 Integration is not facilitated through the provision of sheltered recreation. Therapeutic recreation can justify some measure of segregation, but this possibility aside, sheltered recreation does not promote the right to participation. Hamilton-Smith (1973) in a Report to the then Minister for Tourism and Recreation, wrote that "it is highly desirable that disadvantaged people should be able to use the same recreational services as other people, rather than being the target of special or segregated services."

7.7.8 There is no printed information on recreation and epilepsy which is generally available in Australia. There is accordingly a great need for information which places an appropriate perspective on epilepsy and which would be suitable for recreation professionals, sporting clubs and organisations, and persons who have epilepsy and their families. An accessible information bank containing written and audio-visual materials outlining recreational programmes, ideas and events in which disabled persons are participating would be a useful resource for many sporting and community groups. Properly promoted, these resources could assist many groups to find ways of opening their activities to disabled people.

7.8 COUNSELLING SERVICES

7.8.1 Epilepsy Associations cannot afford to provide specialist counselling services when other counselling services are unable to meet an individual's needs. While in the present context it is not possible to present a full account of the counselling needs of those who have epilepsy and their families, the following comments may serve to give some indication of the issues which they may bring to a counsellor.

I feel a general fear from the community because people don't understand. I feel isolated.

My life is ruled by my son's needs. I get depressed because he is so dependent on me.

still don't really believe my child has epilepsy. My child is going to be normal.

My husband has pulled away from me since we found out about our son's epilepsy. It has affected our marriage.

I am seventy-three and I worry so much as to what will happen to my daughter (who lives with me) when I die.

Sometimes I feel as though I am carrying around an awful secret but I can't tell anyone about my epilepsy. I have a fear of having a fit and other people being horrified by it.

I can't go out much because of my fits.

Counselling on coping with other people's attitudes and having to be able to cope with knockbacks would help.

His teachers keep him out of physical education just because he is epileptic. I don't know how to get through to them that they are over-reacting.

I'm thinking of giving up on doctors. They run tests and give you pills. That's all.

Most of all I want to know about the drugs I have to take and what they will do to me.

We think the medication is slowing him up at school although we have been told that epilepsy by itself can affect learning. Right now my biggest problem is finding out what epilepsy is and what that means: to me... It's a huge shock to have something like this landed on you.

- 7.8.2 Some of these issues require a general rather than a detailed knowledge of epilepsy and its treatment. Specialist expertise should be available to non-specialist community-based counsellors through Epilepsy Association counsellors acting as consultants. Where detailed knowledge is required referral to Epilepsy Associations may be necessary.
- 7.8.3 For country people direct referral is not usually feasible. Close liaison between local counsellors and Epilepsy Association counsellors is correspondingly important. Regionalised counselling services, like those being developed by the Epilepsy Foundation of Victoria, will answer many people's needs more adequately.
- 7.8.4 Counsellors, and social workers generally, must have access to relevant information about the services of Epilepsy Associations, other relevant bodies and all other available resources. Pre-service and in-service education will promote this awareness.
- 7.8.5 Interpreters are essential participants in some counselling situations, yet no materials are available which provide basic information on epilepsy, such as a glossary of terms likely to be used in such situations. Some provision should be made in with regard to this need.

7.9 THE EPILEPSY MOVEMENT IN AUSTRALIA

- 7.9.1 This section begins with a discussion of the informal networks upon which persons who have epilepsy and their families rely. The more formal structures of the epilepsy movement are also considered. Most contacts turned to their family and friends when social difficulties relating to epilepsy arose. Fran within this informal network they were usually able to muster the assistance they required.

My family understands and gives a lot of support. The kids are great.

(35 year old female - Melbourne)

If it wasn't for my parents I'd be a hopeless case - they have got me over the really bad times... I didn't think I would ever hold a job until a friend of Dad's gave me one. I guess he knew me long enough to know that because I suffered from epilepsy that didn't make me an idiot.

(19 year old female - country Victoria)

My friends and family make life easier. They drive me round, lock after the kids if I've had a seizure. I'm very fortunate.

(22 year old female - country Queensland)

- 7.9.2 An Institute of Family Studies (IFS) Report (1983, p24), noted that, in times of illness, 67% of a study sample sought moral and practical support, including advice, within the family. Friends provided this assistance to 39%. This heavy reliance on friends and family underscores the isolation of those who have no informal networks on which to depend.

I think if I could get a job I could make some friends and things would brighten up a lot... I would love to have someone to talk things over with. Epilepsy can really get you down... I know that these are little problems but they get a size when you have to deal with them alone.

(21 year old female - country Tasmania)

- 7.9.3 In the IFS study, welfare services were used by 9% of the sample and services like home help were used by 6%. Of the phone-in callers in the present study, 16% indicated they had used such services and 25% indicated they had used services of the Epilepsy Foundation of Victoria (EFV). Compared to the IFS figure of 9%, the percentage of callers using EFV services was high. This may reflect the level of support needed where chronic disability is involved - a level which may be beyond the capacity of families and friends to meet as adequately as usual.

- 7.9.4 49% of phone-in callers gave no indication that they had heard of the EFV. Over half of these, in response to a question about what services would have helped them, mentioned the need for information on a range of issues related to epilepsy, counselling, discussions with others who had epilepsy and services like respite care and home help. The EFV does meet many of these demands either directly or by referral.

- 7.9.5 Of all the callers who had used the services of the EFV, nearly half indicated they had heard of it through family or friends. The role of informal networks in facilitating help-seeking is clearly crucial.
- 7.9.6 Of all phone-in callers 22% mentioned the need for groups where they could meet others to discuss common problems and issues. Some expressed the wish to be involved in community education through a -group. Other contacts expressed similar interests.

What would help me is to talk to other people with epilepsy who can understand what my problems are. I could find out how they coped.

(Female - country Victoria)

My plan is simple. I want to get a few people together and try to educate the community about epilepsy.

(48 year old female - country New South Wales)

- 7.9.7 The self-help movement has gained great momentum in recent years. In Victoria alone, there are 300 self-help groups affiliated with the Collective of Self Help Groups. There are a number of epilepsy self-help groups - particularly in country areas - and most have formed loose affiliations with, or become branches of Epilepsy Associations. All Associations have encouraged, and often initiated, such groups.
- 7.9.8 The self-help emphasis of these groups enables significant progress to be made. towards the resolution of difficulties experienced by members, assists the social integration of some and decreases the sense, and reality, of isolation for others.
- 7.9.9 Overwhelmingly, those contacts who commented on the services and programmes of Epilepsy Associations praised them. Comments appearing throughout this Report are testimony to the generally favourable light in which they are seen. The small number of negative comments fell into two broad groups. The first group criticised Associations for not providing services of the kind outlined in the previous paragraph. It is true that many Associations do not provide these services, but the criticisms miss the point that they would be provided if the resources were available.

- 7.9.10 A second group believed that the attitudes and responses of Associations were unsatisfactory. Some complained that Associations were unreceptive to offers of voluntary assistance in service delivery and day to day tasks. Others felt that Associations were out of touch with the needs of those who have epilepsy because control of the organisations rested with people who did not have epilepsy. Three criticisms were, however, made more often than others. The first was that Associations were not critical enough of the inadequacies of medical services. The second was that they were not active enough in promoting the rights of persons who have epilepsy in employment. The third, made by at least seven contacts, was that they were reluctant to divulge information about medication and its side-effects. Associations must consider these criticisms, and, where they are found to be valid, appropriate steps must be taken.
- 7.9.11 The Epilepsy Associations are all at different stages of development and their capacity to fulfil the roles outlined in Section 7.9.9 is limited in most cases. To illustrate the differences, the EFV has an annual budget of about \$700,000 and more than 20 staff. The Epilepsy Association of Queensland runs on a few thousand dollars annually with no staff. Uneven access creates disadvantaged and advantaged groups with similar service needs.
- 7.9.12 All Epilepsy Associations have emphasised community and professional education, no doubt in response to the need for education which is constantly expressed by people who have epilepsy. Beyond this similarity, Associations have responded to service needs in different ways and with different priorities. For example, the West Australian Epilepsy Association offers free short stay accommodation at its Perth headquarters for country members attending medical consultations, while the Epileptic Welfare Association of New South Wales provides short courses to assist people in preparing their presentations to employers. Association's activities are dictated by financial resources which given the magnitude of the tasks before them, are for most and probably all in varying degrees, inadequate.

7.9.13 With the establishment of the NEAA in 1983, the epilepsy movement has an independent national focus. At the time of writing, all but one of the seven State and Territory Associations are affiliated with the NEM. It is currently operating without paid staff and without sufficient financial resources to undertake the tasks before it. Yet there is a demonstrable need for a national research, policy, consultative and advocacy focus; for research and production of information and educational resources, and for a central body to facilitate information flow between self-help, State, national, international and other sources.

7.9.14 The Epilepsy Associations can take significant steps towards ensuring recognition of the rights and needs of persons who have epilepsy. The development of a comprehensive plan to meet the needs of persons who have epilepsy is sorely needed in Australia. Epilepsy Associations must form a crucial part of any such comprehensive strategy.

The help they gave us was magnificent when I think of the resources they are working with.. We could not have expected any more though God knows we needed it at the time It is pitiful to see how strapped for money the Epilepsy Association is. It has so much to do - there are so many people with this condition.

(59 year old female - Brisbane)

7.9.15 Throughout this Report, the need for services provided by Epilepsy Associations is stressed. They important roles in information provision to those directly involved with epilepsy and to the community generally; in articulating and advocating the rights and service needs of persons who have epilepsy; in direct provision of counselling and general social work where specialist expertise is necessary; in providing a range of consultancy services to bodies like community-based health services and post-Secondary education institutions ; and in providing services which meet the needs of persons who have epilepsy when other agencies cannot.

7.10 RECOMMENDATIONS

7.10.1 Consumers should be involved in service planning, evaluation and delivery and should, as far as possible, control decision making in these areas (Section 7.1.1 and 7.1.4).

7.10.2 There is a need for independent and reliable comparative information on the treatment, procedures and effectiveness of natural and conventional therapies for epilepsy (Section 7.2.14).

- 7.10.3 Specialist care, including neurology clinics held at regular intervals, should be made available in country areas (Section 7.3.1).
- 7.1.4 Eligibility criteria for IPTAAS should be amended so that people who have epilepsy can attend the nearest appropriate specialist service (Section 7.3.3).
- 7.10.5 The need for special centres for epilepsy should be investigated (Section 7.4.3).
- 7.10.6 Rehabilitation programmes need to address the problems of unemployment which will probably face persons who have epilepsy despite their completing such programmes successfully (Section 7.5.4).
- 7.10.7 Eligibility for rehabilitation programs and the location of these programmes need to be investigated with a strong emphasis on expansion, particularly in country areas, so as to provide a comprehensive service (Section 7.5.5).
- 7.10.8 Reasons for the lack of women in CRS programmes must be investigated and initiatives taken to redress the imbalance between women and men taking advantage of such programmes (Section 7.5.7).
- 7.10.9 The HPAA should be amended to encourage a wider range of work training opportunities (Section 7.5.8).
- 7.10.10 The information needs of rehabilitation professionals and the best way of meeting those needs should be investigated (Section 7.5.9).
- 7.10.11 Consideration should be given to establishing in other States epilepsy specific employment preparation programmes such as the South Australian TAPS Programme (Section 7.6.4).
- 7.10.12 Information which places an appropriate perspective on epilepsy and which would be suitable for recreational professionals, sporting clubs and organisations as well as persons who have epilepsy and their families should be produced, recorded in an accessible form and publicised (Section 7.7.8).
- 7.10.13 An accessible information bank containing written and audio-visual materials outlining recreational programmes, ideas and resources for sporting and community groups should be established and promoted (Section 7.7.8).

- 7.10.14 Appropriate resources including basic information such as a glossary of terms should be made available for use by counsellors and interpreters (Sections 7.8.4 and 8.9.5).
- 7.10.15 The criticisms made by some users of Epilepsy Association services should be considered by the Associations and, where valid, appropriate changes made (Section 7.9.10).
- 7.10.16 A comprehensive strategy to meet the needs of persons who have epilepsy should be developed in Australia. Crucial to the success of such a plan is the inclusion of Epilepsy Associations (7.9.15).

CHAPTER EIGHT

From my experience you can't just walk into a job if you've got -epilepsy. You have to battle it out with all the crazy ideas other people have.

(43 year old male -- country Queensland)

8.1 INTRODUCTION

8.1.1 Workers who have epilepsy may find employment difficult to secure or maintain. This difficulty often poses a considerable strain on financial and personal security, self-esteem and emotional well-being. Frequently life-chances are significantly restricted by mis-informed or discriminatory attitudes held by employers, co-workers and staff in helping agencies.

8.1.2 Averting potential discrimination is a matter most workers who have epilepsy must address. Because so much hinges on having work, they are often unwilling to risk the door being shut against them simply because they have an intermittent disability. It is in this context that the issue of concealment arises.

I never told. It's alright to say people understand but you only have to strike one bastard.

(51 year old male - Melbourne)

8.1.3 Concealment of epilepsy appears to be common in relation to employment. A third of phone-in callers who were employed or seeking work said that they had kept their epilepsy from employers and co-workers. The true level of Concealment is no doubt higher and not without reason as over half these callers said they had been denied jobs or had lost jobs after disclosure.

8.1.4 All kinds of concealment occur (see Chapter 1). Partial concealment involves disclosure either to the employer or some co-workers, but not to all in the workplace. Continuing concealment entails the ever-present worry that a seizure will occur at work, or that in some roundabout way the employer or co-workers will hear of the worker's epilepsy. Such eventualities can lead to job loss or forced resignation because the discriminatory attitudes alter the social environment of the workplace.

TABLE 8.2 Permanent placements (disabled) as percentage of total recruitment 1982

DEPARTMENT	1982 - %
Home Affairs and Environment	20.0
Science and Technology	17.5
Prime Minister and Cabinet (including PSB and Auditor-General)	16.7
Health	15.0
Aviation	11.1
Australian Bureau of Statistics	10.5
Communications	9.7
Education	9.1
Trade and Resources	6.7
Attorney-General	6.1
National Development and Energy	5.9
Aboriginal Affairs	5.3
Transport and Construction	5.0
Administration Services	4.7
Capital Territory	4.4
Foreign Affairs	4.2
Veterans' Affairs	3.5
Employment and Industrial Relations	3.4
Social Security	3.0
Defence	2.9
Industry and Commerce	2.8
Finance	2.4
Immigration and Ethnic Affairs	2.3
Taxation	1,8
Treasury	-
Defence Support	-

Source: Public Service Board

- 8.2.4 Two important requirements were highlighted by the survey, and they mirrored the statements of contacts about what is needed in the area of employment. Firstly there is a clear need for adequate information about epilepsy, and more particularly about epilepsy and employment. Only 9 participants could claim an adequate understanding of epilepsy. Where a person lacks such an understanding, he or she will often rely upon attitudes which are discriminatory. The decision not to appoint or to dismiss a worker who has epilepsy should not be based on inadequate information.
- 8.2.5 Apart from a shallow or incomplete knowledge of epilepsy, some participants raised objections which showed little understanding of its treatment and the potential for seizure control. Concerns were expressed about long and frequent absences from work due to unpredictable seizures and the likelihood of regular hospitalisation and lengthy medical consultations. There were 6 employers who believed workers' compensation premiums would increase if they hired workers who had epilepsy.
- 8.2.6 It is imperative that relevant information about epilepsy be circulated widely to employers. The decision not to appoint or to dismiss a worker who has epilepsy should not be based on inadequate information on the condition.
- 8.2.7 The second requirement, highlighted by the telephone survey, was the employer's need for practical assistance in assessing the job suitability of Workers who have epilepsy. Safety, the potential cost of lost time and productivity, and disruption to the workplace are their legitimate concerns.
- 8.2.8 The precise nature of employers' objections and reservations, and the factors which determine the job suitability of workers who have epilepsy. Nor are there work suitability and assessment guidelines currently available for Australian conditions. Such guidelines should find a ready niche in assessment procedures for permanent appointment within the Australian Public Service, in companies with trained personnel management staff, and in rehabilitation programmes.
- 8.2.9 For small businesses something of a different nature is required. A pamphlet directed at them should be produced. Its emphases should be upon meeting the need for relevant information and answering common but ill-founded objections and reservations. Most importantly it should contain a brief and easy to administer assessment guide that will assist the employer to make appropriate employment decisions. The pamphlet should detail the kind of assistance available from Epilepsy Associations or the Commonwealth 'Employment Service (CES) should they wish to use it.

- 8.2.10 Many employers are reluctant to make use of professional expertise such as that offered by the CES and Epilepsy Associations thus decreasing the chances of finding an employer who is informed and understanding.

I've had good and bad bosses. When I was just starting out I used to think they were all good but these days I start from the other side. I've had to be more careful than other people.

(46 year old female - country NSW)

- 8.2.11 While matters specific to epilepsy can affect job opportunities a person who has epilepsy will benefit from the promotion of equal employment opportunities for disabled workers generally. The Open Employment Strategy for Disabled Persons conducted by the then Department of Employment and Youth Affairs during the International Year of Disabled Persons, 1981, put the issue of equal opportunity before the public eye. Promotional activities of this nature should be on-going.

8.3 THE COMMONWEALTH AS AN EMPLOYER

- 8.3.1 Commonwealth involvement in providing equal employment opportunities (EEO) to disabled persons wishing to join the Australian Public Service (APS) stretches back at least to 1971. In that year the development of EEO Units within the Public Service Board (PSB) began with the appointment of Special Placements Officers (SPOs) in all Regional Offices.

- 8.3.2 EEO policies have contributed to the employment of disabled persons. Table 8.1 shows that people who have epilepsy have benefited - 24 gained appointment to the APS in 1982. This represents 28% of persons having epilepsy who were given selection tests under EEO. People having epilepsy were 6.23% (approximately) of all disabled persons taking selection tests under EEO. Compared to other groups of disabled persons shown in 8.2, those who have epilepsy fared relatively well.

- 8.3.3 However there was insufficient time to research the background to these statistics. A series of questions are raised by them: how many of those tested were denied appointment on medical grounds rather than selection test performance? Are the medical standards used appropriate? Are modifications to selection tests made for EEO purposes appropriate? How many disabled persons approached SPOs regarding APS employment (as distinct from the number tested) and what were their disabilities? What factors influenced the decision not to

administer selection tests to an individual? Without answers to these and other questions the data contained in Tables 8.1 and 8.2 are suggestive rather than definitive. It is not possible to judge the overall success of EEO on the basis of the information presented here. Irrespective of that constraint there are still major policy options to be explored and, at least as far as epilepsy is concerned, some incongruous medical standards to be revised.

- 8.3.4 People who have epilepsy do not necessarily join the **APS** under EEO programmes. Some sat for selection tests and gained appointment on test performance, provided they met medical standards. Others began having seizures after appointment and have concealed them for various reasons.

There's no incentive for me to march up and say I've got epilepsy. What's the point of sacrificing a promotion or superannuation or your job for the sake of honesty?

(Female - Canberra)

I wouldn't have come this far [in the APS] if I'd let on about it when I became epileptic years ago. Open-mindedness is a fickle commodity.

(Male - Melbourne)

- 8.3.5 EEO operates within limits imposed by medical standards applied by Commonwealth Medical Officers (CMOs) to applicants for APS appointment. (Medical standards are set by the PSB and the Australian Government Retirement Benefit Office in consultation with the Department of Health.) For persons who have epilepsy the standards are pointlessly restrictive. Under them many will not gain appointment though they have the required competence. Others will be discouraged from doing selection tests because they know that they will not meet stringent medical standards.

- 8.3.6- In addition to the general standards required for permanent appointment, the Department of Health has confirmed that a person who has epilepsy should not be recommended for appointment where he or she "is liable to recurring major, diurnal fits". However, if there is reliable evidence that no seizures have occurred for two years prior to examination, appointment may be recommended providing it involves no risk to the applicant or others. Appointments may be recommended where an applicant has "minor petit mal or nocturnal epilepsy, or is a 'borderline case". (The letter containing information regarding medical standards is attached as Appendix 4.)

- 8.3.7 Such standards are arbitrary and in fact run counter to principles promoted by the CES and the Epilepsy Associations to private sector employers. They are also at variance with government concern to implement EEO programmes, see Reforming the Australian Public Service, 1983, p33. Unjustifiable exclusion occurs because of the application of irrelevant medical requirements.
- 8.3.8 The occurrence of 'recurring, major diurnal fits' is not relevant for every APS position. The two-year seizure-free requirement is similarly flawed. What constitutes 'minor petit mal epilepsy', 'a borderline case', or 'recurring, major diurnal fits' is open to a wide variation in interpretation. The question of risks arising due to seizures occurring is a relevant matter. It should be assessed according to relevant and reasonable guidelines. It cannot fairly be left to uninstructed discretion. (See Section 8.2.8).
- 8.3.9 The review of medical standards is unavoidable if EEO recruitment programmes are really to offer equal opportunity to persons who have epilepsy.
- 8.3.10 Commonwealth departments and statutory authorities have been under no compulsion to take part in EEO programmes. Some, such as the Department of Aviation and Telecom, have developed their own EEO programmes. The greater number have not. Consequently uneven recruitment levels for disabled persons are evident. Table 8.2 shows remarkable differences in appointment of disabled persons under EEO programmes. The year average for all departments was 3.4%. The very low percentages of placements, or their complete absence, in departments such as the Treasury and Immigration and Ethnic Affairs is at least suggestive of resistance to EEO. It is to be hoped that figures for 1983 will demonstrate that this is not so.
- 8.3.11 Within departments and authorities, the development of EEO policies, appointment of EEO officers and implementation of EEO programmes should attract a high priority. Otherwise EEO will produce uneven results and to that extent will remain a less than whole-hearted effort.
- 8.3.12 Several matters require attention in relation to the application of EEO to disabled persons. It is understood that guidelines used by SPOs in selection testing for disabled persons have been in draft form for several years. If this is the case, then the possibility exists that such guidelines may have been inconsistently applied during that period. (The guidelines used for selection testing under EEO are attached as Appendix 5.) The SPO Guidelines should be formalised. The statistical base for information on the employment of disabled persons under EEO should also be extended to temporary employment and statutory authorities. Attention must be given to retention rates,

support structures necessary to encourage job retention and to the level of recruitment amongst disabled women who appear to have been under-represented in appointments under EEO. (See also Section 8.4.4.)

- 8.3.13 Of critical importance is the ensuring of acceptance and understanding of disabled workers within the APS. The social and informal aspects of the work environment are vital considerations in the success of EEO policies. Staff development activities offer one means to securing that success. SPOs have been involved in training programmes in concert with personnel staff from some departments. However, these programmes appear to have been ad hoc or limited to certain departments. Training opportunities must be expanded if recruitment under EEO is to rise.
- 8.3.14 Recruitment levels should be comparable in all States and Territories and between metropolitan and country areas. General objectives determined by the PSB should provide a framework. At present many statutory authorities determine their own staffing policies or, in arriving at their policies, are only partly subject to the staffing policies that the PSB determines for government departments. EEO policies of the PSB should be applicable to statutory authorities as was suggested in the Report of the Royal Commission on Australian Government Administration (the Coombs Report 1976, Paragraphs 8.3.31 and 8.3.32.). Equity for disabled workers cannot, with consistency, be confined, to one sector of Commonwealth Government responsibility.
- 8.3.15 As will be apparent in many parts of this Report, people who have epilepsy frequently have markedly restricted chances of gaining educational qualifications and skills of a vocational and recreational nature. Many factors contribute to this limiting of opportunities: attitudes to epilepsy (discriminatory and over-protective); exclusion on irrelevant grounds; and poor medical management resulting in either poor seizure control, impaired learning capacity or unnecessary side-effects from medication.
- 8.3.16 The striking of a quota figure for recruitment of disabled persons to the APS offers one means for redress of these inequities. The setting of numerical employment targets for disabled persons by departments and authorities is a further option which is favoured by the Government (Dawkins, 1983).

- 8.3.17 It has been argued that the setting of quotas or targets would lead to discrimination against those who are not disabled. Such an argument ignores the structural and circumstantial disadvantages which have been and are part of the common experience of some groups of disabled persons. Affirmative action measures such as quotas and targets represent an attempt to ensure that disabled persons are able to exercise their rights. The Human Rights Commission Act 1981, in Section 9(2), specifically recognises the value of the principle behind such measures.
- 8.3.18 Factors beyond the control of a large group of persons who have epilepsy have rendered them unable to compete with their peers. The equal enjoyment of their rights is severely hindered if they must compete with their comparatively advantaged peers.
- 8.3.19 To date, the preponderance of appointments under EEO has been in the Fourth Division at base-grade level. These accounted for 81% of EEO placements in 1982. 19% were appointed to the Third Division. (Fourth Division officers are largely clerical assistants. They are lower in the APS hierarchy, and attract lower salaries, than Third Division officers.) The Commonwealth as an employer has promoted EEO in a lop-sided fashion. Merit forms the basis for appointment and promotion, but merit is measured to some extent by educational qualification. EEO could seek to widen the criteria on which merit is judged so that disabled persons who are competent, but for reasons beyond their control have not been able to attain qualifications, are not disadvantaged.
- 8.3.20 The high proportion of Fourth Division appointments is indicative of the difficulties many disabled persons face in gaining equal enjoyment of rights with the population at large. Broadening of merit criteria could be coupled with increased opportunity for part-time study release.

8.4 THE COMMONWEALTH EMPLOYMENT SERVICE

- 8.4.1 Each Commonwealth Employment Service (CES) office has a designated Disabled Persons Officer (DPO) position. DPOs deal with disabled persons registered as seeking employment. The task is a demanding one. Disabled unemployed persons are less favoured for employment than their non-disabled contemporaries.

I've been going to the CES for ages and they're very nice but they can't do much... I can't get a job because epilepsy isn't in demand.

(Female - Hobart)

The only hope seems to be if the CES can find me a job... I try for jobs in the paper but that has not got me very far. Possibly the CES can do better with their contacts with employers.

(37 year old female - country South Australia)

- 8.4.2 The magnitude of the DPOs task is apparent from CES statistic*. For the September quarter of 1983, 7.4% of those registered with the CES as seeking employment were classified as disabled job-seekers. (These statistics define a disabled person as one who appears likely to encounter difficulty in obtaining or maintaining employment because of disability. Therefore not all disabled people contacting the CES appear in these statistics - they are included in overall statistics.)
- 8.4.3 Figures 8.1 and 8.2 show that disabled persons are prone to longer periods of unemployment than their contemporaries - 45.5% compared to 29.4% remain unemployed for nine months or more. A greater proportion of disabled males and females (40.2% and 41.3%) were unemployed nine months or more than were males and females in the general category (22.3% and 24.3%).
- 8.4.4 The position of disabled females is worse than these figures suggest. Fewer disabled women were registered as unemployed than was the general case - 17.8% to 28% (see Figures 8.1 and 8.2). Table 8.3 shows that a registered unemployed disabled person was 4.6 times more likely to be male than female, whereas registered unemployed persons generally were 2.57 times more likely to be male than female.
- 8.4.5 Hidden unemployment amongst disabled women was significantly higher than for other groups. Contributing factors may be a greater incidence of discouragement regarding employment prospects, lower skill or training levels and family influence acting as a restraint against registering as unemployed.
- 8.4.6 Disabled persons, particularly women, are poor relations in the labour market. The position of persons who have epilepsy is difficult to assess. The extent to which epilepsy is concealed from CES officers is unknown. It may be more common when the labour market is in over-supply. As not all disabled persons appear in the disabled unemployed category, the extent to which persons who have epilepsy are more or less likely to appear is unknown.

Figure 8.1 Persons registered as unemployed, excluding disabled registrations. (N=718 218).

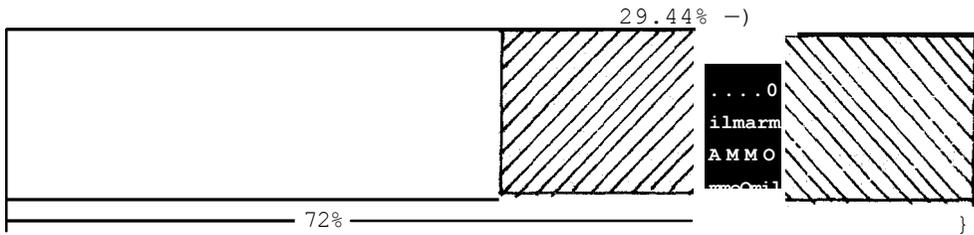
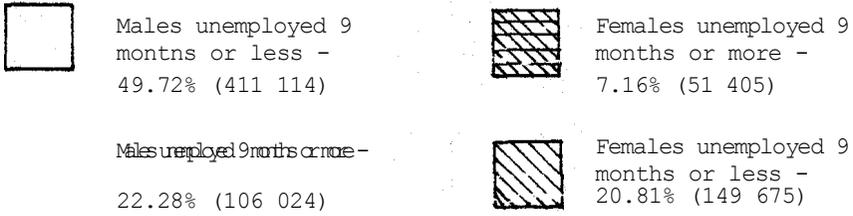
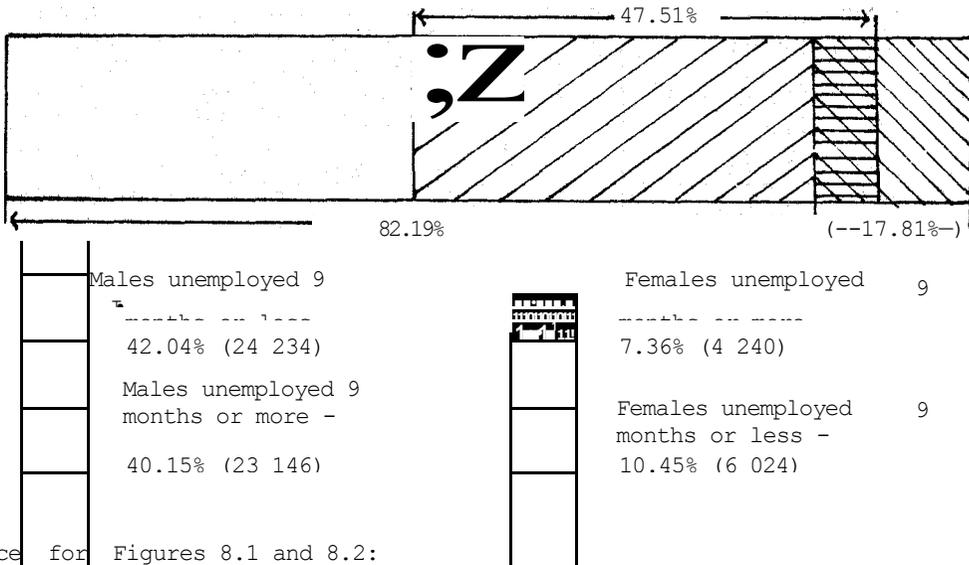


Figure 3.2 Persons registered as disabled unemployed. (N=57 644).



Source for Figures 8.1 and 8.2:
Commonwealth Employment Service Statistics: September Quarter 1983.
Department. of Employment and Industrial Relations. AGPS, 1983.

Table 8.3 Total registered unemployed (excluding disabled) and total classified as disabled registered unemployed by sex.

	Males		Females	
I Total registered unemployed	I 517	138	, 201	080
I Total disabled registered unemployea	47	.380	10	264

Source: Department of Employment and Industrial Relations, Commonwealth Employment Service Statistics: September Quarter, 1983. AGPS, 1983.

Table 8.4 Total number of persons registering during each of four quarters as disabled and seeking work by those with epilepsy as a percentage of that total.

Quarter	isabled egisterations	Those with epilepsy — %
December 1982	16 739	3.61% (605),
March 1983	15 878	3.67% (584)
June 1983	15 712	3.24% (510)
September 1983	17 526	3.14% (551)
Average for four quarter	16 463	3.41% (362)

Source: Department Of Employment and Industrial Relations.

8.4.7 An indication of how those Who have epilepsy may be faring can be gained from Table 8.4. The figures are registrations for each of four quarters. Even accepting that 2% of the Australian population has epilepsy (see Section 2.4.3), persons who have epilepsy are proportionately over-represented in the disabled unemployment group.

8.4.8 Through the efforts of DPOs and specialist support available to them (Employment Counsellors for example) the CES is confronting the challenge to place disabled workers. But further measures must be adopted to meet the challenge more fully. The statistics shown above heavily underscore the meal to promote equity in the workforce for disabled persons.

8.4.9 Several contacts indicated they had found work through the CES. But again the chance factor is at play. Some DPOs execute their tasks with skill and sensitivity, whilst others lack the degree of insight and understanding that their onerous tasks demand.

I was unemployed for over a year. ..[A DPO] got me a job on a special scheme after I more or less gave pp. [The DPO] explained about epilepsy to my employer and I've had no problems.

(43 year old male - country Queensland)

The guy at the CES [a DPO] took a step backwards when he heard I had epilepsy. I confronted him about it I was so angry.

(36 year old female - Melbourne)

The CES put me in the handicapped bracket. I've got a good job now, but they didn't know what to do with me. I told the guy to read a book on epilepsy.

(50 year old male - Melbourne)

8.4.10 A: major shortfall in service delivery is the length of time DPOs serve in their positions - often less than twelve months. This results in disjointed services and never-ending processes of feet-finding and initial training. While this continues to occur, the CES cannot deliver the best service to its clients at the point of primary and on-going contact.

8.4:11 A standard training package and formal selection criteria for DPOs are soon to be developed. These are overdue. Training, conducted by Employment Counsellors, has varied in content and duration from one area to another. Selection, the responsibility of the Office Manager, has sometimes been on the basis of no-one else being available, and has accordingly resulted in unsuitable appointments.

- 8.4.12 Disabled persons and representative organisations of disabled persons must be involved in the development of the standard training package and selection criteria. A consultative process will produce results that reflect user requirements. Amongst issues which appear to need attention are length of DPO service in that position in one office; initial training in block sessions rather than, say, a day a month; the need for in-service training; ensuring that the DPO position is always filled by a trained DPO when it is unattended through resignation or training attendance for example.
- 8.4-13 In relation to epilepsy in particular there are a number of matters requiring attention. DPO training and performance would be enhanced by the availability of appropriate epilepsy reference materials. Current materials appear scanty and it is heartening to note that an epilepsy information guide is planned. The NEAA should be involved in that document's preparation.

I gave my son some pamphlets from the Epilepsy Foundation to take to the lady at the CES because she didn't have any idea about epileptics...It is amazing to me that people like them haven't got all that at their fingertips.

(Parent - Melbourne)

- 8.4.14 Available statistics highlight the importance of the (RS being able to deliver services tailored to meet the needs of disabled persons and employers. There is a need to expand the information base on disabled persons and employment. Adequate information should be available to planners and service providers in the CES and elsewhere. With some fine-tuning, drawing on the experience and knowledge of disabled persons and their representative organisations, the CES could play its role in a difficult environment more fully.

Nobody expects [the CES] to make jobs out of thin air and we know they have got an awful job and times are bad. If they are going to help our daughter the Government should give them more training and more workers.

(Parent - country NSW)

8.5 SHELTERED WORKSHOPS

- 8.5.1 The present status and future directions of sheltered workshops are the subject of contentious debate. This section stands as a contribution to the debate and poses many questions. It does not pretend to offer Solutions to the broad and fundamental matters involved.

- 8.5.2 The reason for separate and lengthy consideration of sheltered workshops is twofold. Firstly, comment upon them was made by at least 35 of the 447 contacts made during the course of this Project. Secondly, the particular relevance of workshops here lies in the higher incidence of attendance by persons who have epilepsy than by the general population.
- 8.5.3 Statistics relating to the incidence of epilepsy in workshops are by no means easy to acquire. An estimate prepared by the Commission for the Control of Epilepsy and its Consequences (USA, 1979), estimates that 3% of those in sheltered workshops had epilepsy. The Commission also shows figures for the Netherlands in which 3.7% Of those in sheltered workshops had epilepsy. Discussions With sheltered workshop staff and professionals in contact with workshops in Australia suggest the percentages here would be rather higher.
- 8.5.4 The pool of disabled people from which workshops draw is more likely to include people with epilepsy. Livingstone (1972), puts persons who have brain damage at a greater risk of epilepsy. As an example he states that 25% to 30% of children who have cerebral palsy (all of whom have brain damage) develop epilepsy. Dykes (1978), in his NSW and ACT study of severely disabled children, found epilepsy was recorded in 1,456, or 14.5%, of his sample.
- 8.5.5 The discussion of workshops in an employment chapter: throws into relief a number of difficult questions besetting assessment of workshops. Is it their purpose to provide employment? Views about their purpose vary markedly. Some are places of employment primarily concerned with productivity and competitive service delivery.
- 8.5.6 Others provide pre-employment training or rehabilitation. This assumes most people attending them will move into open employment. Yet most people in workshops remain in them. Some provide opportunities for socialising and socialisation. Work simply mediates the social environment. Yet complaints of being pressured to complete tasks or being rebuked for talking to others contradict their avowed purpose.

Sometimes they say I should talk to people and that and then they say you're not doing work quickly enough.

(36 year old male - Melbourne) -

- 8.5.7 One view holds that workshops ensure that disabled people can attain reasonable living standards through peripheral workforce participation. Yet rates of pay and the level of the means-tested Sheltered Workshop Allowance make for austere standards.

when there's work to do everybody works really hard but you still only get paid what you always get. If you work hard you should get paid for it... When I think about what I get I think about not going.

(24 year old male - Melbourne)

- 8.5.8 A paternalistic approach is reported in some workshops. Workshops exist to give "less fortunate, handicapped kids" (20 years old or more) something useful to do, giving them the impression that they are productive citizens.
- 8.5.9 Difficulty frequently arises when some or all of those aims are quoted at different times as primary. The resulting conflict of priorities detracts from the overall experience of those attending workshops. Frustration and confusion are, not surprisingly, the outcome. Work is not the most appropriate activity through which to achieve some of the given objectives.; other activities and other environments, would be more apt.
- 8.5.10. Accreditation standards and procedures for sheltered workshops have been developed by ACROD, **An** Accreditation Pilot Project monitored by the Macquarie University's Unit for Rehabilitation Studies is currently trialling them. Accreditation is a significant advance worthy of support. It is a voluntary process and the rights of disabled workers are stressed in the accreditation standards and procedures, Workshops choosing not to participate may not overcome, shortcomings in relation to rights which accreditation would address.
- 8.5.11 Several matters relating to workshops may involve contraventions of disabled persons' rights. The issues are unclear and while uncertainty persists rights may continue to be compromised. The depth of research and analysis required to arrive at a satisfactory understanding of the rights of disabled persons in sheltered workshops was beyond the limits of this Project.
- 8.5.12 Disabled persons have the right to adequate remuneration in useful and productive occupations (see Paragraph 7 of the Declaration). If rehabilitation or pre-employment training is a workshop's primary aim then it may be argued that payment for work done can be set at a lower rate. But if work is the primary purpose, formally or informally, then the issue of remuneration shifts to a different plane. Under such circumstances, do low pay rates and provision of a Sheltered Workshop Allowance meet the prescription of adequate remuneration? Is any element of exploitation, unintended or not, present?

- 8.5.13 If rehabilitation or pre-employment training is the stated objective then some mobility should be demonstrated. The right to engage in useful, productive and remunerative occupations according to abilities seems to have been lost in some instances.

I've been a trainee here [in a workshop] for sixteen years...
I would like to have a job but I don't think I'll get one
except here.

(34 year old male - Melbourne)

- 8.5.14 Disabled persons have the right to join trade unions (see Paragraph 7 of the Declaration). Presumably this right extends to persons working in workshops. If they did join trade unions some novel industrial issues would arise. What alterations, if any, to industrial awards would be necessary? Would productivity and relativity arguments apply to their wage levels? If the present structure of the union movement and conciliation and arbitration machinery cannot cater for workshop employees, is there a structural and institutionalised contravention of rights?
- 8.5.15 A fundamental consideration is whether the existence of sheltered workshops is merely convenient, deflecting the critical issue of integrating the disabled workers into open employment. Does sheltering, the structuring of enclaves, represent an infringement of the rights to integrate or re-integrate into society? Or does sheltering provide a realistic option for many who cannot enter open employment?
- 8.5.16 Other matters require consideration. It appears that most workshops utilise industrial processes which are becoming less common in industry generally. Diversification into developing employment sectors (service and information-based industries, for example) would increase the range of work options in jobs perhaps more likely to be numerous than, say, those in the manufacturing industry where competition is intense. Workshops must be able to train disabled workers in the operation of industrial technology in current use if labour market competitiveness is to be maximised. Financial constraints have prevented workshops from acquiring new technology. The Department of Social Security could consider ways of facilitating its acquisition.
- 8.5.17 As was indicated earlier, the statistical and information base on disabled persons and employment is inadequate. The imbalance between numbers of males (who predominate) and females; variations in proportions of workshop places from State to State and between metropolitan and country areas; the apparent absence of older persons: information about these factors in relation to workshops should be

quantified and explained.

- 8.5.18 Knowledge about epilepsy is apparently scarce in many workshops. This lack of information has led to the unnecessary exclusion of some persons from undertaking work processes with resultant limitations on the acquisition of skills needed in open employment. Administration of inappropriate, and potentially injurious, first aid procedures when seizures have occurred was also reported.

My son is well able to do other jobs in the worksikop. I have tried to explain what his seizures are and that he should be allowed to try other things to get better training. To no avail I an Afraid - the manager seems to think every epileptic will have a serious fit.

(Parent - Perth)

I had a fit one day and when I makeup there was paper in my mouth. Somebody put toilet paper in so I wouldn't bite myself. That's really crazy, isn't it?

(36 year old male - Melbourne)

- 8.5.19 **Abroad** staff development programme could be Provided for workshops, perhaps through Technical and Further: Education (TAFE) or other educational agencies. While information about epilepsy would form part of such programmes (and Epilepsy Associations could contribute in this regard) they could range over a host of issues - for example, tendering, marketing, health and safety, and personnel management.
- 8.5.20 First aid posters on epilepsy which could be accessible to those in workshops may help to ensure the safety of those who have epilepsy.
- 8.5.21 History has not altogether been a wise benefactor and a great deal needs to be done to bring sheltered workshops into line with contemporary attitudes. Many workshops have done so or are attempting to do so. Others have not and those attending are disadvantaged.
- 8.5.22 Perhaps all workshops should become rehabilitation facilities only One option that deserves consideration is the conversion of workshops into co-operative ventures. The following section discusses co-operatives. The notion is certainly relevant to any thinking about the future role of workshops.

We don't get any say in what happens [at the workshop]. should be able to do that. Tell them what we want.

(26 year old male - Melbourne)

8.6 .00-OPERATIVES AND DISABLED WORKERS

8.6.1 Some shortfalls in pre-employment and rehabilitation programmes are discussed in Chapter 7. A number of them could be partly made up by the availability of jobs in worker co-operatives.

8.6.2 Such co-operatives would have advantages for those who have epilepsy. Employment would not be endangered by discrimination on grounds of epilepsy alone. The question of concealment would not arise.

It would be a big relief to get a job knowing that being epileptic would not be used against me for no honest reason.
(Female - country South Australia)

8-6-3 At Present co-operatives are enjoying much attention in Australia. Several Governments have endorsed them as a valuable strategy in dealing with unemployment. The accent is upon initial assistance (financial, training) with the aim of independent, efficient operation in a specified time period.

8.6.4 Co-operatives so established have enabled unemployed people to enter productive employment and to learn a range of skills as a result of sharing common responsibility for the co-operative's success. Co-operatives offer considerable savings to governments. Their workers are no longer recipients of unemployment benefits. They and the co-operatives contribute to revenues through taxes. Some individuals receiving invalid pensions could and would find employment in them.

I've had more jobs than feeds. I've been fired from quite a few jobs after having a seizure at work. I'm on the invalid pension but I'd rather be working.

(53 year old male - Melbourne)

I've tried to get jobs but they won't employ people with epilepsy in factories. I've got an invalid pension but I could be working really. .

(41 year old male - Melbourne)

8'.6.5: The government could provide assistance for co-operatives that provide OPPortunities. to disabled workers. (Disabled worker co-operatives are beginning UD.appear in Victoria already). Several notes of caution should be sounded. Little can be gained by re-inforcing notions of isolation and separateness. They ought to provide a meeting ground for disabled and non-disabled workers.

- 8.6.6 Co-operatives are not replacements for government involvement in pre-employment and rehabilitation programmes. Co-operatives provide employment, not training. They could provide work for disabled people leaving those programmes. The opportunity to learn a variety of skills on the job would increase job options and competitiveness in the labour market. Control of co-operatives should be vested in the workers rather than outsiders having no direct stake in their success. Their guiding principles should be independence, self-reliance and self-determination.
- 8.6.7 **A** great strength of the cooperative idea is that it allows disabled workers to demonstrate their skills and capacities. It allows active promotion and pursuit of workforce equity rather than having to argue for equity on the basis of justice alone. While justice should be the active principle, it does not persuade everybody - and practical demonstrations can be very convincing.
- 8.6.8 Through discussions with governments and relevant Commonwealth departments, the trade union movement, employer organisations, disabled persons and their representative organisations, the Department of Employment and Industrial Relations could develop a co-operative strategy. Co-operatives of this kind would require specialist resources without which their viability would appear somewhat doubtful.
- 8.7 RECOMMENDATIONS
- 8.7.1 Material which will help employers assess the suitability of workers with epilepsy for particular jobs should be produced (Section 8.2.6).
- 8.7.2 Further research should be undertaken to determine:
- i) employers' objections and reservations about employing a person who has epilepsy;
 - ii) - the factors which affect job suitability for persons who have epilepsy
- (Section 8.2.7).
- 8.7.3 Pamphlets on the employment of persons with epilepsy should be produced specifically for small business and should include: relevant information; answers to common but unfounded objections and reservations; and an easy to administer assessment guide to enable employers to make appropriate employment decisions. Attention should also be drawn to professional expertise such as that offered by the CES and Epilepsy Associations (Section 8.2.9).

- 8.7.4 Promotional activities such as those undertaken during the International Year of Disabled Persons, 1981, should be ongoing (Section 8.3.11).
- 8.7.5 Medical standards for persons with epilepsy should be reviewed to enable, EEO recruitment programmes to work more effectively (Section 8.3.9).
- 8.7.6 Within Commonwealth departments and statutory authorities the development of EEO policies, appointment of EEO officers and implementation of EE6 should attract a high priority (Section 8.3.11).
- 8.7.7 Consultation with disabled persons and representative organisations should take place and a standard training package and selection criteria for DPOs should include appropriate information on epilepsy. If a DPO position is vacated for any reason for any period it should be filled by a trained Dm (Section 8.4.12).
- 8.7.8 The information base on disabled persons and employment should be expanded so that adequate information is available to planners and service providers (Section 8.4.14).
- 8.7.9 Broad staff development programmes should be provided for sheltered workshops. Information about epilepsy should form a part of programmes but issues such as tendering, marketing, health and safety and personnel management should also be covered (Section 8.5.19).
- 8.7.10 First aid posters on epilepsy which could be accessible to those in workshops should be produced to ensure the safety of persons with epilepsy (Section 8.5.20).
- 8.7.11 Discussions should take place with governments and relevant Commonwealth departments, the trade union movement, employer organisations, disabled persons and their representative organisations and the Department of Employment and Industrial Relations with a view to developing disabled workers' co-operatives (Section 8.6.8).

CHAPTER NINE

RESIDENTIAL cenals

It is impossible to explain how hard locking after her was. 7. There was not much help but plenty of advice from people who didn't have all the pressures I did... Although it was never said, people thought we were awful to put her in a hospital.

(Parent - country *NSW*)

9.1 INTRODUCTION

- 9.1.1 The Tasmanian Board of Inquiry into the Needs of the Handicapped, (the Webster Report, 1980), underlined the importance of appropriate accommodation:

The way in which people live is governed by how they are accommodated: geographical isolation will reinforce alienation, • large group accommodation will cause dehumanisation, building design and location will limit access to community life and lack of privacy will restrict personal freedom and limit personal relationships. (p 107).

Simply being accommodated is not enough.

- 9.1.2 For most people who have epilepsy, accommodation presents few if any difficulties. The problems they confront are usually mobility-related. Chapter Six explores this at greater length. One contact mentioned moving residence for reasons of mobility rather than preference.

am not allowed to drive... I had to move away from [the suburb] Where I lived for about thirty-five years to be close to work. It was a big wrench to move so far from all my friends and family.

(48 year old female - Adelaide)

- 9 1,3 When difficulties with residential options are encountered, they can be considerable. The Declaration clearly states the first residential priority for disabled persons - living with their families or foster parents. Maintenance in the family home can, however, place great strains on families. If the right to remain at home is to be observed, then certain services should be provided to enable families to owe with the care of a disabled child or adult. Section 9.2 outlines some of the services needed.

- 9.1.4 The Declaration makes it plain that placement in a specialised residential establishment should occur where staying in the family home is not preferred or, as is often the case, not possible. The limits of family endurance may be reached, or even surpassed, and yet the strain cannot be relieved because of insufficient room in special establishments.

His name has been down for three years to go into a place for handicapped adults... The strain on our other children has made a lot of tension... The Government doesn't care about good parents who just can't go on.

(Parent - Melbourne)

- 9.1.5 Most of those living in specialised establishments are in large group accommodation settings, housing perhaps ten to several hundred people. Several contacts noted the inappropriateness of such environments. Section 9.3 briefly takes up this issue.

Would you live with six people in your bedroom? I'm in a better place now with my own room and I can get home when I want to. You couldn't leave the place I used to live in.

(34 year old male - Melbourne)

As an ex-resident of [a nursing home]... there is a tendency among staff to treat residents as children rather than adults... I feel that residential options for persons with epilepsy should at all times be as free of restrictions as possible, no matter how severe the epilepsy. I feel that staff treatment, when the adult with epilepsy is treated as a child, should be censured and moves made to prevent it from continuing.

(Male - country NSW) ,

- 9.1.6 Country people are particularly disadvantaged. While services that help maintain disabled persons at home are available to some extent in cities, families in country areas generally have no such access. The opportunity to enter pre-employment programmes, for example, can be denied because there are insufficient places in specialised establishments (whether appropriate or not) close to the location of such programmes.

Rehabilitation is available for some cases in Adelaide. [This city] does not have these facilities... He could not go into rehabilitation because there was really nowhere he could live.

(Parent - country SA)

What would help me most... [would be] to have a break once in a while... [to have] assistance to get simple housework done Which gets beyond me sometimes. Could there be a subsidy to help people in our position pay someone to come in?

(Parent - country Queensland)

9.1.7 Where disabled people are cared for by their families they sometimes do not learn to care for themselves. The right to live in the family home must be balanced against the right to learn independent living skills. Without such skills a disabled person is constrained in exercising the right to leave home.

9.1.8 Some find themselves in large group accommodation settings because they have insufficient personal resources to buy services that would enable them to live in their own homes. The Department of Social Security is piloting an Attendant Care scheme, the value of which can be illustrated by the following comment.

My story begins in 1976 when I was involved in a collision that left me without the use of my legs, impaired use of my left arm and epileptic... Living with about sixteen other people [in large group accommodation] is frustrating and bad for me mentally - most of them I would not choose to live with - and the invasion of privacy is terrible... I know the NSW (sic) Government is thinking about bringing in an Attendant Care Allowance... It is a pie in the sky to dream about living in my own home until something like this gets up. If I would make one suggestion, this is it.

(Male - NSW)

9.2 SUPPORT SERVICES FOR FAMILIES

9.2.1 Comments received reveal seven services that would help to maintain a disabled person at home. The services, whether offered by voluntary organisations or local, State or Federal Governments, cannot give adequate coverage without an infusion of Government money.

9.2.2 The services are:

- a) day care;
- b) emergency care;
- c) family support;
- d) holiday opportunities;
- e) home help;
- f) home supervision; and
- g) respite care.

9.2-3 Before elaborating on each of these services, two observations should be made. Firstly, their current availability is subject to extreme variation. They are more likely to exist in larger population centres than country areas. Uneven access creates disadvantaged and advantaged groups with similar service needs. No comments 'from one metropolitan area make the point:

Home help has been cut back to holidays only. I really need it.

(Parent - Melbourne)

The council run a home help programme. I could not have coped without that regular assistance to count on.

(Parent - Melbourne)

9.2.4 Secondly, people who have epilepsy are sometimes excluded froth service use because their disability is intermittent rather than chronic. Where epilepsy is concerned eligibility criteria must allow for informed assessment based on need.

- We found it difficult to go out and leave the child with baby-sitters When they weren't aware of the problem. There is a baby-sitting service available for disabled children but our child's epilepsy wasn't considered severe enough.

(Parent - Melbourne)

9.2.5 Day care No parents mentioned their inability to accept full-time or part-time work because of the need to care for disabled children. Others, for similar reasons, had curtailed voluntary activities.

I do get the single parent's pension... I was offered my old job back and had to say no because there was nowhere to leave my daughter that didn't cost the earth.

(Parent - country Queensland)

I would like to show an interest in my other children's schools but it would be silly to commit myself on a regular basis. I have stopped doing Meals-On-Wheels as well, which I loved... My son needs to be looked after by people who know how to deal with him and I can't impose on my friends too much. After all, he is seventeen and can be quite a handful.

(Parent - country Victoria)

- 9.2.6 Emergency care When a crisis arises that makes impossible the care of a disabled person at home, emergency care should be available. Sufficient accommodation, staffed by people trained to deal with crisis situations, is often not available. **Ad hoc** arrangements cannot guarantee that the needs of people in crisis will be competently met.

The unsatisfactory position I am writing to bring your attention to is the lack of places for handicapped people to go in emergencies. I personally know this from when my mother died [1981] and I could not find anywhere for my brother, who is epileptic.

(Country Victoria)

- 9.2.7 Family support General social work, counselling and other services should be available to disabled persons and their families at all times. Accessibility is a key consideration. Where disabled persons living at home attend therapy or other programmes, support must be available to their families to ensure that they are able to gain from such attendance. Epilepsy Associations can obviously play a part in family support.

We found everything for ourselves... **my** recommendation is that everybody should be put in touch with social workers who know what services are around and can advise parents on their retarded kids... There are parents now in the situation we were in five years ago.

(Parent - country Tasmania)

What we find fairly regularly is that our clients make slower progress than they could - even dip out altogether - because what they learn here they do not get the chance to do at home or are openly discouraged from it by their families who are used to dependent adult children... Our resources will not stretch to keeping up the intensive family contact that there needs to be.

(Rehabilitation facility
staff member - Melbourne)

- 9.2.8 Holiday opportunities. Section 7.4 considers the participation of persons who have epilepsy in recreational activities. Holiday programmes conducted by trained staff and open to disabled and non-disabled persons are apparently rare despite the need for them.

Our son is in need of a holiday where he can be with people of his own age doing those things 24 year olds do on holidays. His usual holiday is to be with his parents and this leads to great friction and unhappiness. Trying to get information on this subject has been particularly difficult.

(Parent - country SA)

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9.2.9 Flame help The need for such services was raised by a number of contacts. Many local government authorities provide them. Some have developed specialised services for families with disabled Members.. Expansion, rather than contraction, of home 'help services is desirable. (See comments following Sections 9.1.6 and 9.2.3.)

9.2.10 Bane supervision This entails a trained person caring for a disabled person (and her or his brothers and sisters where necessary) in the family home when parents are absent for short periods. The disabled person may be in her or his teens or older and require more than a baby sitting service. (See also comment following Section 9.2.4.)

Tao often we go alone as one of us has to stay with our son. We take him with us occasionally but, as you can imagine, that ,, is unsatisfactory for all concerned.

(Parent - Canberra)

9.2.11 Respite care This enables disabled persons to leave the family home regularly for short periods. For families, this provides a break from the expense of time, energy and emotional commitment involved in home care.

9.2.12 Respite care can be made available through short-term care in designated small residential settings, or less appropriately in large group settings. Programmes like Interchange in Victoria provide a valuable respite care option. A host family, trained and supported by Interchange staff, is matched with one that has a disabled Child. The host family accepts the Child into its home. Some positive benefits of the Interchange approach are: its provision of parent support; the introduction of disabled children into different caring and stimulating environments; and the fillip to public education about disability generally.

I would like to put my daughter somewhere for a while to give me a rest. A building... for people with epilepsy would help.

(Parent - Melbourne)

Looking after a man of 74 who is partly paralysed and fits several times a week is time consuming. I do not resent it... My question is - why is there nowhere for him to go, even for a few days: a month, to give me time to get out a bit and restore my energies?

(Spouse - country Victoria)

My family has had the marvellous opportunity to be part of a service called Interchange... We have hosted a disabled boy... My awn children have found it very rewarding and I have seen how much our willing involvement has meant to his parents.

(Interchange host parent - Melbourne)

9.3 SMALL GROUP ACCOMMODATION

- 9.2.1 The movement from hostel and institutional accommodation to small group accommodation for disabled people' needing permanent accommodation is the subject of much discussion. It is also of particular relevance to many persons who have epilepsy. Jonas (1980) found that in a South Australian centre providing accommodation for nearly 600 moderately to severely intellectually disadvantaged persons, 38.6% had epilepsy.
- 9.3.2 There ought to be enough places in specialised establishments to cater for disabled persons who can no longer be maintained in the family home or who freely choose to leave it, but who will require support to make the transition successfully. Most accommodation is available in large group settings. Places in small residential units are limited. The past impact of the Handicapped Persons Welfare Programmes and the Aged and Disabled Persons Homes Act has been to secure the place of large group accommodation.
- 9.3.3 An important point concerning accommodation arises in the context of Paragraph 9 of the Declaration (see Appendix I). Large group accommodation settings do not approximate normal life within the community and the full enjoyment of rights may accordingly be impeded by placement in such accommodation. The following comments, taken with those following Sections 9.1.5 and 9.1.8, show that experience of large group settings may be far from that envisaged in the Declaration.

In the hostel things were done on a large scale from meals to showering. It was so different to home he became very depressed and in the end we let him come home.

(Parent - Melbourne)

When my dear wife passed on it had been arranged for me to enter a nursing home... I cannot complain overly about the nurses who did what they could... Lack of privacy, an overwhelming sense of boredom, the regular monotony are part and parcel of old people's homes'. Despite her own problems I thank the Lord my daughter saw fit [if you will pardon my pun] to take me in to her own home.

(76 yearold male - Perth)

- 9.3.4 Small residential units located in residential areas and housing, and holding perhaps four or five people, came closer to normal community conditions than large group accommodation settings. Units must be staffed to fulfil the needs of residents. The level of support necessary will vary from constant care to home help on a regular basis.

- 9.3.5 Management of small residential - units is an important issue.' Government programmes, voluntary associations and community groups that develop these facilities must be accountable for a range of standards. But management should as much as possible be put in the resident's hands if .their lives are to closely resemble normal community experience.
- 9.3.6 The transition to integrated accommodation that small residential units represent: raises financial and industrial issues which can divert attention from the rights of disabled persons. The transition should continue with full acknowledgement of those rights.
- 9.4 SOME TRANSITIONAL ISSUES
- 9.4.1 As the movement towards small residential units proceeds, those providing services within them will need training to fill the roles involved. Those now working in large group settings, some of which are .run on . hospital models, and those who are employed as service -providers to residential units will encounter different environments. -Re-training for different professional carpetencies and attitudes will 'therefore be required.
- 9.4.2 The current provision: and management of residential facilities basically occurs within health or welfare frameworks. The appropriate area of administrative responsibility should be considered. Management, planning, staff training and the tenor of service provision should take into account the needs of the different residential facilities. The orientation must be suited to the need in . question, Which may not necessarily be that historically associated with it.
- 9.5 RECOMMENDATIONS
- 9.5.1 Support services Which enable disabled persons to remain in their homes should be provided (Section 9.1.3).
- 9.5.2 Management of small residential units should as much as possible be under the residents' control (Section 9.3.5).
- 9.5.3 Consideration should be given to the question whether health or welfare areas *of* policy development and administrative responsibility provide an appropriate framework for the management of residential facilities (Section 9.4.2).
- 9.5.4 Management, planning, staff training and service provision should take into account the needs of different residential facilities (Section 9.4.2).

CHAPTER TEN

INSURANCE AND SUPERANNUATION

There are a lot of things put out of reach if you have epilepsy... Insurance is another irritating one. It becomes so expensive that I'm sure other people decide as we did that the expense was too high on top of our other commitments.

(Spouse of 34 year old male - Canberra)

10.1 INTRODUCTION

10.1.1 Life and personal accident insurance and superannuation have important Social benefits. Through them individuals can make financial provision for themselves, and their families, in case of death or accident causing short-term or permanent disability. Superannuation, in addition, enables provision to be made for retirement. Insurance and superannuation are means of ensuring that, drastically altered economic and social circumstances and the consequent dependence on Government income security programmes are avoided upon retirement or loss of income.

10.1.2 The benefits of insurance cover do not extend, under current circumstances, to all persons who have epilepsy. In consequence, such individuals are unable to make provision for economic and social security on the same basis as their peers either because cover is not available to them at all or is available to them on different terms. This is true also of the Commonwealth Superannuation Scheme.

10.1.3 Disabled persons have the right to be-protected against all treatment of a discriminatory nature. Yet the difficulties they face in insurance and superannuation occur because of the presence of disability.

10.1.4 The effects of exclusion, in part or whole, from the benefits of insurance and superannuation extend to the families of persons who have epilepsy. They face real or potential disadvantages because the insured has epilepsy.

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- 10.2.1 As a fundamental operating principle, the insurance industry differentiates between risks. Presence of epilepsy is considered to constitute a higher risk in life and personal accident insurance. Consequently, premiums are adjusted upwards or, if the risk is considered too high, no policy is offered.

People who have epilepsy find the cost of life insurance (the premium they must pay) is higher than the cost to others of the same age. In response they adopt one of at least four courses. Firstly, if the 'cost is judged prohibitive', no insurance is taken even though they may wish to have it. Secondly, insurance is taken and higher premiums paid. Thirdly, cover is taken for a lesser value than than would otherwise have been preferred or deemed adequate. Premiums will be lower as a result. Fourthly, epilepsy is concealed from the insurer so that cover is provided at the same cost to others of the same, age.

- 10.2.3 The effect of concealment is apparently not understood by *some* who choose that course. Failure to disclose relevant information to an -insurer enables an insurer to avoid an insurance contract and to seek redress. The presence of epilepsy constitutes relevant information.

The insurance agent... doesn't know (I have epilepsy). With luck I won't need to claim for anything happening during a fit - it's a chance I have to take.

(Male - country South Australia)

I am under an insurance policy for \$50,000 but only because the epilepsy is kept away from their notice... If you tell a salesman you are on epileptic tablets they don't want to know you.

, (Female - country Queensland)

- 10.2.4 Personal accident insurance is most difficult to secure if a person has epilepsy. It is either unavailable or available at a very high cost. Cover is often taken with an exclusion for accidents attributed to epilepsy. In the words of one insurance contract: "Previous disability clause. Benefits not payable under policy as a 'result of epilepsy attack'".

Inability to secure personal accident cover can have adverse repercussions for self-employed persons or those wishing to establish their own businesses.

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Setting up a business is like jumping hurdles and the biggest hurdle I ran into, literally, was getting insurance for injury that would put me out of action. I couldn't get it unless I agreed that the policy left out epilepsy... Being only partially covered worries me.

(Male country Victoria)

10.2.6 Assessment of risk is based on actuarial data which seeks to determine whether a factor like epilepsy leads, for example, to increased likelihood of accident. If patterns do emerge premiums are adjusted according to the degree of risk, or the risk is deemed uninsurable. Actuarial data used in Australia may not always be accurate for the Australian experience of epilepsy. Some data was compiled outside Australia; some could be regarded as unreliable because it was compiled before the advent in the last two decades of significant improvement in diagnosis and treatment of epilepsy.

10.2.7 Other factors may influence the accuracy of data. Many people who have epilepsy decide not to take out insurance, or are unable to secure it. There is a resultant lack of data in relation to epilepsy and insurance on which actuarial tables can be reliably based. Another factor is illustrated by the following comment. It indicates at least that data gained from a study of claims may be unsatisfactory because insurers may avoid liability under a policy on the basis of circumstances which may be disputed.

My policy was written so that if I had a turn I would not be able to make a claim. The insurance company argued that my injury came about because of a petit mal attack. That is not true. I was fully aware of what was going on - it is still as clear as a bell in my own mind. I didn't walk into the mower - the mower rolled back onto me and I wasn't quick enough to get out of the way... There was no convincing the insurance company and I didn't get my money out of them.

(Male - Melbourne)

10.2.8 There is a need to determine whether actuarial data does reflect Australian experience. If it is found wanting, means must be found to develop accurate actuarial tables. Indeed the Australian Law Reform Commission, in its Report on Insurance Contracts (1982) noted that the main concern which has been expressed in relation to differentiation between risks on the basis of disability is not whether it should be permitted, but whether it is based on accurate data rather than unjustified assumptions made by individual underwriters (p.236).

The Commission further noted (p.243) that in some cases it may be impossible to obtain accurate statistical data. It recommended (p.243) that jurisdiction be conferred on the Human Rights Commission with respect to discrimination in insurance on the grounds of physical or mental disability.

10.3 THE COMMONWEALTH SUPERANNUATION SCHEME

10.3.1 The Commonwealth Superannuation Scheme (CSS) is compulsory for all

permanent employees of the Commonwealth Government and the majority of Commonwealth statutory authorities. Applicants for permanent employment are examined by a Commonwealth Medical Officer who must determine whether an applicant is medically fit for permanent appointment. At the same time the applicant is examined to determine whether he or she meets the General Medical Standard (GMS). The GMS is set by the Commissioner for Superannuation in consultation with the Department of Health.

10.3.2 Failure to meet the GMS does not render an applicant ineligible for permanent appointment. It is used for superannuation purposes. If the GMS is not met a person is issued with a Benefit Classification Certificate (BCC). Any health impairment likely to cause retirement before normal retirement age attracts a BCC. Appendix 4 contains an outline of the effect of a BCC on superannuation entitlements. Persons who retire on invalidity grounds before completing 20 years service, or who die while a BCC is still in force may have their superannuation benefit adjusted downwards if retirement or death is judged to be caused, or substantially contributed to, by the condition specified on the BCC.

10.3.3 It is clearly important that the standards applied to epilepsy are reasonable. Appendix 4 details the current standards. They contain inadequacies like those discussed in section 8.3 which relate to standards for permanent appointment. The GMS is not met where a person is "liable to recurring, major diurnal fits".

The words "recurring", "major" and even "liable" are open to wide interpretation. The relevance of this standard in predicting length of service is open to question.

10.3.4 The same is true of the requirement that a person be "free of an attack, without the use of drugs for a period of at least 5 years". It is of questionable relevance given the success of current methods of diagnosis and treatment in achieving seizure control and avoiding medication side-effects. There seems good reason to urge a review of the GMS with regard to epilepsy in order to determine the relevance and reasonableness of the standards applied.

10.3.5 The ability to provide for the economic and social security of oneself and one's family through the CSS is restricted where epilepsy occurs. That benefits are unequally distributed on the basis of disability is discriminatory. Compensatory measures, or changes to benefit design, appear to be necessary if disability alone is not to enforce disadvantage. The paper "Reforming the Australian Public Service: A statement of the Government's intentions", 1983, contains a commitment to Equal Employment: Opportunity for disabled persons (see Section 8.3). Flowing from this commitment in practice, an increasing number of disabled persons will form a group within the Australian, Public Service: Which is disadvantaged because of disability alone..

10.4 WORKERS' COMPENSATION

10.4.1 Some employers believe that workers' compensation premiums would rise if they hired a disabled person (see Section 8.2.5). This is incorrect and easy to refute. Premiums are arrived at for an individual employer on the basis of the employer's safety record. The act of hiring a disabled person does not, of itself, attract increased premiums.

10.4.2 More problematic is the fear that a disabled person is more likely to suffer a work-related injury than a non-disabled person. Many employers feel it is unreasonable to run a higher risk of workers' compensation claims being made. Workers' compensation is the fastest growing component of labour costs. A higher incidence of claims would attract even higher premiums. This reasoning adds up to a powerful disincentive to employers even though there is evidence (Schwartz, 1978, for example) that in the case of Workers who have epilepsy their safety record is similar to, even better than, their non-disabled counterparts. There appears to be a need for a detailed study of the Australian experience so that the issues in contention can be clarified.

10.4.3 Nevertheless, the disincentive to the employment of people with disabilities is strong because while any employee may suffer work-related injury, workers' compensation is also payable when a pre-existing injury or disability recurs or is worsened due to work-related causes. This factor puts disabled workers at a labour market disadvantage. One possibility for action might be the establishment of a Second Injury Fund as was favoured in the Report of the Judicial Inquiry into the Workers' Compensation Act, 1978 (of Western Australia). A Second Injury Fund is one to which all employers contribute. All employers share any risks involved in employing a disabled worker rather than an employer bearing the risk alone.

10.5 RECOMMENDATIONS

- 10.5.1 A study should be undertaken to determine whether actuarial data on epilepsy reflects Australian experience. If it does not, accurate actuarial tables should be developed (Section 10.2.8).
- 10.5.2 A detailed study of workers' safety records in Australia should be undertaken so. as to compare those of non-disabled workers and workers with epilepsy (Section 10.2.4).
- 10,5.3 A review of . the General Medical Standards for the Commonwealth Superannuation Scheme with particular regard to epilepsy should be undertaken in order to determine the relevant and reasonableness of the standards applied (Section 10.3-4).
- 10.5.4 The possibility of the establishing a Second Injury Fund such as that proposed in the Report of the Judicial Inquiry into the Workers' Compensation Act, 1978 (of Western Australia) should be investigated (Section 10;4.3).

CHAPTER ELEVEN

IMMIGRATION

11.1 INTRODUCTION

- 11.1.1 Five contacts commented on immigration matters. Two were immigrants of over twenty years standing. Both had epilepsy and were concerned about reprisals if it was discovered they had concealed their epilepsy when applying to immigrate:

For twenty-four years I have been what you might call an outlaw... I doubt I'd be sent packing after all this time but I'm not fixing to find out.

(58 year old male - Adelaide)

I have paid my way for twenty years now. I don't want to be sent home because my life is here now.

(53 year old female - Melbourne)

- 11.1.2 Others complained of immigration restrictions imposed on people who have epilepsy.

For three years we've run up against the same stupid rules. My brother-in-law has plenty of money, a job to go to and us to support him and his family if it came to that. It is only that he's got epilepsy which is the stumbling block.

(Female - Melbourne)

- 11.1.3 Epilepsy Associations reported seven requests for assistance to secure acceptance of migration applications in recent years. In two instances the initial rejection was overturned through persistence and the application of pressure. Such a situation is arbitrary and unsatisfactory. More unsatisfactory is the discriminatory nature of Australian law and policy in regard to immigration and epilepsy.
- 11.1.4 Under Australia's present immigration policy, persons who have epilepsy are unable to migrate to Australia although under certain circumstances, discretion can be exercised to allow their immigration (see Section 11.3).

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- 11.1.5 In addition, section 16(1)(c)(i) of the Act provides that a person with a prescribed disease or condition who enters Australia without a specially endorsed entry permit becomes a prohibited immigrant. It reads:

Where ... a person who enters or entered Australia as an immigrant... at the time Of entry is or was a person of any of the following descriptions, namely: ... a person suffering from a prescribed physical or mental condition... that person shall.., be deemed to be a prohibited immigrant unless he is the holder of an entry permit endorsed with a statement that the person 'granting that permit recognizes him to be a person referred to in this sub-section.

- 11.1.6 Regulation 26 of the Migration Regulations (as at October, 1979) lists the diseases and conditions Which Are prescribed for the purposes of section 16 (1) (c) (i). Regulation 26 states in part:

The following diseases and physical and mental 'disabilities and conditions are prescribed for the purpose of paragraph (c) of sub-section (1) of section 16 of the **Act**:-

(a) serious mental deficiency, dementia, insanity, epilepsy, drug addiction, alcoholism...

- 11.1.7 Epilepsy Associations have been critical of the inclusion of epilepsy within the terms of Regulation 26, emphasising as it does that exclusion is the starting point for consideration of all cases Where epilepsy is involved.

11.2 MIGRATION POLICY

- 11.2.1 The Principles of Immigration Policy were introduced on April, 19th, 1982. They guide the implementation of the Migration Act. Principle 4 states in part:

Immigration should be applied on a basis which' is non-discriminatory... The principle of non-discrimination means that policy will be applied consistently to all applicants regardless of their race, colour, nationality, descent, national or ethnic origin, sex or religion.

- 11.2.2 Disability is conspicuously absent from this list. Whether its absence was an act of omission or commission, Principle 4 disregards the Declaration, which states that disabled persons shall be protected against all regulations of a discriminatory nature (Paragraph 10).

11.2.3 Principle 6 states in part:

Eligibility and suitability standards for migrants should reflect Australian social mores and Australian law.

It is inconsistent to debar persons who have epilepsy from permanent residence while social mores have evolved and continue to evolve towards the integration of disabled persons into society and towards the full recognition of their rights.

11.2.4 In addition, Australian Governments have enacted legislation promoting and protecting equality of opportunity and access and respect for the dignity of disabled persons. Given this trend in law-making, it is inconsistent to deny, absolutely, those Who have epilepsy the opportunity to migrate.

11.2.5 A consideration of other nations' policies is instructive. Answers to the following questions were sought from Embassies or High Commissions of 24 nations.

- (a) Would an individual with epilepsy be permitted to become a permanent resident?
- (b) Would members of a family, of which one person has epilepsy, be permitted to become permanent residents?

11.2.6 Of fifteen full replies received, only two nations - Mexico and Venezuela - rejected applicants on the grounds of epilepsy. Of the remaining 13 replies, 9 indicated without qualification that epilepsy was no bar to immigration; - Britain; Canada; Cyprus; France; Holland; Italy; Lebanon; Sweden; and Turkey.

11.2.7 Four nations responded affirmatively, with qualifications: Greece; Ireland; USA; and West Germany. Greece and Ireland grant temporary, not permanent, residence for differing time intervals. USA policy is that epilepsy must not render a person incapable of supporting herself or himself. The West German response was positive except that each application is approved at the discretion of the competent alien's office.

11.2.8 In comparison with nations of similar political, economic and social complexion (Britain; Canada; France; USA), and with nations from which many migrants are drawn (Greece; Ireland; Italy; Turkey) Australia's policy is out of step.

11.2.9 These nations apply non-discriminatory policies to families as well as to individuals wishing to immigrate. Here too Australia is out of step. The Migrant Entry Handbook contains instructions' and procedures to be followed by Immigration officers. Paragraph 4-6.1 states that children with mental or physical handicaps:

regardless of age, dependency or settlement intentions, must be considered as migrating. Failure to meet requirements (usually on the basis of medical reports) will normally result in refusal of all members of the family unit.

11.2.10 Even where the family member who has epilepsy does not intend to immigrate, her or his family may be refused the opportunity. This clearly seems unfair.

11.3 THE SPECIAL CASE

11.3.1 There is room for discretion when epilepsy affects an immigration application Section 16 of the Migration *Act* states a person will not be regarded as a prohibited immigrant if he or she is the "holder of an entry permit endorsed with a statement that the person granting that permit recognises him to be a person" with a prescribed condition.

11.3.2 Chapter 6 of the Migrant Entry Handbook lists circumstances where approval to immigrate may be granted even though health requirements are not met. With epilepsy, much depends on an informed understanding of the condition and its likely prognosis, which can be affected by many variables. Misconceptions abound about epilepsy both in the general community and the medical profession. There is cause for concern that the basis on which discretion is exercised may be inadequate.

11.3.3 Even if it is adequate, treating epilepsy as a "special case" gives rise to misgivings. The process is such that all persons who have epilepsy are excluded unless special circumstances are demonstrated. The starting point is exclusion in contradiction with the Declaration's support of integration and therefore, inclusion, as a first principle.

11.4 IMMIGRATION AND RIGHTS

11.4.1 Denial of the opportunity to immigrate on the basis of epilepsy alone infringes several rights. Broadly they are: that disabled persons are entitled to have their special needs taken into account at all stages of economic and social planning (immigration policy being a component of such planning); and that they shall be protected from all regulations of a discriminatory nature (Paragraphs 8 and 10 of the Declaration respectively).

- 11.4.2 The emphasis of the present policy is on disability. People who have epilepsy are improperly disadvantaged by focusing upon their Seizure condition or disabilities associated with it rather than emphasising their abilities.
- 11.4.3 The disability focus means many disabled persons are unable to contribute to Australian life when they are as much able to do so as other immigrants. Disability itself is as much a part of cultural diversity as language or religion and is part of every culture.
- 11.4.4 Selective immigration excluding disabled persons has several effects. Firstly, it limits, rather than expands or supports cultural diversity. Secondly, it lends credence to the notion that disabled persons form a less worthy sub-group, aside from the cultural mainstream. Thirdly, it stigmatises disabled persons by promoting the "separate class" attitude - a class that can be acceptably singled out for discrimination because of disability.
- 11.4.5 One reason advanced for the disability emphasis is a concern to minimise the costs of disability to Australian taxpayers. Principle 2 of the Principles of Immigration Policy states in part:

As a general rule, Australia will not admit for settlement people who would represent an economic burden to Australia through inordinate claims on welfare, health or other resources.

It is difficult to understand how every person who has epilepsy would represent an economic burden but there is no allowance for individual difference. Every person is excluded. To weigh the cost of epilepsy without considering other factors is altogether too narrow. Concentration on cost ignores the value of potential contributions to productivity through workforce participation, payments to Government revenues, and purchase of goods and services. Contributions to family life, ethnic communities and society generally, even to the resources mentioned in Principle 2 through a professional or voluntary commitment, surely have some place in any assessment of cost.

- 11.4...6 A review of present immigration law as it applies to persons with epilepsy should be undertaken. The Government's right to determine Who shall enter Australia must be exercised with a view to minimising, if not eliminating, infringements of the rights of disabled persons. Every effort should be expended to effectively accommodate those rights.

11.4.7 Organisations of disabled persons must be able to contribute their special knowledge and skills to any review process. They will more readily be aware of infringements to disabled persons' rights. The Declaration supports their involvement in all matters -relating- to disabled persons. A thorough review would bring to light the conflicts between rights and the provisions of the Act. Satisfactory resolution of those conflicts will best be achieved through emphasising ability rather than disability.

11.5 RECOMMENDATION

11.5.1 A review of present immigration law as it applies to persons with epilepsy should be undertaken. From the early stages of the review contributions from organisations of disabled persons should be sought and included (Section 11.4.7 and 11.4.8).

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RECOMMENDATIONS

RECOMMENDATIONS FROM CHAPTER TWO

- 2.8.1 Australian research should be undertaken so as to determine the correlation, if any, between socio-economic background and the incidence of epilepsy (Section 2.4.7).
- 2.8.2 An emphasis should be placed on the provision of services and programmes for those people under twenty years of age with epilepsy (Section 2.4.9).

RECOMMENDATIONS FROM CHAPTER THREE

- 3.3.1 Public education programmes aimed at raising general community awareness of the real nature of epilepsy should be implemented (Section 3.1.4).
- 3.3.2 Materials providing basic information on epilepsy should be produced in different languages (Section 3.2.4).
- 3.3.3 Australian films on epilepsy suitable for children of late primary and early post primary school age and adults should be produced with NEAP input. Films for adults should be suitable for general audiences and for use in professional pre-service and in-service education (Section 3.2.9).
- 3.3.4 Public education programmes should include the provision of well researched and presented material for wide distribution. Funding for the programmes should be adequate to ensure the effective use of such materials (Section 3.2.10).
- 3.3.5 Adequate government financial assistance should be given to the NEAA to enable it to take responsibility for resource development. State Epilepsy Associations should be funded so as to enable them to facilitate educational programmes including the distribution of suitable material (Section 3.2.10).

RECOMMENDATIONS FROM CHAPTER FOUR

- 4.5.1 Educational authorities and Epilepsy Associations should develop curriculum materials on epilepsy (Section 4.3.4).
- 4.5.2 Teacher training courses should include a core unit in special education in which informed discussion of epilepsy should take place (Section 4.3.8).

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- 4.5.3 The ACT time release scheme in which teachers undertake oneyear full time studies leading to a Graduate Diploma in Special Education and then return to their schools to act as resources for teachers of children with special needs should be improved and implemented in all States and Territories. In order to promote this scheme, appropriate courses should be included at Bachelor of Education and Graduate Diploma levels (Sections 4.3;9 and 4.3.10).
- 4.5.4 Vocational counselling and careers education should give consideration to the disadvantages a person with epilepsy may encounter in seeking employment. In particular, information on how to cope with discrimination and how people with epilepsy should present themselves and their epilepsy to potential employers must be included- (Section 4.3.13).
- 4.5.5 The integration of children from special education settings into mainstream education must be accomplished in such a way as to provide for flexibility in the use of teaching skills and the easy movement of children between special and mainstream settings. This 'would require integration of the special and mainstream settings themselves (Section 4.3.16).
- 4.5.6 Integration should only take place when the disabled child is ready and the special and mainstream schools are integrated, Mainstream schools should be socially ready to receive disabled children and the school community must be carefully prepared (Section 4.3.18).
- 4.5.7 A standardised system of recording health or treatment information should be introduced in schools (Section 4.4.2).
- 4.5.8 Such a system should operate in recognition of the right to privacy. Therefore it should be subject to clearance by the child and her or his parents; should be objective and relevant to the child's schooling and should be subject to review by the parents and child who should also retain the right over transfer from one school to another (Section 4.4.3).

RECOMMENDATIONS FROM CHAPTER FIVE

- 5,5.1 Pre-service training for professionals who might come into contact with people who have epilepsy should include instruction on epilepsy or, at least, disability (Section 5.3.2.).
- 5.5.2 All students who might be employed in positions involving service provision or decision making relevant to persons who have epilepsy must learn something of the social perspectives of disability. Issues specific to hidden disability should form part of that learning as should the usefulness and appropriateness of consulting with or referring to organisations like Epilepsy Associations (Section 5:3,4),
- 5.5.3 Intensive instruction about epilepsy, its treatment, social impact and the availability of resources should be part of all courses for health care professionals (Section 5.3.6).

- 5.5.4 Professionals in many disciplines serve and affect the lives of disabled persons. Therefore, professional's pre-service training should be alert and responsible to the needs of disabled people (Section 5.3.9).
- 5.5.5 NEM should be supported by the Government to co-ordinate specialist resource development for pre-service training (Section 5.3.10).
- 5.5.6 In-service education programmes should be implemented for health and welfare and related professional groups (Section 5.4.1).
- 5.5.7 Epilepsy Associations and other organisations with an interest in dealing with epilepsy as well as institutions which may have contact with people with epilepsy should investigate the possibility of conducting joint seminars and other relevant programmes for in-service education purposes (Section 5.4.2).
- 5.5.8 Medical assessments prior to entry to post secondary professional education courses could eliminate some persons who have epilepsy, thus denying them access to employment or practice in the field of their choice on the basis of their epilepsy alone. This places the emphasis on disability rather than ability and ignores the broad work options in most disciplines. Informed vocational counselling should take the place of medical assessment (Sections 5:5.2 -

RECOMMENDATIONS FROM CHAPTER SIX

- 6.4.1 Public transport personnel need to be educated on how to deal with a person who is having a seizure (Section 6.1.6).
- 6.4.2 The particular transport problems experienced by country people with epilepsy need to be addressed (Section 6.1.7).
- 6.4.3 Uniform regulations governing the issue of licences to people with epilepsy should be introduced (Section 6.2.7).
- 6.4.4 A Licensing Advisory Board should be set up. Members should include those with a broad social perspective as well as neurologists and medical practitioners who should be familiar with all aspects of epilepsy. Decisions made by the Board should be subject to review (Section 6.2.9).
- 6.4.5 Eligibility criteria for the Mobility Allowance should be reviewed (Section 6.3.3).

RECOMMENDATIONS FROM CHAPTER SEVEN

- 7.10.1 Consumers should be involved in service planning, evaluation and delivery and should, as far as possible, control decision making in these areas (Section 7.1.3 and 7.1.4).

- 7.10.2 There is a need for independent and reliable comparative information on the treatment, procedures and effectiveness of natural and conventional therapies for epilepsy (Section 7.2.14).
- 7.10.3 Specialist care, including neurology clinics held at regular intervals, should be made available in country areas (Section 7.3.1).
- 7.1.4 Eligibility criteria for *IPTAAS* should be amended so that people who have epilepsy can attend the nearest appropriate specialist service (Section 7.3.3).
- 7.10.5 The need for special centres for epilepsy should be investigated (Section 7,4.3).
- 7.10.6 Rehabilitation programmes need to address the problems of unemployment which will probably face persons who have epilepsy despite their completing such programmes successfully (Section 7.5.4).
- 7.10.7 Eligibility for rehabilitation programs and the location of these programmes need to be investigated with a strong emphasis on expansion, particularly in country areas, so as to provide a comprehensive service (Section 7.5.5).
- 7.10-.8 Reasons for the lack of women in CRS programmes must be investigated and initiatives taken to redress the imbalance between women and men taking advantage of such programmes (Section 7.5.7).
- 7.10.9 The HPAAs should be amended to encourage a wider range of work training opportunities (Section 7.5.8).
- 7.10.10 The information needs of rehabilitation professionals and the best way of meeting those needs should be investigated (Section 7.5.9).
- 7.10.11 Consideration should be given to establishing in other States epilepsy specific employment preparation programmes such as the South Australian TAPS Programme (Section 7,6.4).
- 7.10.12 Information which places an appropriate perspective on epilepsy and which would be suitable for recreational professionals, sporting clubs and organisations as well as persons who have epilepsy and their families should be produced, recorded in an accessible form and publicised (Section 7.7.8).
- 7.10.13 An accessible information bank containing written and audio-visual materials outlining recreational programmes, ideas and resources for sporting and community groups should be established and promoted (Section 7.7.8).
- 7.10.14 Appropriate resources including basic information such as a glossary of terms should be made available for use by counsellors and interpreters (Sections 7.8.4 and 8.9.5).

- 7.10.15 The criticisms made by some users of Epilepsy Association services should be considered by the Associations and, where valid, appropriate changes made (Section 7.9.10).
- 7.10.16 A comprehensive strategy to meet the needs of persons who have epilepsy should be developed in Australia. Crucial to the success of such a plan is the inclusion of Epilepsy Associations (7.9.15).

RECOMMENDATIONS FROM CHAPTER EIGHT

- 8.7.1 Material which will help employers assess the suitability of workers with epilepsy for particular jobs should be produced (Section 8.2.6).
- 8.7.2 Further research should be undertaken to determine:
- i) employers' objections and reservations about employing a person who has epilepsy; the factors which affect job suitability for persons who have epilepsy (Section 8.2.7).
- 8.7.3 Pamphlets on the employment of persons with epilepsy should be produced specifically for small business and should include: relevant information; answers to common but ill-founded objections and reservations; and an easy to administer assessment guide to enable employers to make appropriate employment decisions. Attention should also be drawn to professional expertise such as that offered by the CES and Epilepsy Associations (Section 8.2.9).
- Promotional activities such as those undertaken during the International Year of Disabled Persons, 1981, should be ongoing (Section 8.3.11).
- 8.7.5 Medical standards for persons with epilepsy should be reviewed to enable EEO recruitment programmes to work more effectively (Section 8.3.9).
- 8.7.6 Within Commonwealth departments and statutory authorities the development of EEO policies, appointment of EEO officers and implementation of EEO should attract a high priority (Section 8.3.11).
- 8.7.7 Consultation with disabled persons and representative organisations should take place and a standard training package and selection criteria for DPOs should include appropriate information on epilepsy. If a DPO position is vacated for any reason for any period it should be filled by a trained DPO (Section 8.4.12).
- 8.7.8 The information base on disabled persons and employment should be expanded so that adequate information is available to planners and service providers (Section 8.4.14).

- 8.7.9 Broad staff development programmes should be provided for sheltered workshops. Information about epilepsy should form a part of programmes but issues such as tendering, marketing, health and safety and personnel management should also be covered (Section 8.5.19) -
- 8.7.10 First aid posters on epilepsy which could be accessible to those in workshops should be produced to ensure the safety of persons with epilepsy (Section 8.5.20).
- 8.7.11 Discussions should take place with governments and relevant Commonwealth departments, the trade union movement, employer organisations, disabled persons and their representative organisations and the Department of Employment and Industrial Relations with a view to developing disabled workers' co-operatives (Section 8.6.8).

RECOMMENDATIONS FROM CHAPTER NINE

- 9.5.1 Support services which enable disabled persons to remain in their homes should be provided (Section 9.1.3).
- 9.5.2 Management of small residential units should as much as possible be under the residents' control (Section 9.3.5).
- 9.5.3 Consideration should be given to the question whether health or welfare areas of policy development and administrative responsibility provide an appropriate framework for the management of residential facilities (Section 9.4.2).
- 9.5.4 Management, planning, staff training and service provision should take into account the needs of different residential facilities (Section 9.4.2).

RECOMMENDATIONS FROM CHAPTER TEN

- 10.5.1 A study should be undertaken to determine whether actuarial data on epilepsy reflects Australian experience. If it does not, accurate actuarial tables should be developed (Section 10.2.8).
- 10.5.2 A detailed study of workers' safety records in Australia should be undertaken so as to compare those of non-disabled workers and workers with epilepsy (Section 10.2.4).
- 10.5.3 A review of the General Medical Standards for the Commonwealth Superannuation Scheme with particular regard to epilepsy should be undertaken in order to determine the relevant and reasonableness of the standards applied (Section 10.3.4).
- 10.5.4 The possibility of the establishing a Second Injury Fund such as that proposed in the Report of the Judicial Inquiry into the Workers' Compensation Act, 1978 (of Western Australia) should be investigated (Section 10.4.3).

RECCMENDATION FROM CHAPTER ELEVEN

11.5;1 A review of present immigration law as it applies to persons with epilepsy should be undertaken. From the early stages of the review contributions from organisations of disabled persons should be sought and included (Section 11.4.7 and 11.4.8).

DECLARATION ON THE RIGHTS OF DISABLED PERSONS

The General Assembly,

Mindful of the pledge made by Member States, under the Charter of the United Nations; to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

Reaffirming its faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, the Declaration of the Rights of the Child and the Declaration on the Rights of Mentally Retarded Persons, as well as the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and other organizations concerned,

Recalling also Economic and Social Council resolution 1921 (LVIII) of 6 May 1975 on the prevention of disability and the rehabilitation of disabled persons,

Emphasizing that the Declaration on Social Progress and Development has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

Bearing in mind the necessity of preventing physical and mental disabilities and of assisting disabled persons to develop their abilities in the most varied fields of activities and of promoting their integration as far as possible in normal life,

Aware that certain countries, at their present stage of development, can devote only limited efforts to this end,

Proclaims this Declaration on the Rights of Disabled Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

1. The term "disabled person" means any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities.
2. Disabled persons shall enjoy all the rights set forth in this Declaration. These rights shall be granted to all disabled persons without any exception whatsoever and without distinction or discrimination on the basis of race, colour, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation applying either to the disabled person himself or herself or to his or her family.
3. Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.
4. Disabled persons have the same civil and political rights as other human beings; paragraph 7 of the Declaration on the Rights of Mentally Retarded Persons applies to any possible limitation or suppression of those rights for mentally disabled persons.
5. Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.

6. Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthotic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration.

7. Disabled persons have the right to economic and social security and to a decent level of living. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions.

8. Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning.

9. Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom. If the stay of a disabled person in a specialized establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.

10. Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.

11. Disabled persons shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons and property. If judicial proceedings are instituted against them, the legal procedure applied shall take their physical and mental condition fully into account.

12. Organizations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons.

13. Disabled persons, their families and communities shall be fully informed, by all appropriate means, of the rights contained in this Declaration.

DECLARATION ON THE RIGHTS OF MENTALLY RETARDED PERSONS

The General Assembly,

Mindful of the pledge of the States Members of the United Nations under the Charter to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

Reaffirming faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, the Declaration of the Rights of the Child and the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and other organizations concerned,

Emphasizing that the Declaration on Social Progress and Development has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

Bearing in mind the necessity of assisting mentally retarded persons to develop their abilities in various fields of activities and of promoting their integration as far as possible in normal life,

Aware that certain countries, at their present stage of development, can devote only limited efforts to this end,

Proclaims this Declaration on the Rights of Mentally Retarded Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.
2. The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.
3. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.
4. Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.
5. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.
6. The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offence, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.
7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

Answers to the following questions formed the basis for Truch of Chapter Five, "Professional Education's.. The distribution of the questions, and the level of response, is outlined in 5.2.

1. In courses conducted within your Faculty, how much time, if any, is devoted to consideration of:
 - a. epilepsy as a condition and its treatment?
 - b. the social impact of epilepsy on an individual and on her/his family?

the social impact of disability on an individual and on her/his family?
2. How is the learning structured (lecture, discussion, placement) where time is devoted to matters raised in Question 1?
3. What strengths are evident in the manner in which your Faculty deals with these matters?:

What shortcomings are evident?

What assistance, if any, would your Faculty require to bolster the strengths and minimise the weaknesses present?

What roles, if any, could be developed by the Epilepsy Association in your State to assist your Faculty in bolstering the strengths and minimising the weaknesses identified?
4.
 - a. Does your Faculty admit students who have epilepsy?
 - b. Are there any special conditions attached to the entry into your Faculty of students who have epilepsy?



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COMMONWEALTH OF AUSTRALIA

IN REPO PLEASE QUOTE 80/6753
 IW.BG
 Med.q.D.

2 December 1983

Mr Rob Sheehan
 672 Nicholson Street
 NORTH FITZROY VIC. 3068

Dear Mr Sheehan,

refer to your letter of 31 October 1983 addressed to Dr B.P. Kean, concerning your study into epilepsy and human rights:

The answers to your queries concerning medical standards administered by this Department are as follows:-

1. Medical standards applied to persons who have epilepsy and who wish to take up employment within the Commonwealth Public Service

An applicant may be considered to be medically fit for permanent appointment to the Commonwealth Public Servicewhere, in the opinion of the examining Commonwealth Medical Officer (CMO), the applicant is of sufficiently sound health to allow him to serve efficiently for at least 3 years or, in the case of a prospective trainee or apprentice, for the length of the training period (including work on the job during training) plus a further 3 years.

The applicant:

- (i) should be able to carry out all the duties of the position;
- (ii) should not require more than normal periods of sick leave.

The following information is given to CMOs to assist them in assessing an applicant's capacity to serve efficiently for at least 3 years -

"Epilepsy: Appointment should not be recommended if a person is liable to recurring major, diurnal fits. It may be recommended where there is reliable evidence that there has been an absence of attack during the 2 years preceding the examination (with or without medication) and the appointment involves no risk to the applicant or others. Appointments may also be recommended where applicants suffer from minor Petit mal or nocturnal epilepsy, or is a borderline case. Supporting evidence and all reasons for the recommendation should be given."

Applicants for permanent appointment are also examined to see whether they meet the General Medical Standard. This standard has been adopted for superannuation purposes so that the Commissioner for Superannuation can determine whether or not there is a risk that the appointee will retire on invalidity grounds or die before reaching maximum retiring age because of a present condition or a condition that has been present in the past. For epilepsy this is -

(a) Standard not met where a person is liable to recurring major diurnal fits.

(b) Standard met if:

(i) a person has been free of an attack, without the use of drugs for a period of at least 5 years, and

(ii) performance of duties to maximum age or retirement is expected.

(c) Resumption of duty of pensioners

A pensioner invalidated with epilepsy may be certified as fit to return to employment if:

(i) the condition is adequately controlled by medication, there has been no significant attack for at least 2 years, and there has been no more than one nocturnal attack in any 3 month period,

(ii) the CMG is satisfied that the person is cooperative and prepared to follow medical instructions,

(iii) his medical history, including sick leave records and clinical examination supported by a specialist report and electro-encephalogram indicates that the epilepsy is unlikely to prevent effective performance of his duties, and

(iv) the duties are unlikely to involve danger to the applicant or others, e.g. it would not be expected that the applicant would drive public transport.

(d) Resumption after sick leave may be recommended where the conditions set out in paragraph (c) above have been met.

Where a person does not satisfy the General Medical Standard but is otherwise fit for appointment he is granted a Benefit Classification Certificate by the Commissioner for Superannuation. If this Certificate is in force when the person retires on the grounds of invalidity, or dies, the superannuation benefit payable may be adjusted. The benefit will be adjusted if the Commissioner for Superannuation is of the opinion that the death or incapacity of the person was caused or was substantially contributed to by the condition specified

in the Benefit Classification Certificate or by a condition or conditions connected with such a condition.

2. Setting of Medical Standards

The standards for appointment and the General Medical Standard are set by the Public Service Board and the Australian Government Retirement Benefit Office, respectively, in consultation with senior medical officers of the Commonwealth Department of Health. Standards for appointment to special occupations or to Statutory Authorities are generally set by the employing authority concerned, in consultation with the Department of Health.

3. Revision of Standards

The standards are kept under review and amendments are made as and when deemed necessary.

4. Seizure-free period prior to employment

Applicants should have been free of recurring major, diurnal fits for a period of 2 years preceding the medical examination. (This is discussed in detail in answer to your first question)

I trust the above information answers your queries.

Yours sincerely,:

(Z.D. Welch)
Senior Medical Officer
International Health & TB Branch

In a letter to the Public Service Board, dated 22 August 1983, a series of questions were put relating to the Board's policy on Equal Employment Opportunity for disabled persons. One question sought information regarding the administration of selection tests to disabled persons seeking permanent appointment to the Australian Public Service.

In a letter received from the Board, dated 3 November 1983, this question was answered as follows:

"Guidelines are issued to the Board's Regional Offices for the testing of disabled people. These are included as part of the Board's Test Manual. Within these guidelines epilepsy is treated as a disability necessitating the use of modified selection tests and test administration procedures; it is considered that the effects of medication taken to control the epilepsy may place candidates at a disadvantage in comparison with other applicants'. This applies particularly where 'speed and accuracy' tests are used. The alternative tests recommended for use under these circumstances are modified in terms of their content and time limits to effectively remove the 'speed' component from the test. A copy of the guidelines is attached for your information."

EPILEPSY PHONE-IN

BACKGROUND

Phone-ins are being used more frequently as a means of gathering views and perspectives on social issues and problems from those who are affected by them. The advantage of a phone-in is its anonymity and the availability of telephones to most members of the community.

Although many people within institutions do not have open and private access to telephones, it is difficult to cater for the variety of languages within the community and it is costly for those who make STD calls, just over 100 calls were received on the day. The average call lasted about 17 minutes and useable information was gained from 96 of the calls.

This appendix on the conduct and result of the epilepsy phone-in is based upon notes and a report prepared soon after the phone-in was held. Some further refinement of information gathered from the phone-in took place after the above mentioned report was completed.

ORGANISATION

Publicity was arranged with the co-operation of most Melbourne AM and FM radio stations, most suburban newspapers and an interview on a morning TV program.

The Epilepsy Foundation of Victoria made its premises available and four lines were open for calls between 8.00 am and 8.00 in on Saturday, 10 September 1983.

-Volunteer interviewers were from a variety of backgrounds, mainly nurses and teachers, and they attended a training session prior to the Saturday. The questionnaire was quite long, but it seemed that those who rang in were happy to work through it.

Follow-U0

It was necessary to ensure that any callers who wanted to could receive further information on epilepsy or further personal contact. Sixty-five callers requested further information. Sixteen requested personal contact. Epilepsy Foundation staff made time available to carry out these important tasks.

Medical

67% of callers commented on medical services. Of these 19% were happy with the services they received and 69% were dissatisfied with the services they received.

Of those who were satisfied, the most frequently recorded causes for satisfaction were:

doctors were informative about epilepsy and the treatment being adopted;
 the doctor was supportive in relation to social problems: linked to epilepsy and directed them to appropriate support services; and
 doctors assisted them in making enquiries or dealing with prejudice when it was experienced (filling an advocacy role).

Of those who were dissatisfied the most frequently mentioned causes of dissatisfaction were:

doctors do not communicate sufficiently about Medication Side-effects or long-term effects of medication, nor about alternatives to medication;
 doctors do not give those with epilepsy and their families sufficient, or even any, information about epilepsy itself;
 doctors do not appreciate the Social problems of having epilepsy; and
 doctors do not direct people with epilepsy to social support agencies that could assist them.

Several callers observed that doctors appeared to be inadequately informed about epilepsy.

It is interesting that 8% of callers who commented on medical services said they now preferred to consult with naturopaths, chiropractors or acupuncturists. By and large the Epilepsy Associations have tended to press the importance of conventional western medicine. People are beginning to use alternative treatment methods and it seems that the Epilepsy Associations must be informed about these treatments and support those people who wish to use them. These people still have to deal with epilepsy and if they choose to seek alternative treatments it seems churlish to say to them that the Epilepsy Associations cannot assist because they do not support alternative treatments or do not know anything about them.

8% is a small number, but the number of alternative treatment practitioners is growing as is their popularity. This factor cannot be ignored however much disagreement there may be about the use of alternative medicines.

Education Needs

74% of callers made some comment indicating the need for more education about epilepsy. Of these:

- 90% stressed the need for better community education because of the ignorance and prejudice within the community;
- 39% stressed the need for more and better information about many different aspects of epilepsy and its treatment for persons with epilepsy and their families;
- 34% stressed the need for better education of GPs and teachers; and
- 27% stressed the need for better education of employers.

Clearly there is still such prejudice and ignorance in the community and many people mentioned the adverse affects it has on their lives.

Employment

60% of callers commented upon employment issues. Of these:

- 34% said that having epilepsy had caused them to lose jobs or be denied jobs;
- at least 21% had concealed their epilepsy from employers and CD workers for fear of losing their jobs; and
- 7% of callers said the QM officers had not understood epilepsy sufficiently.

Frequently made comments were:

- there is a need for employer and co-worker education;
- there is a need for better careers advice in schools; and
- there is a need for sources of employment advice for adult job-seekers with epilepsy.

5% of callers were receiving an invalid pension, two of whom noted that they could, and would prefer, to be working. 5% of callers were receiving unemployment benefits. Two callers were in sheltered employment.

Recreation

27% of callers mentioned recreation. Of these 46% cited epilepsy as the reason advanced for denying them the opportunity to participate in recreational activities. The remainder were able to participate, many successfully, though some felt that concealing their epilepsy was the reason they were able to take part.

Two callers mentioned difficulties in participating in their chosen recreations because of transport problems.

Mobility

Of the 17% of callers who mentioned problems related to driver's licences, 25% said they had concealed their epilepsy in order to gain their licences.

9% of all callers mentioned problems of social isolation due to their ineligibility for a licence.

Two callers mentioned annoyance at having to get full medical check-ups every twelve Months in order to retain their licence. Most of the tests carried out were unrelated to epilepsy.

Insurance

5% of Callers mentioned they were unable to obtain insurance of various kinds (accident, sickness, worker's compensation) because of epilepsy.

Groups

22% of callers mentioned the value of, or the need for, self-help/discussion/social groups.

GENERAL COMMENTS

A Matter of chance - it was clear that finding friends, employers, sporting clubs, government officers and doctors who had appropriate attitudes and sufficient understanding of epilepsy is a matter of chance. That the ,life-chances and social well-being of those with epilepsy is something of a lottery is a matter for concern.

The burden of Concealment - at least 47% of callers had concealed their epilepsy from one or more, in some cases all, of relatives, friends, employers, co-workers, sporting clubs, government officials and insurance companies. Overwhelmingly, the reason advanced for Aping so was the fear of: reprisal loss of social contact, Ices of financial security, loss of licence, loss of the opportunity to participate in sport, loss of dignity in the face of prejudice and ignorance.

CONCLUSION

More information could be drawn from the comments recorded during the phone-in. However, the above gives some idea of the major concerns that were highlighted. In a sense, the phone-in verifies information already :known., however, it is the first step towards quantifying the real extent of the issue.

For the Epilepsy Associations, the results of the phone-in are heartening. Of those callers who had used the services of the Epilepsy Foundation of Victoria the information, counselling and support functions were a significant factor in helping them to deal with their epilepsy and its attendant problems. While most Epilepsy Associations at present cannot provide the range of services the Epilepsy Foundation provides, the services they do provide are obviously crucial to those with epilepsy.

The oft-mentioned needs, education, information, support (whether through group meetings, counselling or by telephone), and understanding are all provided in some measure by Australia's Epilepsy Associations. Several callers made the point that such Associations fill the needs of those people who do not fit the 'categories' with which other services deal.

TABLE 1: Callers by age by sex by caller category

AGE	TOTAL	MALE	FEMALE	PE ¹	Pt ²		
Up to 12	-	-		-	-	-	-
- 13 20 N= %	8.33 (8)	2.08 (2)	6.25 (6)	8.33 (8)	-		-
21 3 - 0 N= %	21.87 (21)	8.33 (8)	13.54 (13)	12.5 (12)	5.20 (5)	3.12 (3)	1.04 (1)
31-40 % N=	29.16 (28)	9.37 (9)	19.79 (19)	18.75 (18)	7.29 (7)	2.08 (2)	1.04 (1)
41 -50 % N=	21.87 (21)	4.16 (4)	17.70 (17)	12.5 (12)	6.25 (6)	3.12 (3)	-
51 -60 % N=	12.5 (12)	5.20 (5)	7.29 (7)	8.33 (8)	2.08 (2)	1.04 (1)	
61+ % N=	6.25 (6)	2.08 (2)	4.16 (4)	3.12 (3)	2.08 (2)	1.04 (1)	-
TOTAL % N=	100.00 (96)	31.25 (30)	68.75 (66)	63.54 (61)	22.19 (22)	11.45 (11)	2.08 (2)

- PE = Person with Epilepsy
- Pt = Parent

- 3. R = Relative
- 4. 0 = Other

APPENDIX SEVEN

TESTING ARRANGEMENTS FOR THE HANDICAPPED

This section briefly covers the procedures for testing the physically handicapped.

All handicapped persons applying for entry to the Public Service should be referred to the Special Placements Officer. This Officer is responsible for arranging individual test sessions, deciding what format the selection test should take and referring the more difficult cases to Selection Techniques Section in Canberra. Apart from applicants for the CAT and CST, all cases should be referred to this section for advice on selection testing. For the CAT and CST, advice should be sought only for the more difficult cases. Listed below are the various modified versions of the CAT and CST and the circumstances in which they should be used:

CAT

enlarged cat	for partially sighted persons
test G in unlimited time	for those persons whose handicap is likely to slow them down
normal administration	for those persons whose handicap will not slow them down

CST

Braille version (subtests 4, 6, 9)	for blind persons
enlarged CST	for partially sighted persons
subtests 4, 6, & 9 in unlimited time	for those persons whose handicap is likely to slow them down
normal administration	for those persons whose handicap will not slow them down.

All Regional Directors have been issued with copies of the enlarged CAT and CST. Braille versions of the CST are held by Selection Techniques Section and sent out when requested.