



EPILEPSY IN AUSTRALIAN POLICY:

**A review of Australian health and social welfare policies
which recognise and redress the impact of epilepsy on
individuals, their families and the Australian community.**

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Illness
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A report on behalf of the Epilepsy Foundation of Victoria

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EXECUTIVE SUMMARY

1. The aim of this report is to explore the extent to which the impact of epilepsy on people's lives is recognised and addressed by governments in their policies.

Policy papers were analysed from approximately 1984 to 2007. Comparisons were made with similar documents internationally.

2. Australian research indicates that people with epilepsy, their families and carers are socially excluded and this impacts on their quality of life as they are unable to participate fully in the lives of their communities.

Employment, welfare, education and health services are major areas where people with epilepsy experience exclusion.

3. Discrimination legislation falls short of redressing the massive stigma and discrimination faced by people with epilepsy. In its current form of a complaints-based system the structure is inadequate.

Employment policies such as 'Welfare to Work' focus on the unemployed individual and do not address the systemic barriers, including employer misperceptions. People with epilepsy may meet all the criteria for employment and still not be successful. Employment and job retention for all people with disabilities are shown to be complex, multidimensional matters by international research.

Education should be the gateway to employment and a good quality of life for people with epilepsy but many young people with epilepsy do not complete school. The reasons for this are not well understood and there has been little attention to improving school retention rates. Policies around education have not addressed the needs of students with epilepsy at all.

Epilepsy has been neglected in health policy. Though a chronic condition and one that is likely to increase amongst Australia's aged, there has been no planning for this. Considerable work has been undertaken in the United Kingdom to improve the quality and safety of health services in epilepsy.

4. Epilepsy is poorly understood and suffers from confused definitions, sometimes being defined as an intellectual disability or as a medical condition.

The lack of data relating to incidence and prevalence of epilepsy is a barrier to developing policies and services to improve the lives of people with epilepsy.

5. The neglect of epilepsy in all these major policy areas has profound implications for people with epilepsy, their families and carers. Affirmative action for people with epilepsy is required across all policy areas. Many of the initiatives from overseas would be of benefit in Australia. This requires the attention of State and Federal Governments.

1. INTRODUCTION

1.1 Aim

The aim of this report is to explore the extent to which the impact of epilepsy on people who have epilepsy, their families and carers and the community is recognised and addressed in government policies.

1.2 Methods

This report is the result of a literature review of Australian Commonwealth and state government policies where epilepsy would be expected to receive recognition, for example in policies covering disability services, health services, employment and welfare. The literature review covered a 21 year period from approximately 1986 to 2007.

Documents were analysed in terms of the extent to which they recognised and introduced measures to redress the impact of epilepsy on individuals, their families and carers and the broader community. A gap analysis was undertaken to identify the gaps in relevant policies where the needs of people with epilepsy could reasonably be expected to be addressed but were not. Where possible, seminal policies, discussion and research papers from the UK, USA, Canada and New Zealand were also accessed to identify how other nations had employed policies to redress the impact of epilepsy. This comparison provided another means to recognise gaps in Australian policy and examples of measures to redress the impact of epilepsy.

1.3 Limitations of this report

This report has not considered all the issues of importance to people with epilepsy, their families and carers. It has not considered policies relating to housing, driving and the participation of people with epilepsy in the design and delivery of services. It has not considered the needs of other cultures, including indigenous people. It may be surmised that these are areas and needs that require as great attention as the areas that have been under consideration.

2. BACKGROUND

In 2006-7 The Epilepsy Foundation of Victoria and the Chronic Illness Alliance undertook a project to explore those aspects of living with epilepsy people would like to see addressed through social and applied research. One of the principal findings of the project 'Researching the Personal Impact of Epilepsy' (Walker, 2007) was that people with epilepsy perceived themselves as socially excluded from a range of activities that most other people accessed without question.

People with epilepsy, their families and carers had real-life examples where they had experienced discrimination and been subjected to exclusionary practices. In speaking of these experiences they adopted the language of social exclusion: participants in the project reported they had been excluded from areas such as employment, educational opportunities, sports and community activities.

The reality of these experiences is supported by other recent research activities. In 2006-7 Brown undertook an analysis of the National Health Survey data relating to people reporting epilepsy in the National Health Survey (NHS). Data are collected by the Australian Bureau of Statistics from a regular randomised sample of around 20,000 private dwellings across Australia. Data from the survey questions asking respondents if they have epilepsy has not been analysed until now. The analysis of the 2004-5 NHS provided results regarding the prevalence of epilepsy in Australia. Results about the employment of people with epilepsy in Australia are from the previous NHS of 2001. Brown's statistical analysis indicates that across a range of measures, those respondents with epilepsy had reduced life chances compared to the rest of the population. People with epilepsy were more than three times more likely to be out of the workforce than people with other chronic illnesses when all other important factors such as age and gender were held constant. This was mirrored in those people having lower average incomes and educational outcomes such as a lower average school leaving age. People with epilepsy were also less likely than the population as a whole to be married. Anxiety and stress levels were also higher amongst those with epilepsy.

In 2007 the Joint Epilepsy Council of Australia published the results of a survey undertaken with 467 people with epilepsy and 496 carers of people with epilepsy. While this survey should be viewed with circumspection because of its methodological limitations, its respondents reported high levels of psychological stress, that epilepsy was a barrier to participating in employment, education, sport and social activities. Transport was a problem for many participants in this survey, with some seventy per cent not driving a car, and relying on either public transport or other people to drive them. People with epilepsy living in rural and regional Australia reported no or poor access to specialists and some reported poor access to General Practitioners as well.

3. SOCIAL EXCLUSION

The concept of social exclusion provides us with a means by which to measure the extent to which policies recognise and redress the impact epilepsy has on individuals with epilepsy their families and the community.

Social exclusion has been defined by Levitas (2007) as a

'complex and multidimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities available to the majority of people in society, whether in economic, social, cultural or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole.'

Rodgers et al define it this way

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

While Levitas' definition emphasises the multidimensional nature of social exclusion, Rodgers et al's emphasises the structural nature. Based on Rodgers' definition exclusion of any group from participation in the various activities of their community is structural; it is experienced by groups of people because it has a framework that supports its existence. Rodgers et al see markets (or the economy) as an important part of the framework. Public policy also plays a role in shaping economies and other areas. But social exclusion may result from unintended outcomes to public policies and a failure to respond to its existence.

Saunders (2007) argues that social exclusion is multidimensional. It operates across institutions and community attitudes, often engendering barriers that come to seem 'normal' to those who are not excluded by them. The dimensions identified by Burchardt (1995) also reflect the structural nature of social inclusion when it is embedded in a community.

- Consumption, including having an income to consume a range of goods and services.
- Savings, including savings, pensions, home ownership and investments.
- Production activities, which includes paid employment, volunteerism, education or caring for others.
- Political activities ranging from community and neighbourhood involvement to the more formal political engagement.

- Social activities which range from social interactions with family and friends, leisure activities and identifying with cultural, neighbourhood and spiritual groups. (Burchardt et al. cited in Peace 2001).

In Australia, Saunders (2007) has identified three dimensions of social exclusion:

- Disengagement
- Service exclusion
- Economic exclusion

Disengagement refers to being unable to participate in leisure, hobbies and community activities. Service exclusion refers to lack of access to services, such as health and disability services or no access to a bank or perhaps utilities such as gas and electricity. Economic exclusion encompasses lack of access to liveable incomes, employment opportunities, having few assets and no resources to fall back on. Saunders (2007) identified key groups likely to experience social exclusion. These include sole parent families; unemployed people; people with a disability; public housing renters and indigenous Australians. People with a disability, Saunders considers suffer relatively high rates of exclusion from banking services, childcare and have low rates of participation in community activities and social life.

We will use Saunders' dimensions to examine policies where people with epilepsy should find themselves represented in order to feel they have some inclusion in the activities of their communities. Where possible we will broaden those dimensions to include those of Burchardt.

Social inclusiveness and social exclusion are compounded by government policies, either as a deliberate action, as an unintended outcome of a policy or its entire absence. Public policy, whether deliberate, unintended or absent plays a central role in maintaining social exclusion in other social institutions.

4. THE CONTEXT IN WHICH POLICY IS DEVELOPED

4.1 Policy context in Australia 1983-2007

Government policies are generally formulated on the basis of prevailing ideologies. Internationally, over the last three decades, the prevailing ideologies have been variations of neo-liberalism (Quiggan 1999). Neo-liberalism is marked by a shift to free-market domestic policies, privatisation of government services, capital market deregulation and the abandonment of welfarist interventions (Quiggan 1999). In Australia we can date the formal Government adoption of neo-liberalism from the Hawke Government in 1983. Since then Australians have become familiar with terms such as ‘user pays’; ‘mutual obligation’; ‘welfare dependency’ and workplace agreements. There is now an increased emphasis on individualism and being responsible for oneself and one’s family rather than looking to community and government supports.

Over the last two decades, Liberal and Labor Governments in Australia, both Federal and state, have pursued policies to reflect this ideology, attempting to withdraw government services and replace them with private ones. Electoral resistance to complete privatisation of all health services and the abandonment of all forms of social welfare has tempered this process. In this report we consider the extent to which this ideology has influenced policies to assist people with epilepsy, their families and their carers.

4.2 Social inclusion and policy developments

Policy is important to consider in relation to social inclusiveness and people with epilepsy because policy has the capacity to drive social inclusion of groups marginalised by community attitudes or to redress poor access by groups to the full range of services. The current Federal Government recognises this and has adopted a policy of social inclusiveness. Government departments are being asked to consider how their policies and services might promote greater social inclusion.

Neo-liberal policies have not been driven by concern for social inclusion, though governments have tried to justify the changes they have made to social welfare on the basis that providing people who were formerly unemployed with employment is inclusive in its outcomes if not intent.

Allocational policies which finance programs to produce long-term behaviour changes may be introduced under neo-liberalism in order to reduce future costs to the government. ‘Sunsmart’ is an example of this where the program aims to reduce the costs of treating skin cancer. They are the policies most likely to improve social inclusion as they target groups whose health or welfare has suffered through neglect. However, in some cases those policies that allocate resources in one area do so at the cost of other groups of people. Current health policy provides a good example. The predominance of attention and resources directed towards ‘life-style’ diseases, their prevention and management (Smedley and Syme 2000) results in the relative neglect of diseases such as epilepsy.

4.3 Where would we expect to find epilepsy discussed in public policy?

The extensive international literature on epilepsy documents that epilepsy constitutes a disease requiring treatment and care; it results in deficits in relation to education and employment; it leads to poverty, disability and discrimination (WHO 2001; Scambler & Hopkins 1986; Jacoby 2002; Fisher et al 2000). Work undertaken in Australia recently and cited above (Brown 2007 and Walker 2007) indicates that Australians with epilepsy have a similar experience of social exclusion. To address social exclusion generally and in relation to education, welfare, employment, discrimination and access to high quality and safe treatment we would expect Australian Federal and State governments' policies relating to health, welfare, disability, discrimination, and employment policies to offer strategic approaches.

5. REPRESENTATIONS OF EPILEPSY IN POLICIES

5.1 'Out of the Shadows'

The World Health Organisation (WHO) argues that epilepsy is one of the most stigmatised conditions in the world and that the prejudice that is faced by people with epilepsy is often worse than the condition itself (WHO 2001). The expression 'Out of the Shadows' used by WHO for its campaign to improve attitudes towards epilepsy is a clear indication of its social exclusion on a global scale. In Australia, member organisations of the Joint Epilepsy Council of Australia (JECA) have developed programs in conjunction with the WHO campaign and work towards improving the quality of the lives of Australians with epilepsy.

5.2 Human rights, discrimination policies and epilepsy.

Human rights and discrimination policies overarch other policies relating to human endeavour in Australia. In 1985 the Human Rights Commission published its report *Epilepsy and Human Rights* which was an exploration of the human rights issues faced by people with epilepsy. With remarkable prescience it is subtitled 'a badge of exclusion'. The Human Rights Commission argued that, as a 'hidden disability', misconceptions could arise about epilepsy. When a person with epilepsy 'was discovered' those misconceptions could lead to discrimination. The project of which the report is the outcome explored areas of human rights that came under Commonwealth responsibilities. It covered areas of education, employment, mobility, residential options, insurance and superannuation, provision of services and immigration. It was the first such project undertaken on epilepsy in Australia.

The project identified issues relating to community attitudes towards epilepsy in all of the above areas which led to discrimination. In its recommendations the report called for government financial assistance for the then national association working on behalf of people with epilepsy to undertake development of resources for educational institutions and employers.

Commentary:

For the greater part of the report the then national epilepsy association (National Epilepsy Association of Australia) was identified as the agency to carry out some of the recommendations. However some recommendations are made with no suggestion as to who was responsible for their carriage. Broad recommendations such as staff development programs being undertaken or that material about epilepsy to help employers should have been made available means that no-one took responsibility for these matters. Additionally the development of material for employers was not necessarily going to result in its use by employers.

This problem of recommendations where no responsibility is assigned has a long history. In 1993 Bowman and Virtue, discussing public policy in relation to women caring for children with a disability makes the point that many policy changes are not accompanied by the structures necessary to support their implementation.

5.3 Disability Discrimination Act (DDA) 1992

The DDA came into force in 1993 and has been amended several times since, the last time being in 2005. The DDA prevails over all other State and Territory legislation in order to eliminate deficiencies and inconsistencies in each of the State's legislation.

The objects of the Act are to:

- (a) Eliminate discrimination against persons on the grounds of their disabilities in the areas of:
 - (i) work, accommodation, education, access to premises, clubs, sports and
 - (ii) the provisions of goods, facilities, services and land and;
 - (iii) existing laws; and
 - (iv) the administration of Commonwealth laws and programs; and
- (b) To ensure as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community; and
- (c) To promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community.

The Act encourages organisations to develop and register Disability Action Plans. The Plans demonstrate an organisation's willingness to address internal issues relating to discrimination against people with disabilities. The Disability Discrimination Commissioner is also responsible for investigating complaints and undertaking conciliation before the Act (Lindsay 1996). There are now some 3000 complaints per year made to the Federal, State and Territory jurisdictions which the Commonwealth Human Rights Commissioner argues is a miniscule number of complaints since there are some one in five Australians with a disability (Innes 2007).

Some of the general criticisms relating to the Disability Discrimination Act identified by Lindsay (1996) relate to the lack of community input into its design and subsequent amendments; the poor funding of the Commissioners' Office and lack of community awareness. Most relevant to people with epilepsy is that it is 'complaints-driven' and complainants are obliged to act on their own behalf.

'If a consumer product we've purchased is not of sufficient quality, we take it back and complain; if our landlord fails to carry out necessary repairs, we complain. However---if we are discriminated against on the grounds of our disability, most of us just grin and bear it, or turn the other cheek.' Graeme Innes, Human Rights Commissioner, 2007.

Commentary:

Given that people with epilepsy are more stigmatised than 'most of us' who 'just grin and bear it' it is unlikely that many people with epilepsy are willing to make complaints or know of their rights to do so. Another deficiency for people with epilepsy is that many of the acts of discrimination they face are shrouded in ambiguity and very difficult to prove. Examples of such ambiguity are: not being offered a job

interview when a person with epilepsy has disclosed their diagnosis, but being informed that the position is no longer available; being refused a job because the person with epilepsy does not have a drivers' licence, even though driving may not be an important part of the duties; being left out of a sporting team and given no reason. However perhaps the greatest deficiency where people with epilepsy are concerned lies in the generic nature of the Act. Epilepsy is not spelt out as a disability; some people with epilepsy do not regard themselves as disabled though they do regard themselves as discriminated against; other people with epilepsy will not be prepared to speak up in defence of themselves, partly because there is little in the Act that encourages them to do so or because they may consider that in comparison to other disabled people their needs are less.

The 2008 discussion paper on disability and employment in Australia notes that the Commonwealth government uses varying definitions of disability and impairment depending on the purposes, though this largely relates to eligibility for Commonwealth services or payments (O'Connor and Shorten 2008). However, these varying definitions may pose some problems in relation to epilepsy being characterised as a disability. This was found to be the case in American court decisions, where disability was not clearly defined and means that a determination of whether a person is limited in major life activity must be made on a case by case basis. This limits the Act's usefulness in addressing systemic issues.

Definitions of disability in the US also vary between the American Disability Act (ADA) and the Social Security Act. These differences are related to the purposes of the Act. Where the ADA is meant to protect people from discrimination, the Social Security Act provides benefits for people too disabled to work. Following the 'Sutton' Case in 1999, where the US Supreme Court found that poor vision which could be corrected by wearing spectacles so that the person did not in fact have a disability under the ADA, United Airlines was not found to have discriminated by refusing someone with poor eyesight employment (Cornell University Law School 1999). Kaplan the Director of the World Institute on Disability argued that:

Under the recent Supreme Court decision in the Sutton case, a person can be fired from a job because he or she has epilepsy, for example, and yet if that person were taking medication to control the epilepsy, he or she would be barred from fighting back using the ADA. Furthermore a person with epilepsy that is controlled with medication would not fit the Social Security definition of disability, which means this person has neither law to fall back on. D Kaplan 1999, (quoted by Centre for Accessible Society 1999)

Anomalies exist in the United Kingdom Disability Discrimination Act 1995, where people have to prove their disability to be eligible for services under that Act (Delany & Moody 1999). People who have been misdiagnosed with epilepsy and have faced discrimination are not covered by it. Similarly people whose epilepsy is mild and not long term may be considered to have no redress under the DDA 1995. The authors of this article concluded that the DDA was of limited value for people with epilepsy largely due to limited access to tribunal decisions and its limited protection.

In a final analysis, the Australian Act is self-limiting in addressing the needs of people with epilepsy and discrimination. International research and Australian research all report that discrimination against people with epilepsy continues in most of the areas the Act is designed to address, namely work and education, as well as in the recognition by the community of the rights of people with epilepsy. Some recent examples from the Disability Discrimination Commissioner demonstrate the ongoing discrimination faced by people with epilepsy.

A complainant with epilepsy alleged he had been discriminated against on the grounds of his disability. He had worked as a gardener for a number of years, then resigned to take up another position. Several months later he re-applied for a position with the respondent but was unsuccessful as the respondent considered his performance and attendance had been unsatisfactory and that his epilepsy had been the cause of a number of work accidents. The complainant provided medical evidence that his epilepsy was under control and the complaint was eventually resolved by conciliation, which included assistance to find another casual position, an apology, removal of documents from the complainant's personal file and a small amount of financial compensation.

Parents complained that a special school had failed to accommodate their son's disabilities, which included autism, intellectual disabilities and epilepsy. The child had been expelled because of behavioural problems. The complaint was resolved when the school agreed to formulate individual plans for pupils, undertake training on autism and develop procedures for better communication between the school and the families.

A woman with epilepsy complained that she had been banned from a bowling alley. This had been precipitated by a poorly bowled ball when she needed to sit down at the onset of a seizure. Following conciliation the managers of the bowling alley agreed she could return and also paid compensation. (From 'Not Happy Jan: Speech for Epilepsy Action AGM, Graeme Innes, Human Rights Commissioner 2007).

These case studies provide some indication of the systemic issues faced by people with epilepsy around the issues of employment, sport and recreation activities and education. However a complaints-based approach, where the final resolution is a court of law on a case by case basis, is not a meaningful way to remove systemic discrimination.

McIntosh and Phillips (2002) in their discussion paper on disability support and services in Australia acknowledge that there is significant unmet need with respect to support and assistance for people with disabilities. Many people receive no support at all, especially in areas of employment, respite services and accommodation. The more recent survey published in 2008 (Phillips 2008) demonstrates that unmet need has not changed, with over 5000 people requiring employment support. People with epilepsy may fall into this category. In 2000, Ohlin identified that the Commonwealth government's weakening of community advocacy services and the use of disability brokerage services meant that areas of unmet need were even less likely to be identified and addressed (McIntosh and Phillips 2002).

5.4 Policies relating to work preparedness and employment.

In 1999 Chaplin argued on behalf of the International Bureau of Epilepsy Employment Commission that employment was a crucial consideration where the needs of people with epilepsy were concerned. Disability equal opportunity policies enacted across the world had made access to employment a central component of their enactment, where employment is recognised as the major factor in contributing to quality of life.

Most people with epilepsy concede their condition is a barrier to employment. Many argue that it is not the condition itself that constitutes the barrier but employer and colleague attitudes toward people with epilepsy (Smeets et al 2007; Bautista & Wludyka 2007). Research undertaken by Brown (2007) demonstrates that Australians who have epilepsy are three times more likely to be unemployed than other Australians. This statistic suggests that similar attitudes may be at work in Australia.

Since 1996, all Australians with disabilities, including people with epilepsy have been faced with the changing policy environment concerning disability support from the government and employment. Current policies largely support the view that individuals must take the responsibility to equip themselves for employment and to actively seek a position.

This is despite the wealth of literature demonstrating that all people with disabilities face both personal and structural barriers to accessing employment and despite the disability discrimination acts, people with disabilities and the foundations that work for them have received little or no help to address these barriers.

‘Welfare to Work’ was introduced in Australia in 2006. Similar programs were introduced in the US and UK. All are designed to place unemployed people back into the workforce and reduce their dependence on welfare benefits. These policies have been introduced into Western countries in the face of declining employment rates of all people with disabilities. The reasons for this decline remain controversial. (Burkhauser et al 2007).

Commentary:

At one level, such policies may be seen as beneficial since unemployment promotes long term dependence and long term disadvantage. At another level, those people who are most disadvantaged are subject to punitive programs which attempt to force them into work by withdrawing benefits or placing them on lower payments. Overall, many people in this category find themselves in poorly paid, part-time or casual employment with little hope of advancement, because of their health or lower education. Australian Council of Social Service (2007) makes the point that there are some 700,000 people on disability support pension, many of whom want to work. Similarly there are some 600,000 parents on parenting pensions who would like to work. Many of them have less than a Year 10 education, and others have problems with childcare, transport and poor health.

ACOSS pointed out in 2007 that ‘Welfare to Work’ programs are most effective when there is investment in training, education and support, as happened in Denmark

and Ireland. . This has not taken place in Australia, where, there are far fewer assistance packages to encourage employers to employ long term unemployed people. With more than a million people unemployed or on benefits in Australia and having to look for work, competition for positions is strong. ACOSS recommended that in the case of people with disabilities there was a need for double the numbers of Disability Employment Network and Personal Support Program places to reduce the barriers to working.

However, the Disability Employment Network and the Personal Support Programs only address deficits in individuals with some attempt to improve the workplace they may go into. The Disability Employment Network provides services such as training in specific job skills, interview skills, on-the-job training and support for co-workers. The Personal Support Program is an employment program that support individuals who face additional barriers such as homelessness and drug dependency. The support program helps people with services such finding stable accommodation and a stable social life and vocational training. Although there is some emphasis on providing working conditions to accommodate people with disabilities such as employer assistance schemes and workplace modifications these only come into play once a person has actually achieved employment.

A survey undertaken in Ireland demonstrates that people with disabilities returning to work or remaining in work is not simply a case of providing access to brokered job support agencies (Gannon and Nolan 2004). Women and older workers are more likely to leave work after contracting a disability or chronic illness. Family circumstances such as having children are as likely to play a role as the disability itself. When the disability hampers daily activities, this increases the likelihood of leaving work. However economic circumstances also play a role in whether a person remains in employment after the onset of a chronic illness or disability. Where a person comes from a disadvantaged household this increases the likelihood that person will leave work after the onset of disability.

People with a chronic illness or disability in Ireland are likely to be out of work (Gannon and Nolan 2004). The survey demonstrated that approximately 60% of those who became chronically ill or disabled were in employment in the year before onset. Their employment rate fell to 46% in the year of onset of the illness or disability, while one year later their employment rate remained well below what it was before the onset of chronic illness or disability.

Interestingly for the purposes of this current report, Gannon and Nolan (2004) inquired how the probability of remaining unemployed was affected by no longer reporting a disability. Though the numbers in their survey who reported having done this were small the likelihood of their becoming employed rose by several percentage points.

Research undertaken across Germany, United States, Britain and Australia demonstrates that more needs to be done than simply providing people with disabilities with employment support services (Burkhauser et al 2007). Working age German men with disabilities have a higher income and are more likely to be employed than in the other three countries. This may be partly explained by the 'work-first' policy, where there is no financial support given unless the job-seeker has

exhausted all possibilities. However, this seemingly draconian approach is supported by other processes. All Germany companies employing more than 20 people are subject to a quota system where at least 5% of their employees must be drawn from the disabled population. Where quotas are not filled the company pays monthly penalties. In addition representatives of the disabled in each company negotiate flexible conditions on behalf of disabled employees.

Research also demonstrates that policies and programs need to be directed towards special needs groups. A research report undertaken on behalf of the Irish National Disability Authority explores the inclusion of women with disabilities in the labour market, across Western countries (O'Connor et al 2007). Women with disabilities are less likely to be employed than men with disabilities or women without disabilities. They are less likely to use employment services or be referred to rehabilitation services than men with disabilities. O'Connor et al (2007) noted that the Australian government's funding of employment services regardless of gender resulted in assisting 31,000 people with disabilities of whom 67% were men. They argue that while both men and women with disabilities face similar barriers to accessing employment women with disabilities may experience these barriers differently. Many women with disabilities have family commitments, many being single parents and there are few supports so they can return to work. Gender bias means that employment for women with disabilities is not seen as important as it is for men with disabilities. International comparisons show that women with disabilities are more likely to be in the poorest paid jobs and most likely to be the most impoverished members of their community. Most of the problems faced by women with disabilities, the report asserts, relates to both gender bias, as well as a prejudice against disablement. Women with Disabilities Australia, concurring with research in Ontario, Canada (Fawcett 2000) identified that the barriers to women with disabilities being employed in Australia were: employers and colleagues attitudes; poor job design, lack of attendant care in the workplace, inflexible work arrangements, lack of access to education and vocational training, inadequate or expensive transport, lack of self-confidence and assertiveness, lack of access to employment services.

People with mental illness have been consistently identified in literature as comprising another special needs group with regard to employment. In Australia the unemployment rate for people with mental illness is closer to 20% compared with 8% for people with physical or sensory disabilities. Where labour force participation is concerned, 28% of people with mental illness may be employed while the rate for people with physical or sensory disabilities is 50% (O'Connor & Shorten 2008).

In Australia, despite the introduction of support programs to assist people with disabilities to return to work the employment rate of people with a disability has continued to fall, despite the growth in the Australian economy (O'Connor & Shorten; 2008).

O'Connor and Shorten (2008) argue that this means that a specific strategy is required to address these issues. A strategy includes supports and training for people with disabilities and mental health problems but would also work to increase positive attitudes among employers and build their confidence in hiring and maintaining people with disabilities and mental illnesses. On this basis, there is a good argument to be made that people with epilepsy who are able to work would benefit from a

specific strategy to improve workplace understanding of epilepsy and to build the confidence of employers in hiring and maintaining people with epilepsy.

5.5 People with epilepsy and employment opportunities:

Unemployment of people with epilepsy in Australia is likely to be very high. Brown's 2007 analysis of the National Health Survey data found that some 30% of people with epilepsy were employed full time and 17% were employed part-time. The JECA survey had 12% of the people surveyed in employment. Brown's analysis was closer to similar surveys undertaken in Europe (The RESt-1 Group 2001). Sach and Associates (1991) working from a small and unrepresentative sample of people with epilepsy in the 1990s estimated the employment rate of Victorians with epilepsy was three times higher than the then general unemployment rate of 10%. There are little data on the underemployment of people with epilepsy in Australia. The indirect cost of epilepsy related to unemployment and underemployment in the US is estimated to be 86% of the total cost of the disease (Bautista & Wludyka 2007).

Commentary:

Australians with epilepsy report they want to work. Many of them report experiences of applying for positions and having no success, once they have disclosed their condition. Not holding a drivers' licence is often seen by people with epilepsy as an excuse for not being offered a position (Walker 2007). Most people interviewed in 2007 who had held jobs for any length of time reported that their epilepsy was well under control and they had made a point of not disclosing their condition to anyone at work. Most people with epilepsy felt that others, including employers and work colleagues found epilepsy confronting (Walker 2007).

The report of these views and experiences is not singular. Fisher et al (2000) reported from a US survey that some respondents found employment difficulties were the 'worst thing' about having epilepsy. A total of 17% of the survey population reported that epilepsy affected their employment performance and only 37% of the survey was employed at the time of the survey. Beran and Read (1981) surveyed 51 Australian adults with epilepsy where nearly half the total had experienced job discrimination.

A US survey (Malachy et al 2001) estimated unemployment of people with epilepsy to be between 13% and 25%, and recorded similar responses regarding discrimination. This report distinguished between 'felt' stigma where people with epilepsy considered they had been subjected to stigma in their employment and 'enacted' stigma where people with epilepsy could report an actual case of stigma. Beran and Read (1981) found that of their small sample of 51 Australian, a third of them considered people with epilepsy were less productive than those without epilepsy. This suggests a level of internalised or 'felt' stigma.

Seizure types, their severity and side effects of medications all play a part in employability. However attitudes of employers are also significant in whether a person can retain a position or attain a new position. However some of the research is equivocal with regard to epilepsy and employability. Jacoby's research in this area showed that the majority of people with well-controlled epilepsy were employed and those who were not attributed it to causes other than epilepsy. The survey undertaken by Fisher et al (2000) had a minority number who were employed while Scambler and Hopkins (1980) argued that social class and seizure activity played an important role

in the employment of British people with epilepsy, concluding that the fear of being discriminated against meant they did not disclose their condition or seek advancement.

Research shows that epilepsy is far more poorly received in the workplace than other conditions (Harden et al 2004). Workers who were surveyed showed a greater level of discomfort and anxiety at the thought of having someone with epilepsy as a colleague compared to someone with depression or MS; and a high level of anxiety were they to be faced with the unpredictability of epilepsy. Sach and Associates (1991) identified employer attitudes as an important component in employment for people with epilepsy in Victoria. The survey identified fear of the unknown, lack of understanding about the condition and concern that there would be higher costs related to loss of productivity and Workcare premiums.

An anxiety held by employers and work colleagues relates to safety issues. A recent survey undertaken across eight European countries using a matched control group demonstrated that while the number of accidents was higher among people with epilepsy they were not related to epilepsy and the injuries that resulted were minor (Cornaggia et al 2006). Indian research in 1992 found that 'epileptic employees' working in hazardous industries performed better than those 'epileptic employees' working in less hazardous industries (Dagupta 1992). When 'epileptic employees' were compared with employees with dermatitis it was found the employees with epilepsy took less time off, did more shifts and had less promotion

Sach and Associates in their survey in 1991 found that only 10% of their respondents had had an accident due to epilepsy while at work. The same survey found that the respondents had taken far less sick leave in the previous 12 months than other surveys demonstrated for the general community. However those who had taken sick leave due to their epilepsy had taken a higher average number of days.

5.6 Employment programs and epilepsy in Australia: a short and selective history.

The strong historical association between epilepsy, mental health and disability services in Australia has contributed to the lack of employment opportunities for people with epilepsy in Australia. In the nineteenth century and continuing well into the twentieth century people with epilepsy were held to be intellectually incapable of undertaking full time employment. These lowered expectations of what people with epilepsy were likely to achieve also led to lowered expectations in educational achievements. People with epilepsy, along with other people with disabilities such as vision impairment, or paraplegia were likely to be offered employment in 'sheltered workshops' or very basic labouring.

Attitudinal changes towards epilepsy, assisted by better seizure control with newer medications meant that people with epilepsy, their families and doctors saw more opportunities to complete education and to seek participation in the open employment market. Community attitudes about the suitability of employing people with epilepsy were shown to have changed markedly in Britain between 1940 and 1980 which most likely reflect similar changes in attitudes in Australia (Sach and Associates 1991).

In the last quarter of the twentieth century special assistance to people with epilepsy seeking employment largely came from the epilepsy foundations. Following a program model created by the Epilepsy Foundation of America, the Training and Placement Service (TAPS) in 1976, Sach and Associates recommended the Epilepsy Foundation of Victoria develop a similar program. TAPS was reported to have a 55% placement rate. Training Opportunities in Pre-Employment Skills (TOPS) was developed by EFV in 1992. Both programs comprise workbooks providing vocational counselling and employment skills such as applying for jobs and creating a resume. Both workbooks provide skills training to integrate having epilepsy and being employed. Where TAPS was concerned there was also a component to educate employers and to establish relationships with them with a view to placing people with epilepsy in positions. This component was not part of the EFV's TOPS.

The evaluation of TOPS (Sach and Associates 1994) showed that of the 181 applications, 98 people actually attended the course by the end of 1993. A further 36 applicants enrolled in the course in 1994. By the end of March 1994, 31 people with epilepsy had been employed. Of those 31, 14 were in full time employment, 10 in part-time employment and 7 in short term positions. There is no means to measure if this result was a direct outcome of participating in the program or purely coincidental. This evaluation also recommended that more work was required with employers, such as promoting an employment service to employers and providing information to employers about epilepsy in the work place so that employers had a basis on which to make informed decisions about employing people with epilepsy.

In the 1990s the epilepsy foundation in NSW ran a 'STEPS' Program to provide people with epilepsy with employment skills. Currently, there is a training program being conducted from South Australia's Epilepsy Centre in conjunction with Right Time Training Services.

Given the changing market for training people with disabilities, which has been driven by government policies relating to work and disability, the foundations are more likely to refer people with epilepsy to services such as WISE Employment or Disability Employment Action Centre (DEAC). The foundations are more likely to confine themselves to providing information on rights and basic skills.

5.7 The legacy of this history of employment programs for people with epilepsy.

Historically the foundations caring for people with disabilities have provided employment programs and employment opportunities for their clientele. They have done this on the basis that employment opportunities in the open market were not available to their clientele. Some foundations such as those for the deaf or blind established large workplaces and offered long-term employment. In some instances people with disabilities benefited from being able to demonstrate their capabilities and made transitions to the open employment market. Many have been assisted in this through government funded organisations such as Disability Employment Action Centre (DEAC), the Commonwealth Rehabilitation Service and specialist services at Centrelink.

Employment programs for people with epilepsy have been developed and provided by the foundations in recognition that there are no other means for people with epilepsy to prepare themselves to participate in paid employment. This recognition

includes the knowledge that people with epilepsy remain unwelcome in the workplace by both employers and other employees. Programs have been limited by funding to short-term projects which provided basic skills to individuals.

In adopting this model of disability employment, there was no means to address employer and employee attitudes towards employing people with epilepsy. Since many people with epilepsy have good seizure control with the newer drugs there is less need to learn basic skills or these skills can be learned elsewhere and the greatest need is to address employer and employee attitudes. At the same time, such employment programs lend themselves to retaining these attitudes since they reinforce the view that people with epilepsy are so intellectually incapacitated they require this level of training.

But equally important is that the model of disability employment itself has a major flaw. Nineteenth century foundations undertook training and employment of people with disabilities because they accepted that people with disabilities were not part of any government policy or program. In doing so, they upheld the view that people with disabilities were not suited for mainstream employment but could be gainfully occupied. In adopting this model, the epilepsy foundations have allowed governments to retain a nineteenth century attitude towards people with epilepsy, who in most cases are both intellectually and physically able to work. The legacy of a model of disability employment is that governments do not recognise a responsibility towards the employment needs of people with epilepsy.

5.8 Access to education by people with epilepsy.

Brown's work demonstrated that Australians with epilepsy were far less likely to complete secondary education and progress to tertiary education. Similar results have been recorded in other countries for people with epilepsy. The implications of this level of under-education have been well documented in international studies. In the USA, Fisher et al (2000) found that people with epilepsy are less likely to graduate from high school or college than people without epilepsy. Part of the problem in completing education relates to learning abilities. There are estimates that a quarter of students with epilepsy have learning disabilities (Clarke 2007). One study found that academic problems were higher among students with epilepsy than students with other chronic conditions (Fastenau et al 2008). Learning disabilities including decreased retention and communicativeness as well as depression may be caused by anti-epileptic medications and/or psychiatric disorders or school absenteeism. It should be noted that such learning disabilities can be addressed.

Cognitive problems in children with epilepsy have been found to be common by researchers (Hoie et al, 2008). Varying degrees of educational underachievement are associated with different forms of epilepsy and may include underlying brain damage (Hoie et al, 2008). However, the reasons for children with epilepsy not achieving academically are not completely clear (Vanasse et al 2005). The majority of children with epilepsy do not have learning difficulties or intellectual impairment, but still under-achieve academically. Some students report they require different teaching models as they learn differently or at differing rates to other students. Some students report a distinct lack of sympathy regarding the effects of seizures on their ability to complete work while others report they have difficulty getting special consideration

for examinations because of their seizures. Having a seizure the night before an exam may mean the loss of the year's work.

Other factors contributing to under-achievement relate to attitudes of teachers, with some students with epilepsy reporting teachers expecting them to underachieve (Walker 2007). In Africa and South East Asia teachers' attitudes relate to beliefs about epilepsy being contagious or related to witchcraft. US research showed that teachers in a US school were generally positive but there were gaps in knowledge around learning and cognitive abilities as well as safety in the classroom (Bishop et al 2006).

The Disability Standards for Education 2005 clarify the Disability Discrimination Act in relation to education at all levels. The Standards cover enrolment, participation, curriculum development, accreditation and delivery, student support services and the elimination of harassment and victimisation.

However the Disability Standards for Education 2005 were developed after a Senate Inquiry in 2002 which documented that the differing definitions of disability used in the Disability Discrimination Act 1992 and by the States for student disability funding purposes created problems (The Senate, Education, Employment and Workplace Relations Committee). The definitions adopted by the various states leads to wide disparity in the numbers of students estimated to have a disability and the conditions that are deemed disabilities (AEU 2003). The major problem arises that states began funding students with disabilities in the nineteen eighties without any standard formulas. The wide definition of disability adopted in the DDA 1992 has meant that greater numbers of students now qualify for State disability funding. The broad definition of disability adopted by the DDA creates resource problems for all educational institutions as well as competition among the various disabilities. The Disability Standards for Education 2005 do not solve these problems.

The Australian Education Union 2003 argued in its submission to the Productivity Commission Inquiry on the Disability Discrimination Act 2003 that the incidence of children with a disability increased significantly over the decade with the incidence in schools ranging from somewhere between 12% and 20%.

Learning disabilities and difficulties which include a wide range of mild intellectual disabilities, dyslexia, acquired brain injury, ADD/ADHD and significant medical conditions, may also be excluded from definitions of disability in the States. There is no suggestion that epilepsy receives any special attention in schools despite the considerable evidence that children with epilepsy require some special attention.

One of the submissions that the Inquiry received was from The Autism Association of NSW argued that there is a:

'tremendous growth in the realisation of how many children there are with autism. For instance, we estimate that in New South Wales between 5,000 to 15,000 children have an autism spectrum disorder. If that is converted nationally it ranges from approximately 16,000 to 48,000 students across the country. That figure is based on a range of epidemiological studies that have been done over the last few years around the world.'

In July 2008 the Department of Education, Employment and Workplace Relations (DEEWR) announced the following initiatives to support children with autism in education:

- professional development for up to 1,800 teachers and other school staff to support school students with autism to achieve better educational outcomes
- workshops and information sessions, including access to online workshops and information for up to 5,800 parents and carers of school students with autism.

Similar initiatives are required for children with epilepsy, given the established evidence that learning disabilities play a role in their educational underachievement. Most children with epilepsy will not require special education, however, they will benefit from attention to their deficits in order to correct those deficits.

Epilepsy Action UK (2007) recommended with regard to educational testing and assessment some students with epilepsy will be more reliably assessed by their own teachers than using formal assessment; that the statutory process of academic assessment, (for example, the UK GCSE or in Victoria the VCE) takes into account the needs of students with epilepsy; schools themselves need to take responsibility that students with epilepsy are not discriminated against. Coursework might also be a fairer form of assessment for students with epilepsy than formal examinations, since it provides them with the ability to work at their own pace. However, Epilepsy Action (UK) considered that some forms of coursework may impose stresses similar to undertaking formal exams. Where there are no alternatives to formal examinations students with epilepsy should be informed of their rights with regard to their disability (House of Commons 2007). Epilepsy Action (UK) in its All Parliamentary Report noted the lack of staff training on epilepsy which would assist staff to deal with students' problems in learning. Epilepsy Action called on the UK Dept for Education to ensure that all teachers received appropriate training on working with children with special needs who were now an accepted part of the school population of government schools. It recommended each student with epilepsy have an individual education plan, all schools receive training regarding the impact of epilepsy on learning, and epilepsy be regarded as a learning disorder rather than purely as a medical disorder.

In Australian state education systems, epilepsy receives little attention in terms of a learning disorder or little attention regarding the poor academic achievements of students with epilepsy even though they may have no intellectual impairment. This may in part be due to the perception that it is primarily a medical condition. But this cannot be the whole answer since the historical antecedents still burden epilepsy with views that it is a psychiatric disorder or intellectual disability.

State education departments offer basic information about epilepsy first aid and in some cases have epilepsy management plans such as Western Australia's Department of Employment Education and Training providing a download of Epilepsy Action (NSW) Epilepsy Management Plan. Better Health Channel (Victoria) suggests that institutions such as schools should have policies around epilepsy management and first aid.

The consequence is that students with epilepsy access an education within a resource-starved system, where they compete for resources with other children with illnesses and disabilities. Generalist tools to assist schools to deliver services to students with disabilities provide no guide to better understand the needs of students with epilepsy who may learn differently or at different rates; who struggle with medications and their side-effects. Students with epilepsy may face harassment and victimisation in the schoolyard and while these behaviours are dealt with under the Disability Standards of Education there are no guidelines for identifying the extent of the problems and dealing with them in the schoolyard.

5.9 Health policies and epilepsy

The medical treatment and care of epilepsy is recognised in Australian health policy in the Medical Benefits Scheme (MBS) and the Pharmaceutical Benefits Scheme (PBS). The care of people with epilepsy in hospitals is part of the Australian Health Care Agreements. Medical care of epilepsy takes place in hospital-based clinics and in General Practice. Private medical specialist practice is also an important part of epilepsy care. Nurses specialising in epilepsy care are now part of the scene.

Beyond government funding for excellent medical care and treatment, epilepsy receives no more attention in health policies. For example there does not appear to be any workforce planning for the future requirements of the care of epilepsy. While Australia's Health 2006 contains one reference to epilepsy in its more than 500 pages, Australia's Health 2000 pointed out that epilepsy contributed to the burden of disease with its cost to the health system of \$157 million in 1993-4. No steps have been taken by government to lower the burden of epilepsy to the community and to the Australian health system.

This lack of attention contrasts with the attention the subject has received in the United Kingdom, where in 2001 the UK Chief Medical Officer called for improved standards of epilepsy care and treatment pointing out that:

'services for people with epilepsy fall short of what might be expected in modern chronic disease management. In particular:

- *up to 20% of patients may be misdiagnosed and receive inappropriate and unnecessary treatment.*
- *approximately 30% of patients with active epilepsy are not receiving treatment from a specialist.*
- *one in 12 of people with epilepsy in the United Kingdom are not referred to a specialist at all.*
- *on average it takes six months to a year from the onset of a first seizure to definitive diagnosis and treatment.*
- *epilepsy in pregnancy is managed to a variable standard.*
- *standards of care generally are fragmented and patchy.'* (Annual Report of Chief Medical Officer United Kingdom 2001).

In the 2007 report, 'Wasted Money, Wasted Lives' the All Party Parliamentary Group on Epilepsy called on the government to review its 2003 Action Plan. This Action Plan had called for more government spending to improve access to neurology

services; improved pathology and post-mortem services to address shortfalls in current practices; improve support and information to bereaved families; introduce medicines management programs; offer education to general practitioners who had an interest in epilepsy and to improve the care of pregnant women with epilepsy.

The report also calls for the National Institute for Clinical Excellence (NICE) guidelines of 2004 to be fully implemented. These guidelines establish standards of medical care for people with epilepsy. Similarly, a National Service Improvement Framework (NSIF) was established in 2005 with the aim of improving the standards of the treatment and care of people with long term neurological conditions, with the report calling for it to receive funding for its implementation. The report also calls for increased access to surgery, improved general practice services for people with epilepsy, greater access to MRI and EEG facilities. Given the extensive time lapse of some eight years between training neurologists and other specialists in epilepsy the report also called for a program to increase their numbers.

Epilepsy specialist nurses receive attention in this report. Their roles in supporting patients to manage their epilepsy properly are acknowledged. With approximately 152 specialist nurses in England there are recommendations that this should be increased to 920. To achieve this, the report recommended the UK Dept of Health develop a plan to increase the number of specialist nurses.

Overall, the All Party Parliamentary Group called for increased funding for epilepsy services in its report. The report demonstrates that while there are deficits in UK policies and services, there is also a history of efforts to address these deficits, especially with regard to the safety and quality of health services for people with epilepsy in the UK.

In 2001 the United States National Association of Epilepsy Centers published updated guidelines for essential services, personnel and equipment for specialist epilepsy centres in the USA (National Association of Epilepsy Centers 2001). Its report sets out the requirements for epilepsy care arguing that most people with epilepsy require care at a primary or secondary care level. It also sets out the standards and types of equipment required at each level of care.

Gruman et al (1998) argue for improved health care in the USA. They argue that poor quality health care produces needless suffering from uncontrolled seizures affecting people's abilities to participate in education and employment. Health care costs could be better used if they were not diverted to managing adverse events that arise in poorly managed care. Gruman et al (1998) argue that improving the health care of epilepsy has not received a lot of attention in the US because most seizures are well controlled and most of the costs of management are borne by private individuals. They argue that low incidence conditions such as epilepsy fit well into a model of managed care which is now widely used in other chronic conditions. Managed care includes screening, assessment, care planning with the person, follow up and information.

On the basis of international experience, there are three important issues that require health policy attention in Australia regarding the broad spectrum of health services for people with epilepsy. The first relates to the recognition of epilepsy as a long-term

or chronic condition. The next relates to safety and quality in epilepsy treatment and care. The third issue relates to the equality of access to health care for people with epilepsy. (Given that there has been such a lot of development in improved services for people with cancers diabetes etc. in our system of social insurance there is an ethical question arising that people with epilepsy deserve similar access.)

5.10 Epilepsy as a chronic condition in an ageing society

In 1999 the Australian Government established the National Chronic Disease Strategy. Chronic diseases such as arthritis, asthma, heart disease, stroke, diabetes and depression were estimated to cost the Government \$35 billion on 2000-2001, with some 3 million Australians estimated to have a chronic condition. The Federal Government committed some \$210 million to Enhanced Primary Care Packages in General Practice and began to develop chronic disease self-management programs. \$14.4m over four years was set aside for the development of a nationally coordinated chronic disease self-management program for those Australians with chronic and complex health concerns.

This strategy was largely aimed at the ageing population in Australia. It undertook to improve primary care for older people with chronic illnesses which were largely in the 'lifestyle' category of asthma, heart disease, diabetes, stroke, depression and musculoskeletal diseases. The Victorian Burden of Disease study has shown that these diseases account for almost three quarters of the years of life lost (YLL) and of years lost to disability (YLD)

http://www.health.vic.gov.au/healthstatus/bodvic/bod_current.htm.

Self-management programs of which the Stanford University Chronic Disease Self-Management Program was then the favoured model, were said to be based on a partnership between the person with the disease, their families and health professionals, in which they are encouraged to play an active role in:

- monitoring and managing symptoms and signs of illness,
- managing the impacts of illness on their lifestyle, emotions and interpersonal relationships,
- and adhering to treatment regimens.

Since 2000 the program has grown and has become an established feature of the healthcare system with each State establishing its own chronic disease management program. In 2005 the Federal Government developed its chronic disease strategy, still aimed at older people with 'lifestyle' diseases and now focusing on early intervention through primary care. Systems of care were reviewed in a number of conditions by developing national service improvement frameworks. Wagner's model of care which emphasises individualised health plans and partnership where health professionals and consumer work together to meet agreed goals has been hugely influential (refs). Self-management remains an essential feature of chronic disease management but has been extended to include a range of strategies rather than limiting it to the Stanford program.

The Government promotion of chronic disease management programs in Australia has improved health service delivery for specific conditions. It has led to the up-skilling of primary care health professionals such as General Practitioners in the treatment and

care of people with chronic conditions such as type 2 diabetes, chronic heart failure, COPD, depression, stroke and depression. It has opened up new areas of health service research where research centres such as the Centres for Clinical Research Excellence (CCRE), the earlier General Practice Evaluation Program (GPEP) and new research programs in Departments of General Practice across all universities with medical schools. In turn this has led to research being undertaken in nursing schools and allied health and new partnerships have been formed with consumer focused bodies such as Consumers' Health Forum, Health Issues Centre and Chronic Illness Alliance.

The establishment of the Consumer Focus Collaboration in the 1990s led to the voices of health consumers being included in the design and establishment of new services for people with cancers, musculoskeletal diseases, asthma and diabetes.

Much of this research has led to a greater understanding of what people need to manage a chronic condition in the long term. In recognition of the needs for a range of supports beyond the clinical, the Federal government has actively supported the creation of new Medical Benefits Scheme (MBS) items to provide support services beyond the clinical for people whose chronic illnesses fit these 'lifestyle' definitions.

While epilepsy fits all definitions of a chronic illness it has remained largely unrecognised in health service policy, with the exception of the recent establishment of the CCRE in Neurosciences at the Austin Hospital, Victoria. Even were one to adopt the limited definition that chronic disease are largely related to lifestyle and ageing a proportion of epilepsy incidence falls into this category.

The ageing population in Australia means that epilepsy requires more attention. Epilepsy has been found to be common in older people. A United Kingdom study found that the incidence rose steadily in people aged over 69 (Stephen & Brodie 2000) and that its causes were likely to be related to stroke, dementias and alcohol consumption as well as head injuries.

Seizures in older people may be partial and may go unrecognised, since the temporary loss of concentration or a state of confusion may be attributed to 'old age' or Alzheimer's. Medications, the most common form of treatment in older people may be difficult to manage because of potential interactions with other drugs the older person is taking.

It is impossible however to estimate the disease burden of epilepsy amongst older people in Australia. The Victorian Burden of Disease Study 2001, shows that neurological disorders increase with age so that some 19% of DALYs relate to neurological disorders after the age of 65, but this category does not seem to include epilepsy, the report at one stage including epilepsy in 'intellectual' or genetic disorders. It also appears that any data that might have been collected for this report was from population health surveys which rely on self-reporting, notoriously unreliable with regard to epilepsy. The lack of data is not confined to Victoria or Australia. Chisholm (2005) estimates that the global burden of epilepsy has a distribution of approximately 25% in people aged 65 and older in developed countries including Australia.

5.11 Safety and quality considerations in epilepsy

The Chronic Disease Management strategies adopted by governments across the country have provided health professionals through continuing education with a better understanding of the chronic conditions in their communities. This is a safety and quality issue in its own right. But the scant attention paid to epilepsy in health services policies including chronic disease management means that data regarding the relative safety and quality of Australian epilepsy services are not readily available.

Lack of education on epilepsy of health professionals at the primary health care level may mean there is poor understanding of drug interactions or of their optimum use in cases of co-morbidity, which is most likely in older people. Moreover, lack of systematic consultation with users of epilepsy services means that their experiences of services, either good or bad, are not available for service improvement purposes.

None of this implies that individually medical services have not themselves undertaken measures to improve the safety and quality of their service. Rather it implies that people with epilepsy, their families and carer have no means of judging which services are safer or of higher quality and that systematic and consistent improvement is unlikely to take place.

Systematic and consistent improvement across all sectors of the health system contributes to a safer, high quality service. This includes coordination of all the services people with epilepsy, their families and carers require to achieve an optimal quality of life. Coordinated services means the person receives investigative, clinical, pharmacologic services and referrals to counselling and information services. The person is able to move between primary and tertiary care as they need through a consistent referral system without knowledge of their diagnosis and care being compromised. The person with epilepsy, their family or carer needs to be able to access a range of generalist, allied and specialist services including neurosurgeons, general practitioners, specialist epilepsy nurses, psychologists, neuropsychologists, counsellors and occupational therapists. The person with epilepsy, their family or carers requires access to services that assist them with finding or maintaining employment or completing an education. Older people who do not need some of these services still require support, information and advice. They may require Extended Aged Care in Health (EACHD) packages such as those provided to people with Alzheimer's disease. All people with epilepsy should know they can be followed up and assisted with these matters by trained service providers at the State Epilepsy Foundations which are part of the integrated package of care for epilepsy. These matters are not left to chance.

A well-coordinated service that provides the full spectrum of services must be subject to workforce planning with a view to creating a decade long plan for services. This is especially the case where the ageing population may mean higher incidence of epilepsy amongst older people. Planning is required for the number of neurologists, neurosurgeons, technologists, specialist epilepsy nurses, support staff and allied health professionals. Such planning needs to take into account the needs of rural and regional people with epilepsy, the future housing options of older people with epilepsy. It also requires research on the location of investigative equipment, the amount of equipment required and the location of neurosurgery. Health informatics

including data collection and data sharing as well as coordinating services must be integrated in such a plan.

5.12 Equality of access to health services for people with epilepsy

Health services for people with chronic conditions that are part of the National Chronic Disease Strategy or a National Health Priority have undergone many changes, including additional funding, service redesign and coordination. This has included giving attention to issues of access and equality so that people from CALD communities, people of lower socio-economic status, rural people and indigenous people have access to services. Services for people with epilepsy have received no such attention and there are little data to understand the access and equality issues for people with epilepsy with regard to their services.

6. DISCUSSION:

6.1 Policy gaps or policy chasms?

This report has argued that Australians with epilepsy have areas of serious neglect that if addressed would result in a range of benefits to people with epilepsy, their families and carers. Principally, neglect occurs in areas relating to:

- discrimination of people with epilepsy throughout the community;
- reduced access to education and employment opportunities;
- health policies.

We have undertaken a broad overview of policy areas where one could expect to see strategic directions for the benefit of people with epilepsy. From this broad overview, a picture emerges where concern for epilepsy is absent and where the needs of people with epilepsy receive no attention.

Gaps in services and policies to benefit people with epilepsy were recognised more than twenty years ago. In 1985 there were suggestions made by the then Human Rights Commission to address the exclusion of people with epilepsy. In 2007 the Human Rights Commissioner reported cases demonstrating that people with epilepsy still experienced discrimination in their daily activities. The problem is that there are no measures to address these gaps.

Policies such as the Disability Discrimination Act have been designed to diminish discrimination throughout the whole Australian population by penetrating social institutions such as educational facilities and workplaces. Consequently they should benefit people with epilepsy. However, this ‘broad brush’ approach means that the deeply embedded fear of epilepsy and consequent discrimination of people with epilepsy is barely modified or easily overlooked. The DDA has a number of weaknesses. The first is that as a complaints-based approach it is not able to address systemic discrimination. Complaints in themselves do not generate systemic data. Secondly, where people with epilepsy are concerned they are far less likely to make a complaint. Similar Acts in other countries contain weaknesses and anomalies and do not address the discrimination faced by people with epilepsy in those countries.

Australians with epilepsy are likely to be unemployed. This may have little to do with their condition or their capacity to work. It is more likely to be related to attitudes towards them by employers and work colleagues. Data for this have been available since the 1990s. However, research demonstrates that it is not simply a case of providing skills training to people with epilepsy. Programs are required to address the attitudes of employers and work colleagues and to address the fears they have regarding workplace safety and absenteeism which are largely unfounded. Gender-based issues such as women with epilepsy who also have families to care for need more attention, when it comes to work retention issues. Government programs are not designed to address this level of social complexity in employment and workplaces. Research demonstrates that far more needs to be done at government level to support people obtaining and retaining employment.

Historically, people with epilepsy were seen as either unemployable or suitable for ‘sheltered workshops’. It is likely that this attitude still impacts on wider community

attitudes, although it no longer has any grounding in reality. In the 1990s epilepsy foundations have attempted to improve opportunities for people with epilepsy to undertake paid employment. The most recent programs have failed possibly because they were not designed to meet the needs of the individuals who were looking for work and because they did not address the above systems issues that are not in the individual's control.

If we accept the premise that education is the key to a better life generally and employment specifically, some of the complexity surrounding epilepsy and schooling requires further research. It is not clear whether epilepsy or epilepsy medication impacts on learning skills but this is likely to vary from individual to individual. School, teachers and parental expectations are also impact factors that require more research. What is clear is that students with epilepsy and their schools require greater support to complete their education, successfully. Considerable assistance has been given by governments recently to assist schools work better with students with autism. Possibly students with epilepsy require far less assistance and different models of learning and have very good outcomes. There is little to suggest that state based education departments have a full understanding of epilepsy or are likely to provide support for children with epilepsy at present. Largely any work undertaken by schools and education departments relates to risk management and no work has been undertaken to improve academic outcomes of students with epilepsy.

There are clinical centres specific to the health care of people with epilepsy in Australia. Medical research in epilepsy is also undertaken. Many people with epilepsy benefit from new anti-epileptic drugs and developments in surgery. When the health care of people with epilepsy is compared to people with other conditions however, there have been few innovations. For example, people with other chronic illnesses have benefited from continuing education across health care services. They have also benefited from health service research initiatives and such initiatives as chronic disease self-management programs. The Chronic Disease Strategy of the Federal Government has led to more allied health services being covered by the Medical Benefits Scheme. The lack of health policies associated with epilepsy care means that health care has not developed greatly beyond the clinical. The foundations then attempt to fill the gaps for people with epilepsy in this regard, providing allied health services, emotional support and equipment such as alarms. There is very little understanding of the burden of epilepsy in the community and on the individual because there are few statistics produced about it. The health care requirements of indigenous people with epilepsy remain largely a mystery.

7. CONCLUSION AND RECOMMENDATIONS

7.1 Disability or chronic illness?

This overview of policies in relation to epilepsy has also highlighted that an outstanding complication is the multiple descriptors of epilepsy in documents. Historically it has been seen as an intellectual disability or even a psychiatric problem. Currently it is regarded as a disability or a medical condition.

Each term carries its own limitations. The generic use of the term disability means that those people with epilepsy who do not regard themselves as disabled and those people disabled by epilepsy who do not want to be identified as having epilepsy remain ‘in the shadows’ in Australia. Those people with epilepsy who see themselves as part of the medical model—that is their interests lie in health care rather than in disability care, may not seek services from the disability sector. Still another problem emerges because the definition of disability itself is variable (Phillips 2008) so that people with epilepsy may fit a category in some instances and not in others.

Where policy development is concerned these conflicting characterisations suggest that no one policy area has any responsibility for improving the quality of life of Australians with epilepsy. It may explain the reason that epilepsy appears nowhere in policies.

RECOMMENDATION 1: Those policies from which people with epilepsy can expect assistance to improve the quality of their lives should be reviewed to ensure barriers and inconsistencies are removed.

7.2 Social exclusion and the lack of policies to assist people with epilepsy.

At the outset of this report we have argued that policies provide the capacity to foster social inclusiveness and to redress social exclusion. There is a large body of evidence that indicates Australians with epilepsy are socially excluded across all the levels where social exclusion operates:

- Disengagement
- Service exclusion
- Economic exclusion (Saunders 2007).

People with epilepsy are not necessarily engaged in community activities, such as sporting activities, simply because their participation is not welcomed. Additionally they may not be engaged in a range of community activities by default, that is they cannot afford them or they cannot access them by public transport. Their participation in some community activities may be limited by their health or their educational levels. People with epilepsy are excluded from services. Where health services are concerned, they are excluded by distance and travel barriers. However the services they most require such as support services may be limited by the cost or the availability of the services. Some people with epilepsy may be excluded from education because there are no learning supports or it is provided in a manner not conducive to their learning. Access to other services may be limited by income. Economic exclusion largely relates to an inability to access employment opportunities, which we have seen is the case for many people with epilepsy.

Where there are no policies to foster the social inclusion of groups or individuals in the broader community, policies themselves become the basis for legitimating social exclusion at all other social levels including community, private enterprise and social interactions between individuals.

RECOMMENDATION 2: There is an urgent need for policies, programs and community campaigns to encourage the social inclusion of people with epilepsy in the broader, everyday Australian community.

7.3 Policies to assist with social inclusion of people with epilepsy

Policies are required to foster affirmative action in favour of people with epilepsy. Such policies need to be instituted at all levels of government but most particularly at the Federal level.

Policies that will be most effective for people with epilepsy must relate to creating systemic changes in Australian attitudes towards people with epilepsy instead of policies which try to make people with epilepsy conform to perceived norms of the 'well' citizen.

The most important areas where policy could provide long term attitudinal changes are in employment, welfare, education and health policies.

Thus policies relating to employment and work retention must recognise the needs of people with epilepsy in the workplace and provide them with flexible work arrangements, workplace modifications and transport assistance. At the same time, employers and work colleagues must be offered education in order to accept the differences and to understand the safety issues. Legislation requiring that employers have a quota of their workforce from the disability sector would benefit all people with disabilities, including people with epilepsy.

Similarly where education is concerned students with epilepsy require far more support and understanding. Research is required on the reasons students with epilepsy underachieve. Different models of learning should also be researched, including more flexible forms of academic assessment. No student with epilepsy should be in the position that they fail an examination because they cannot get special consideration for their seizure activity. Funding for consistent support services at schools is required and this can only come about through government programs.

Welfare and discrimination legislation requires affirmative action in favour of people with epilepsy. Policies and programs are required that are specifically built on the premise that people with epilepsy are unlikely to assert their rights in the face of stigma and discrimination. Such programs should offer supports such as transport, aids and equipment to promote secure independence. The foundations supporting people with epilepsy, their families and carers require assistance to give adequate support to their clients since the foundations are safe and confidential sources of support. Staff in Centrelink and other welfare brokerage organisations requires more education on the needs and capacities of people with epilepsy.

The Chronic Disease Strategy should be extended to cover epilepsy as a chronic illness. People with epilepsy who do not live in metropolitan areas, indigenous people

with epilepsy require greater access to all services. Services such as allied health and support services need to be extended to people with epilepsy.

RECOMMENDATION 3: There is an urgent need for specific policies and programs related to employment, welfare services, discrimination and health services to address the fundamental needs of people with epilepsy in these essential areas of life.

RECOMMENDATION 4: Epilepsy foundations in Australia provide nearly all the services outside medical services that people with epilepsy and their families and carers need. They require funding to provide adequate services.

7.4 Data to support policy development

As this discussion paper has explored each policy area it has become evident that there is very little data to support policy development. For example there are wide variations in the incidence and prevalence of epilepsy; there are only estimates on how many people have uncontrolled epilepsy; there is little information on how many students with epilepsy there might be in schools and universities. There are little data on how people with epilepsy cope in the workplace and the numbers who might need help. Better data collection is a first step to providing policies and ultimately services that benefit people with epilepsy, their families and carers.

RECOMMENDATION 5: Data are required to support the development of appropriate policies and services. Data should be collected and collated nationally by the Australian Bureau of Statistics and other government funded bodies to ensure it is accurate and reliable.

This discussion paper has found that there are no government policies that will lead to the social inclusion of people with epilepsy in Australia. The United Kingdom All party Parliamentary Group for Epilepsy has used the adage ‘wasted money, wasted lives’, which would as easily refer to the position of epilepsy in Australia.

Government policy must lead the changes necessary to improve the lives of people with epilepsy, their families and carers. The extent to which public policies include the needs of people with epilepsy, their families and carers is a measure of the extent to which the same people are socially included or excluded throughout the wider community.

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