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Disability and People from Non-English Speaking Background Communities

**Acting Race Discrimination Commissioner** 



Human Rights and Equal Opportunity Commission

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### Foreword

Dr William Jonas AM Acting Race Discrimination Commissioner

This paper highlights some important discrimination issues facing people with disabilities from non-English speaking backgrounds. Our concern to address these issues initially arose following discussions between the former Race Discrimination Commissioner, Zita Antonios, and members of the National Ethnic Disability Alliance (NEDA). As we looked into the issues raised by NEDA, the scarcity of information on the intersection of disability and racial discrimination became increasingly apparent. Clearly there was a need to examine possible human rights breaches experienced by specific groups in Australian society.

This paper, however, does not pretend to be a comprehensive analysis of what is a particularly complex subject area.

Rather, it aims to:

- identify some key issues facing people with disabilities from non-English speaking backgrounds;
- identify some strategies to assist people with disabilities from non-English speaking backgrounds; and
- provide a resource for people with disabilities in this group and other interested parties.

During the preparation of this report HREOC consulted a broad cross section of stakeholders and drew on the expertise of a wide range of individuals and organisations. Some useful ideas emerged. The more significant of these centre around improved access to interpreters, ongoing consultation, better information dissemination in community languages and increased availability of culturally appropriate services.

I offer this paper as a contribution towards furthering the agenda of better, more appropriate service provision and improved human rights for people with disabilities from non-English speaking backgrounds.



## **Executive Summary**

Following consultation with a broad cross-section of stakeholders, the Race Discrimination Commissioner prepared this paper to highlight some important discrimination issues facing people with disabilities from non-English speaking background communities.

Its aims are to:

- identify some key issues facing people with disabilities from non-English speaking background communities;
- identify some strategies to assist people with disabilities from non-English speaking background communities; and
- provide a resource for people with disabilities in this group and other interested parties.

#### Definitions and Data

The first section of Chapter 1 provides a comprehensive overview of a variety of terminology used to define disability and an analysis of the descriptor 'non-English speaking background'.

The second section of this chapter examines the most recent available data on the prevalence of disability in the Australian population in general and for non-English speaking background communities in particular.

An analysis by Black and Maples of the 1997 National Data for Disability Services provided under the Commonwealth/State Disability Agreement stated that the distribution of the reported primary disability type varied among country of birth groups. Psychiatric disability, vision disability, acquired brain injury and neurological disabilities were more likely to be reported for those service recipients born outside Australia.

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The same analysis indicated that of 63,108 service recipients, only 3.1% were born in non-English speaking countries. The lower than

average levels of usage of disability services by people from non-English speaking backgrounds has been attributed to a range of factors including lack of awareness of disability services, cultural inappropriateness of the services and inappropriateness of the survey questions.

Overall, current statistical information on disability for non-English speaking background people both nationally and across states and territories is inadequate and an impediment to the development of policy initiatives for the effective planning and targeted delivery of disability services.

#### Human Rights Framework

Chapter 2 provides a comprehensive overview of international human rights covenants and domestic legislation, which sets the context for the discussion that follows. Australia is signatory to a range of international covenants which commit national governments to recognise and protect civil, social, cultural, political and economic rights.

#### Attitudes and Misconceptions

Chapter 3 examines community attitudes towards disability and highlights some experiences of people with disabilities from non-English speaking backgrounds. Chapters 3–5 include empirical research and provide a range of case examples that demonstrate clear human rights violations, set within the framework of the particular international or domestic laws that may apply. They also examine the adequacy or inadequacy of service delivery at various levels and where appropriate, highlight good practice in service provision.

People with disabilities are routinely marginalised, stigmatised and dehumanised regardless of their community affiliations. Depending on the disability and society's different perceptions of the disability they may often be:

- stereotyped as 'others', who are less than whole and seen as defective;
- regarded as 'eternal children' and a burden;
- expected to constantly prove competence;
- assumed to have limitations that the person does not in fact have;
- 'judged' according to the manner in which a disability was acquired;



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- not viewed in a multi-dimensional way and therefore not accorded the same human rights as able-bodied people; and
- regarded as objects of shame who may be being punished for a perceived misdeed.

Furthermore, the empirical research clearly indicates that people with disabilities from non-English speaking background communities are often further stigmatised and isolated because of attitudes and misconceptions prevalent in the broader community as well as in their own communities. In respect of the broader community, disadvantage is compounded by discriminatory attitudes towards disability and ethnicity. Again, this raises the issue of multiple disadvantage in cases where an intersection of variables (such as disability, class, ethnicity, gender and sexuality) determine a person's identity. In their own communities, lack of educational opportunities to address discriminatory attitudes, adherence to some traditional beliefs that negate the rights of people with disabilities and the sheltered and isolated nature of some communities could contribute to the preservation of myths about disability.

#### Consultation, Participation & Culturally Appropriate Services

The Commonwealth Disability Strategy and the Commonwealth/State Disability Agreement generally acknowledge the importance of consultation with people with disabilities and their carers and their participation in advisory and review bodies and processes. Furthermore, the Charter of Public Service in a Culturally Diverse Society lists consultation and participation as integral strategies to achieving effective communication that should enhance the delivery of services. The Charter is potentially a significant document as it has been endorsed by all tiers of government and is intended to represent a nationally consistent approach to the delivery of culturally responsive government services.

Literature, case examples and good practice examples cited in this chapter clearly demonstrate that culturally appropriate services, designed and implemented in consultation with people with disabilities from non-English speaking backgrounds, are essential to accessible service delivery and basic human rights.

#### Communication and Access to Information

The inability to access information and communicate effectively in English has been consistently identified as a major barrier for people

from non-English speaking backgrounds. People with disability from these groups are no exception. These difficulties are compounded by prejudicial attitudes and preconceptions regarding disability which exist among the broader society as well in their own communities.

This chapter concludes that interpreters, bilingual staff, community education and easily understood information about disability services in community languages are essential in addressing barriers to access in this area.

#### Conclusions

The concluding chapter identifies a range of strategies (pages 58–61) for:

- awareness raising and education;
- improving the cultural appropriateness of service delivery; and
- improving communication.

It is imperative that governments and service providers implement these strategies to make services more accessible and rectify breaches of human rights.

#### **References and Appendices**

This paper also contains five appendices and a useful list of references. Appendices 1 and 2 contain the abbreviations and a comprehensive discussion regarding the various definitions of disability used in Australia. Appendix 3 lists the main provisions of the *Disability Discrimination Act* 1992 and the *Racial Discrimination Act* 1975. Appendices 4 and 5 provide information regarding the National Ethnic Disability Alliance and list the recommendations of the *National Disability Advocacy Program Review* report.

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## Introduction

People with disabilities from non-English speaking background communities sometimes experience multiple layers of discrimination – discrimination on the basis of disability, race or ethnicity, gender and/or sexuality. Invariably, discrimination results in isolation, fear, exclusion and alienation.

Some significant barriers affect people with disabilities from non-English speaking backgrounds. These may include:

- lack of information about rights and the availability of services in appropriate community languages;
- lack of interpreters or information about them;
- lack of culturally appropriate services;
- myths, misconceptions and negative stereotypes about disability and ethnicity in the general community; and
- prejudice against people with disability from members of their own communities.

To raise awareness and address these issues, advocacy organisations often form bridges between individuals and service providers, identifying people's needs and channelling information to service providers and policy makers. They also provide information, support and advice to their clients, their families and carers, so that they understand their rights and can make informed decisions.

This is especially true of specialist advocacy bodies representing clients with disabilities from non-English speaking background communities. Poor grasp of written or spoken English, lack of interpreters in clients' languages, unfamiliarity with rules and regulations and occasional fear of authority are likely to make disability services inaccessible to clients and contribute further to their marginalisation and isolation. Specialist advocacy services can and do perform an invaluable role by advocating on behalf of such clients and enabling them to deal with government agencies, service providers and others on a far more equal footing.

The peak advocacy body for people with disabilities from non-English speaking backgrounds is the National Ethnic Disability Alliance (NEDA), a coalition of a number of state member organisations.<sup>1</sup>

Several years ago, the Federal Minister for Family Services initiated a comprehensive review of the National Disability Advocacy Program. The outcome of that process, released in July 1999, was the *National Disability Advocacy Program Review Report*. The report contained 14 recommendations.<sup>2</sup>

Recommendation 7 noted the need for:

Strategies to address the needs of people with disabilities from Aboriginal and Torres Strait Islander backgrounds, diverse cultural and linguistic backgrounds and rural and remote communities to be developed in consultation with advocacy services.

The report highlighted the marginalisation and isolation resulting from disability and cultural differences; some traditional attitudes in individual ethnic communities in dealing with disability issues; the low participation rate of people from non-English speaking background communities in disability services; and the inadequate focus by some mainstream disability organisations on issues facing people from these communities. These findings recognised an unmet need for the provision of more appropriate services to people from non-English speaking backgrounds.

It is against this backdrop that HREOC prepared this paper. It aims to raise community awareness and identify at least some of the key human rights issues facing people with disabilities from non-English speaking background communities. It does so by locating a range of pertinent issues within a human rights framework.

The paper begins with a comprehensive overview of the vexed issue of consistency of terminology when defining disability. The first chapter establishes the meanings for 'disability' and 'non-English speaking background' that are adopted throughout this paper.

In Chapter 2, a comprehensive explanation of international and domestic human rights instruments provides the context for the discussion that follows. The report then draws together and analyses a significant amount of literature. A strong feature and common thread throughout the report is the inclusion of literature citing empirical research relevant to each of the themes under discussion:

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- 1. Details of NEDA's affiliated members are at Appendix 4.
- 2. See Appendix 5

- Attitudes and misconceptions (Chapter 3);
- Consultation, participation and culturally appropriate services (Chapter 4); and
- Communication and access to information (Chapter 5).

These chapters examine community attitudes towards disability and highlight some experiences of people with disabilities from non-English speaking backgrounds. They provide a range of case examples that demonstrate clear human rights violations, set within the framework of the particular international or domestic laws that may apply. The adequacy or inadequacy of service delivery at various levels is also examined and where appropriate good practice in service provision is highlighted.

In the concluding chapter, the report identifies a range of strategies for

- awareness raising and education;
- improving the cultural appropriateness of service delivery; and
- improving communication.

These strategies are offered as a starting point to redress the significant disadvantages experienced by people with disabilities from non-English speaking backgrounds. From the incorporated research and findings of this paper, it is evident that a great deal more work needs to be done to ensure that people with a disabilities from non-English speaking communities fully enjoy their human rights.



Chapter 1

## Definitions & Data

Some terms and concepts need to be clarified at the beginning. This section explains the terminology adopted throughout this paper. It defines 'non-English speaking background' and 'disability'. It also summarises the most recent available data on the prevalence of disability in the Australian population in general and for non-English speaking background communities in particular.

#### Terminology

Definition of 'non-English speaking background'

The Commonwealth Government currently uses 'culturally and linguistically diverse people' to describe the complex and multicultural nature of Australian society. This is an inclusive term that encompasses people from English and non-English speaking background communities.

Yet access to services and programs for some migrants and refugees is affected by an inability to communicate in English. For people with disability who are not fluent in English, the problems may be even more complex. Hence, in this issues paper, which focuses specifically on access and equity, the term 'non-English speaking background' is used.

Both terms have advantages and disadvantages. The term, 'non-English speaking background' commonly refers to people who were born overseas in a non-English speaking country or have at least one parent in that category. When the term was introduced as a standard descriptor, the linguistic and communication issues affecting immigrants, refugees and their children were of paramount concern. Communication is one of the keys to ensuring that people's human rights are not infringed but this is only one part of the picture. Physical characteristics such as skin colour or cultural beliefs and practices that may be different from the wider community are all relevant. Accordingly, some view the term 'non-English speaking background', with its focus on language, as inadequate because it



does not extend to these additional characteristics of difference. However, despite its limitations, the term remains a useful phrase in this context to describe a group of people who may experience communication difficulties with the English language and discrimination based on ethnicity.

Finally, in any analysis of ethnicity and related issues it is essential to emphasise that ethnicity or linguistic background forms only one part of a person's identity. Identity is multi-dimensional and no adequate understanding of the realities facing people from non-English speaking background communities is possible without considering the intersection of ethnicity with, for example, disability, gender, sexuality, socio-economic status, age, religion, profession and many other factors.

#### Definitions of disability

The word 'disability' has a number of definitions.<sup>3</sup> As commentators such as Madden and Hogan have argued, it is important to define disability accurately and precisely because '...better national information on disability relies on consistent definitions to underpin the gathering of statistical data'.<sup>4</sup>

Disability is defined in a variety of ways depending on who does the defining, for what purpose and in what circumstances. Generally, the following definitions of disability are used in Australia:

- definitions used by activists and advocates;
- broad inclusive definitions for anti-discrimination measures and population research;
- definitions for generic or mainstream services;
- definitions for income support; and
- definitions for disability support services.

Without accurate national data on disability in general and among specific groups, it is difficult to plan appropriate services and much more difficult to bring about policy change and influence community perceptions in this area.

Appendix 2 of this paper provides an overview of a range of definitions. Two key definitions are provided by the World Health

<sup>3.</sup> For a more comprehensive discussion, see Appendix 2.

Madden, R. and Hogan, T., 1997, The Definition of Disability in Australia: Moving Towards National Consistency, Cat. No.DIS 5, Australian Institute of Health and Welfare (AIHW), Canberra.

Organisation (WHO) and the *Disability Discrimination Act* 1992 (DDA). In 1980, the WHO published the International Classification of Impairments, Disabilities and Handicaps (ICIDH-1) as a guide for the classification of diseases. The ICIDH-1 is regarded as a conceptual framework for disability that includes three dimensions - impairment, disability and handicap.

In 1993, the WHO revised ICIDH-1 across all three dimensions. Accordingly, the revised International Classification of Impairments, Disabilities and Handicaps (ICIDH-2) used the following criteria to define disablements:

- losses or abnormalities of bodily function and structure (impairments);
- limitations of activities (disabilities); and
- restrictions in participation (formerly called handicaps).

The ICIDH-2 adopted a conceptual model in which functioning and disablement are regarded as ' ... outcomes of an interaction between a person's physical or mental condition and the social and physical environment'.<sup>5</sup>

The definition of disability under the DDA is very broad. The definition is not intended to change the day-to-day concept of disability, but has been made as broad as possible to ensure any person who is treated less favourably on the basis of a past, present, future, real or imputed disability has access to remedies under the Act.

Section 4 of the DDA defines disability as:

- (a) total or partial loss of the person's bodily or mental functions; or
- (b) total or partial loss of a part of the body; or
- (c) the presence in the body of organisms causing disease or illness; or
- (d) the presence in the body of organisms capable of causing disease or illness; or
- (e) the malfunction, malformation or disfigurement or a part of the person's body; or
- (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour; and includes a disability that:



5. World Health Organisation (WHO) website at http://www.who.int/msa/mnh/ems /icidh/brochure.

- (h) presently exists; or
- (i) previously existed but no longer exists; or
- (j) is imputed to a person.

Appendix 2 discusses the remaining definitions in detail.

#### National disability profile

According to the 1998 *Disability, Ageing and Carers* survey, there were over 3.6 million Australians with a disability, representing 19.0% of the total population.<sup>6</sup> The report also stated that '... Of those with a disability, 87% (3.2 million) experienced specific restrictions<sup>7</sup> in core activities<sup>8</sup>, schooling or employment'.

#### By sex and age

The same survey results indicated that the percentage of males and females with a disability was similar but differed across age groups.<sup>9</sup> Comparing disability rates for people with a specific restriction across genders produced similar results (17% of the total population). However, since both sexes were not evenly distributed across age groups, the overall disability rate for males (20% of the total population) was slightly higher than for females (18% of the total population).

On the connection between age and disability, the survey found that:

the rate of disability increased with age, from 4% for children aged 0-4 years to 84% for those aged 85 and over. ...Among older people, the rates of severe and profound disability were markedly greater for females.<sup>10</sup>

6. Australian Bureau of Statistics (ABS), 1998, *Disability, Ageing and Carers: Summary of Findings*, Cat. No. 4430.0, ABS, Canberra.

- Specific restrictions are: Core activity restrictions; and/or schooling or employment restrictions.
- 8. Core activities are: *Self care*—bathing or showering, dressing, eating, using the toilet and managing incontinence; *Mobility*—moving around at home and away from home, getting into or out of a bed or chair; and using public transport; and *Communication*—understanding and being understood by others; strangers, family and friends. Core activity restriction may be: *Profound*—unable to perform a core activity, or always needing assistance; *Severe*—sometimes needing assistance to perform a core activity; *Moderate*—not needing assistance, but having difficulty performing a core activity; and *Mild*—having no difficulty performing a core activity, but using aids or equipment because of disability.

<sup>9.</sup> Supra note 6 at 5.

<sup>10.</sup> *Id.* 

#### By disability groupings

The 1998 *Disability, Ageing and Carers* survey reported that 85% of those surveyed nominated physical conditions (eg. arthritis) as the cause of their disability.<sup>11</sup> In contrast, 15% of those surveyed nominated mental or behavioural disorders as their main condition.

In 1998, the Australian Institute of Health and Welfare (AIHW) published an analysis of the 1997 data collected as part of the Commonwealth/State Disability Agreement (CSDA) National Minimum Data Set (NMDS).<sup>12</sup> Approximately 67% of survey respondents nominated 'intellectual disability' as their primary disability type (ie. the disability type with the most affect on the service recipient's everyday life).

The next most frequently reported primary disability types were:

- physical disability (11.6%);
- psychiatric disability (6.1%); and,
- acquired brain injury (3.6%).

In 1998, the AIHW also published an analysis of the data on open employment services collected during 1995–96 and 1996–97 periods for people with disabilities.<sup>13</sup> The analysis showed that of the primary disability groups (ie. intellectual/learning, psychiatric, physical, acquired brain injury, neurological, vision, hearing, speech and deaf and blind), people with a psychiatric or a neurological disability had the least likelihood of having had a job. The report also indicated that people with disabilities who had a job during the reporting periods received more support than those who did not.<sup>14</sup>

#### By birthplace

A number of surveys in Australia categorise people with disabilities from non-English speaking background communities according to their places of birth, not whether or not English is spoken at home. It should be noted that birthplace is not always a reliable indicator of ethnicity. However, for obvious reasons, it is the most commonly used indicator.



 Supra note 6 at 7.
 Black, K. and Maples, J., 1998, Disability Support Services Provided Under the Commonwealth/State Disability Agreement: National Data, 1997, Cat. No. DIS 12, AIHW, Canberra.
 Anderson, P. and Golley, L., 1998, Open Employment Services for People with Disabilities 1995-96 and 1996-97, Cat. No. DIS 11, AIHW, Canberra.

14. *Ibid* at 93.

#### The Survey of Disability, Ageing and Carers: Australian Bureau of Statistics (ABS)

The 1998 *Disability, Ageing and Carers* survey listed the number of all persons with disabilities according to their birthplace. The data was organised according to geographical region and sub-regions. It indicated that over 900,000 or approximately 25% of all people with disability were born outside Australia.<sup>15</sup>

The Demand Study<sup>16</sup> commissioned for the 1996 Yeatman Review of the CSDA, which analysed the data from the ABS 1993 *Survey of Disability, Ageing and Carers,* indicated that 74.7% (446,089) people in households with a severe or profound handicap were born in Australia, 9.9% (59,123) in other English speaking countries, and 15.4% (92,078) were born in non-English speaking countries.

The Demand Study<sup>17</sup> also reported that people from non-English speaking background communities were:

- as likely as the rest of the population to report severe or profound handicap in the 1993 survey;
- less likely to be using CSDA services, possibly related to the likelihood that they are less likely to have an intellectual disability or other early onset disability because of the Australian immigration health screening processes; and
- less likely to report unmet need for help.

#### Disability support services provided under the Commonwealth/State Disability Agreement: national data

In the 1998 AIHW report analysing the CSDA data, the information regarding the birth country of the recipients of CSDA-funded services<sup>18</sup> (derived from NMDS) was recorded as: Australia, other English-speaking countries, and non-English speaking countries (ie. countries other than Australia, United Kingdom, Ireland, New Zealand, Canada, South Africa or the United States of America). This classification is currently under review.<sup>19</sup>

Black and Maples who analysed the 1997 data stated that, of the 63,108 service recipients with known countries of birth, 57,040 (90.4%) were born

<sup>15.</sup> *Supra* note 6 at 22.

Madden, R., Wen, X., Black, K., Malam, K. and Mallise, S., 1996, Commonwealth/State Disability Agreement Evaluation: Supporting paper 2 - The Demand Study, AIHW, AGPS, Canberra.

<sup>17.</sup> Ibid at 54.

<sup>18.</sup> The CSDA-funded services are grouped according to the following service types: accommodation support, community support, community access, respite and employment. Each service type includes a number of subgroups and programs.

<sup>19.</sup> Supra note 12 at 63.

in Australia, 1,568 (2.5%) in 'other English-speaking' countries, 2,003 (3.1%) were born in 'non-English speaking' countries and the country of birth was 'not known or stated' for 2,497 (4%) of the total recipients.<sup>20</sup>

The same analysis showed that the distribution of the reported primary disability type varied among country of birth groups. Intellectual disability was the primary disability type for 68% of service recipients born in Australia, but only 42% of those born in other English-speaking countries and 44% of those born in other countries. Psychiatric disability, vision disability, acquired brain injury and neurological disabilities were more likely to be reported for those service recipients born outside Australia.<sup>21</sup>

The lower than average prevalence of disability in general and certain disability types<sup>22</sup> such as intellectual disability in particular among people from non-English speaking background communities may well be attributed to the stringent medical screenings of potential migrants before being granted approval to migrate.

In addition, Black and Maples stated that service recipients born outside Australia were more likely than those born in Australia to be represented in the older age groupings. Of recipients born in Australia, 22% were aged 45 or over, compared with 41% of recipients born in 'other English speaking countries', 36% of recipients born in 'non-English-speaking countries and the country of birth was 'not stated' for 1% of the total recipients.

#### **Disability Services Census — Commonwealth Department** of Family and Community Services (DFCS)<sup>23</sup>

The 1997 Disability Services Census Report revealed that:

- approximately 4% of consumers accessing employment services for people with disability were born in a non-English speaking country (unchanged from 1995);
- in 6% of cases, English was not the main language spoken at home;
- the most commonly spoken languages other than English were Italian, Greek and Arabic/Lebanese (sic).

20. *Supra* note 12 at 19-20. During 1993 and 1994, the Commonwealth, all States/Territories and AIHW jointly developed the NMDS. The first data set collection took place in 1995. The current available data set is for 1997.

21. Supra note 12 at 19.

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22. *Supra* note 12 at 19-20. Black and Maples define the disability types as those most likely to arise from conditions present at birth, or the early developmental period.

23. The DFCS collects information from those organisations it funds to deliver disability services. This information is then published as a report. The 1997 report — third in the series - contains the main findings from the 1997 Commonwealth Disability Services Census. It includes all Commonwealth funded print disability, advocacy, information and employment services.

## Open employment services for people with disabilities — national data<sup>24</sup>

The 1998 AIHW report<sup>25</sup> contained a number of interesting findings:

- For workers in both 1995–96 and 1996–97, people with a preferred spoken language other than English received less support than did other workers whose preferred spoken language was English, and the difference had increased from one year to the next;
- However, for the same period, people with a preferred spoken language other than English received more support on average at the time of getting a job, which is the peak time for support. Yet during the period before and after getting a job they received less support on average;
- For workers in 1997–98, the average support for non-workers was the same for both groups but it was slightly higher for workers whose preferred spoken language was other than English. This was unlikely to be statistically significant in light of the small sample size;<sup>26</sup>
- For clients without a job there was no difference on average in 1995–96 and 1996–97 between the two groups;
- In both 1995–96 and 1996–97 people with a preferred spoken language other than English were slightly more likely to have been employed than others; and
- In 1996–97, an average worker with a preferred spoken language other than English worked over three hours longer per working week.

# The need for streamlining and national consistency

Over the last decade, Commonwealth, State and Territory governments have been involved in a number of initiatives that have emphasised the need to streamline the use of terms, definitions and concepts in the disability field.<sup>27</sup>

For instance, the Commonwealth Disability Strategy recommended the following:

- 24. The National Information Management System (NIMS) for open employment services in Australia collates national data on open employment services for people with a disability and on clients of these services. The data collection was initiated on 1 January 1995.
- Supra note 12 at 86-88 and private communication between AIHW and HREOC, 17 June 1999.
   Unpublished data, Anderson, P. and Golley, L., 1999, Open Employment Services for People
- with Disabilities, 1997-98, AIHW, Cat no DIS 14, Canberra. Cited with permission from AIHW. 27. For a comprehensive list of these initiatives see Madden and Hogan, *supra* note 4 at 4–6.

By 1997 the Disability Task Force, in consultation with the Australian Institute of Health and Welfare and the Australian Bureau of Statistics, will develop a framework for ensuring consistent core disability definitions and data collection methods are used in all government collections, to improve comparability of information on Commonwealth employment and other relevant programs.<sup>28</sup>

The Disability Task Force is no longer in operation. However, the DFCS, in conjunction with the ABS and the AIHW have continued work on this front. One example has been the establishment of the Disability Data Reference and Advisory Group (the Group) by the AIHW in 1996.<sup>29</sup> The Group aims to:

- promote the improvement and harmonisation of disability data collections in Australia at the national level;
- further the work on consistency of definitions recommended by the Commonwealth Disability Strategy...; and
- promote the effectiveness of Australia's participation in the revision of the ICIDH, and to ensure, as far as possible, that Australian views shape the revision, and that the revised ICIDH becomes a useful and accepted tool in the Australian context.

Nationally, one of the long-term projects of the Group is to provide input to the National Community Services Data Dictionary (NCSDD). The AIHW is hoping to have a small number of data items accepted in 1999 for inclusion in the NCSDD.<sup>30</sup>

Professor Anna Yeatman, in her 1996 Review of the Commonwealth/ State Disability Agreement, made similar recommendations as discussed above.<sup>31</sup> Her recommendations were based on the supporting Demand Study conducted by the AIHW.<sup>32</sup> This Demand Study indicated that data collection could be improved in a number of ways:

• Increased effort to move towards more consistent definitions of key terms and data items, including disability itself, so that the main relevant data collections become more relatable, this work would include working on data at the 'borders' of disability to make health, epidemiology and disability more consistent and mutually relevant; this area of improvement underpins the other three;

<sup>28.</sup> For more information see Department of Health and Family Services (now Department of Family and Community Services (DFCS)), 1997, *Commonwealth Disability Strategy: The Second Progress Report*, Canberra.
29. The membership of the Group includes relevant Commonwealth departments and agencies, community organisations, advocacy bodies (including the Federation of the Ethnic Communities' Councils of Australia (FECCA) and independent experts.
30. Based on private communication between AlHW and HREOC, 25 June 1999.
31. Yeatman, A., 1996, *Getting Real: The Final Report of the Review of the Commonwealth/State Disability Agreement*, AGPS, Canberra, Recommendations 34 and 35.
32. *Supra* note 16.

- Enhancements to the next ABS survey on disability in the Australian population, in particular by relating the survey more directly to the CSDA target group, by expanding the range of activities considered and by further work on 'disability type' and reasons for not receiving enough formal or informal assistance;
- Enhancements to State and Commonwealth administrative information systems, including the CSDA Data Set...; and
- Enhancements to related administrative data systems, perhaps by the development of a 'module' or small package of data items that would be consistent among related disability service collections. Key items worthy of consideration would be: disability type, age, sex, and level of support....

Notwithstanding the above recommendations, quite clearly there is an additional need for national disability data collection which records ethnicity in a uniform and comprehensive way. Currently, no such mechanisms are in place.

#### Disability data & the demand for services

The report *Australia's Welfare 1997*<sup>33</sup> emphasised the need for accurate national data on disability in order to estimate the extent of unmet need for disability services.

The report also noted that problems in the definition, conceptualisation and survey sampling methods are responsible for the lack of progress in establishing national prevalence estimates for disability among Indigenous peoples in Australia.<sup>34</sup> Similarly, there are no national prevalence estimates regarding disability for people from non-English background communities. The lack of information in this area perhaps could be explained in similar terms.

The findings of the Demand Study for the Yeatman Review's *Getting Real* Report<sup>35</sup> regarding people with disabilities from non-English speaking communities are not easy to interpret. The Demand study reported that people with disability in this group were less likely to be using CSDA services and less likely to report unmet need for help. This is:

not only because of the effects of health screening processes, but also because of frequently voiced doubts about the cultural appropriateness of services, information about services and survey questions.<sup>36</sup>



<sup>33.</sup> Australian Institute of Health and Welfare, 1997, *Australia's Welfare, Services and Assistance*, Cat. No. AUS-8, AIHW, Canberra at 304.

<sup>34.</sup> *Id.* 

<sup>35.</sup> Supra note 31.

<sup>36.</sup> Supra note 16 at 54.

The lower than average level of usage of disability services by people from non-English speaking background communities was also highlighted by the former Race Discrimination Commissioner in the 1995 State of the Nation Report:

The difference in usage, as indicated by the literature listed below, would seem to be due to a combination of lower levels of awareness of disability services by people of non-English speaking backgrounds, and the inability of such services to meet the needs of non-English speaking background clients.<sup>37</sup>

Professor Yeatman also pointed out that the aggregate figures derived from the *Ageing and Carers Surveys* give a poor idea of the demand pattern of people from non-English speaking backgrounds for services, because:

the geographic distribution of non-English speaking background communities is uneven across Australia, and it is much more concentrated in Sydney and Melbourne than elsewhere.<sup>38</sup>

In Professor Yeatman's view, relatively little is understood about the needs of people with disabilities from non-English speaking background communities and further work based on inter-governmental cooperation should be undertaken in this area. To this end, she recommended that:

The Australian Institute of Health and Welfare work with the Bureau of Immigration, Multicultural and Population Research in the oversight, design and commissioning of a study of demand by people from non-English speaking backgrounds for disability services, and of how this demand may best be met given the nature of the disability service system and its resource base.<sup>39</sup>

The Bureau of the Immigration, Multicultural and Population Research was disbanded in 1996. In light of AIHW's expertise in this area, it is perhaps the most suitable information and statistics agency to carry out such demand studies. However, in light of AIHW's limited resources, any such study would have to be funded either directly by the Commonwealth Government<sup>40</sup> or through other sources.<sup>41</sup>

Overall, as discussed above, the available statistical information on disability among non-English speaking background peoples is at best patchy and at worst a hindrance to the development of policy initiatives for the effective planning and targeted delivery of disability services.

- 37. Human Rights and Equal Opportunity Commission, 1995, *State of the Nation Report*, AGPS, Canberra at 183.
- 38. *Supra* note 31 at 46.
- 39. Supra note 31 at 48.

- 40. AIHW currently receives its core funding from the Commonwealth Department of Health and Aged Care.
- 41. Approximately half of AIHW's funding is now provided through contract work. Based on private communication between AIHW and HREOC, 25 June 1999.

Chapter 2

## Human Rights Framework

This section provides the broad human rights framework for the issues discussed in this paper. There are a range of international covenants to which Australia is a signatory. These covenants commit national governments to recognise and protect a broad range of civil, social, cultural, political and economic rights. They are complemented in some areas by relevant domestic legislation administered by HREOC.

Following the devastation of World War II, Australia played a major role within the newly created United Nations in drafting the *Universal Declaration of Human Rights* (UDHR). The UDHR is a common statement by the nations of the world that human dignity requires the recognition of all people's fundamental human rights. The declaration lists the fundamental rights all people are entitled to including rights to political participation, civil liberties, economic rights, social rights and rights to culture. After more than 50 years in operation, the UDHR remains a powerful instrument that, while not legally binding, carries immense moral force.

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

(Article 1, Universal Declaration of Human Rights)

Adoption of the UDHR prompted the negotiation of a raft of human rights instruments that now form the basis of a significant body of international law. Of particular significance are the *International Covenant on Civil and Political Rights* (ICCPR) and the *International Covenant on Economic, Social and Cultural Rights* (ICESCR) which, together with the UDHR, form the *International Bill of Human Rights*.

These covenants encompass a broad range of fundamental rights. The ICCPR commits national governments to recognise political and procedural rights such as the right to vote and equal protection of the law as well as civil liberties such as the right to life and freedom of movement, opinion and association.

The ICESCR recognises that individuals must hold rights in other areas of life to enjoy and participate fully in civil society. The ICESCR commits nations to recognise:

- economic rights, such as the right to work, to just and favourable conditions of work and to social security;
- social rights, such as the right to health, education and to an adequate standard of living including adequate food, clothing and housing; and
- cultural rights, such as the right to take part in cultural life and to enjoy the benefits of scientific progress.

#### The right to non-discrimination

Both the ICCPR and the ICESCR recognise the right to non-discrimination. Both Covenants state that all members of society are entitled to enjoy their rights equally 'without discrimination on grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.'<sup>42</sup>

Article 26 of the ICCPR states that:

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

The UN Human Rights Committee, the body established by the ICCPR to monitor the implementation of the Covenant, stated that Article 26 creates an obligation to ensure that the legal system is free from any form of discrimination, not only discrimination in relation to fundamental rights.<sup>43</sup>

Australia respects this body of international law as a cornerstone of the global effort to protect and promote human rights. Australia believes that pursuing these standards is the responsibility of all states.

To complement the broad scope of the ICCPR and the ICESCR is a myriad of supporting international covenants, conventions and declarations many of which are particularly relevant to the Australian context when considering the issue of disability among people of non-English

<sup>42.</sup> Article 2(1) ICCPR, Article 2(2) ICESCR.

<sup>43.</sup> Human Rights Committee, General Recommendation 18. Non-discrimination (1989) UN Doc HRI\GEN\1\Rev 1, Article 12.

speaking background. The right to non-discrimination is supported by many instruments of international law. International instruments that prohibit racial, disability and sex discrimination include the

- Convention on the Elimination of All Forms of Racial Discrimination (CERD);
- Declaration on the Rights of Disabled Persons; and
- Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

These international conventions are directly reflected in Australian domestic law by the:

- Racial Discrimination Act 1975 (RDA);
- Disability Discrimination Act 1992 (DDA; and
- Sex Discrimination Act 1984 (SDA) respectively.

The relationship between international human rights instruments and domestic laws is fundamentally a legal one, in the sense that the relationship forms a part of the broader matter of how the spheres of international law and domestic law interrelate. This is so because all the major international human rights instruments fall within the widely defined boundaries of international law. However, they do not all do so in the same way and with the same effect. Certain instruments are considered to be binding on Member States (Covenants and Conventions), while others – though not totally without legal force – are considered to be aspirational only (Declarations and Resolutions).

The ICCPR, ICESCR, CERD, CEDAW and Convention on the Rights of the Child (CROC) are all examples of the former kind of strictly binding instrument, and the UDHR, the Declaration on the Right to Development, the Declaration on the Rights of Disabled Persons and the Vienna Declaration and Programme of Action are examples of the latter, aspirational documents.

In Australia, the RDA, DDA and SDA are administered by HREOC, which also has statutory responsibility for the *Human Rights and Equal Opportunity Commission Act* 1986 (HREOCA) and the following seven international human rights instruments:

- ICCPR;
- International Labour Organisation (Convention No. 111) on Discrimination (Employment and Occupation);



- CROC;
- Declaration on the Rights of the Child;
- Declaration on the Rights of Disabled Persons;
- Declaration on the Rights of Mentally Retarded Persons; and
- Declaration on the Elimination of All Forms of Intolerance and of Discrimination Based on Religion or Belief.

All seek to bring into operation within Australia the human rights standards agreed to internationally. In addition, economic, social and cultural rights require ongoing action, often in the form of government policies and programs, to ensure that rights are recognised and progressively advanced.

The legal source of the binding nature of these treaties (at whatever level) is variously located. First, it is to be found in the words of the individual treaties themselves. Some treaties are directorial in the language they use. For example, the CROC stipulates that State Parties *shall* respect and ensure the rights set forth in the Convention (Article 2), and the CEDAW states that parties *shall* take all appropriate measures to guarantee women's rights (Article 3). The ICCPR and the CERD adopt less demanding terms in that they recognise that States have *undertaken* to protect the rights they contain. Least demanding of all are such instruments like the Declaration on the Rights of Disabled Persons which simply *'calls* for national and international action ...'.<sup>44</sup>

It is essential to realise that the relationship between Australian municipal law and international law is not one of subordination. As a consequence of Australia signing or ratifying a treaty, Australia does not thereby fall under the dictates of the United Nations. Neither New York nor Geneva replaces Canberra as Australia's seat of government. Such a transplantation of power does not even happen when we do decide to incorporate international law into our domestic legal system.

In fact, there is no clearer signal of the ultimate authority of the Commonwealth Parliament than when it takes the active step of endorsing an international treaty by incorporating it into municipal law. It is true that there may be great pressure placed on Parliament to do so, but ultimately it is Parliament that chooses whether or not to take the step, and therefore whether or not the international provisions become part of Australian law.<sup>45</sup>

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See HREOC website at www.hreoc.gov.au/hr\_explained.
 *Ibid.*

#### Formal versus substantive equality

In international law, the right to non-discrimination is a right to substantive equality not simply a right to non-discrimination in formal treatment. The UN Human Rights Committee has held that the right to non-discrimination prohibits actions that have either the purpose or effect of nullifying or impairing the enjoyment of a group's human rights.<sup>46</sup> The Committee also found that at times the principle of equality requires the introduction of special measures to address causes of discrimination and disadvantage.<sup>47</sup> This may entail the development of specific programs to achieve substantive equality given the different social and economic positions of different ethnic groups. International law therefore recognises that it is a legitimate activity of governments to respond to cultural and racial inequality by developing specific programs that ensure equality of access.

#### **Rights to culture and freedom from racism**

Linked to the right to non-discrimination and included within the fundamental rights of the ICCPR, is the recognition that ethnic, religious and linguistic minorities have a right to a distinct culture.<sup>48</sup>

Indigenous communities have most frequently relied on the right to a distinct culture. International law suggests that non-Indigenous ethnic minorities also possess the right to develop and maintain their culture.<sup>49</sup> This is supported by statements of other international organisations such as the *United Nations Educational, Scientific and Cultural Organisation* (UNESCO) Declaration on Race and Racial Prejudice.<sup>50</sup>

The right to a distinct cultural identity suggests that immigrants are not expected to relinquish their cultural affiliations after taking up residency in a new nation. New citizenship is not conditional on cultural assimilation.

In Australia, for more than two decades, the official policy of multiculturalism has underpinned government initiatives aimed at ensuring that all people have equal access to government and its services; providing the support required for new migrants to successfully settle; supporting the development of cultural heritage and community languages; and creating mechanisms for people to seek redress from discrimination.

<sup>46.</sup> Human Rights Committee, General Recommendation 18 op cit at Article 6 and 7.

<sup>47.</sup> Ibid at Article 10.

<sup>48.</sup> ICCPR, Article 27.

<sup>49.</sup> Committee on the Elimination of Racial Discrimination, General Recommendation XXI, Article 5.

<sup>50.</sup> Article 1(2) provides that: All individuals and groups have the right to be different, to consider themselves as different and to be regarded as such. However, the diversity of lifestyles and the right to be different may not, in any circumstances serve as a pretext for racial prejudice.

Both international and domestic law recognise peoples' right to be free from racism. CERD also commits nations to take actions to discourage activities that strengthen racial division.<sup>51</sup> Nations are required to take steps to prevent actions promoting racial hatred or theories of racial superiority, a requirement that formed the basis for Australia's domestic legislation prohibiting acts of public racial hatred.<sup>52</sup>

International and domestic human rights law therefore recognises that people with disabilities from non-English speaking background communities have a right to a distinct culture and can expect that Australian society will take action to protect these rights.

#### The role of HREOC

HREOC investigates alleged infringements under anti-discrimination legislation and attempts, where possible, to resolve these matters through conciliation. HREOC also inquires into acts or practices that may infringe human rights or may be discriminatory. HREOC's mission statement is

To promote respect for, and observance of, the human rights of all people in Australia and their access to equal opportunity.

In addition to its complaint handling responsibilities, HREOC has responsibility for developing, conducting and fostering research, educational and other programs to combat discrimination. Section 9 of the RDA prohibits racial discrimination on the basis of race, colour, descent, national or ethnic origin.<sup>53</sup> In addition, Part IIA of the RDA prohibits unlawful offensive behaviour based on racial hatred. The role of the Race Discrimination Commissioner is to address racial discrimination and prejudice and to promote understanding, tolerance and friendship among racial and ethnic groups.

HREOC's disability-rights work is based on the DDA and the HREOCA, as it relates to people with a disability, including issues arising under the *Declaration of the Rights of Disabled Persons*. Under the DDA, HREOC also undertakes research, educational and policy work to promote greater equality and enjoyment of human rights for people with a disability. Sections 5 and 6 of the DDA prohibit direct and indirect disability discrimination.<sup>54</sup>

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51. Article 2, CERD.
 52. Part IIA, RDA.
 53. See Appendix 3 for a more comprehensive discussion.
 54. *Id.*

Each Act operates independently of the others. There is therefore no scope within a single complaint process to simultaneously consider claims under, for example, the RDA and the DDA, even though there may be an intersection of discrimination issues experienced by people with disabilities from non-English speaking background communities.<sup>55</sup>

# Rights of people with disabilities from non-English speaking backgrounds

Most immigrants to Australia have chosen to become citizens. The 1996 Census statistics showed that 67.8% of the overseas-born population had become Australian citizens. In the financial year 1997–98, over 110,000 people became Australian citizens.<sup>56</sup>

Some individuals, however, are not Australian citizens, either because they have not yet been in Australia long enough or have chosen not to take up Australian nationality. International human rights law recognises that nations must be able to accord different rights to citizens and non-citizens. Certain political rights, the right to vote for instance, arise because an individual has chosen to become an Australian citizen.

However, host countries are also required to recognise certain rights among non-citizens. The ICCPR provides that nations must recognise the rights of all individuals subject to their jurisdiction.<sup>57</sup> This suggests that non-citizens have basic human rights that should be recognised and provided for.

Similarly, CERD allows nations to draw distinctions between citizens and non-citizens, but not to act in a way which deprives non-citizens of fundamental human rights provided for in instruments such as the *Universal Declaration*, nor to draw distinctions against non-citizens because of their race, colour or ethnic or national origin.<sup>58</sup>

At the international level, the *Declaration of the Rights of Disabled Persons* provides a broad and comprehensive framework on minimum standards of protection of human rights a state should accord people

<sup>55.</sup> For more information refer to Astor, H., 1995, A Question of Identity: The Intersection of Race and Other Grounds of Discrimination in Racial Discrimination Act 1975: A Review, HREOC, Sydney.

<sup>56.</sup> Australian Bureau of Statistics, 1999 Year Book Australia, Number 81, ABS, Canberra, 1999. Australian Bureau of Statistics, Population—Citizenship, Australia Now—A Statistical Profile, 6 January 2000 and Department of Immigration and Multicultural Affairs, Australian Citizenship, Fact Sheet 66, 27 October 1999.

<sup>57.</sup> Article 2, ICCPR.

<sup>58.</sup> See General Recommendation XI on non-citizens adopted 19 March 1993.

with disabilities. In the Australian context, these rights are to be protected irrespective of whether the individual concerned has Australian citizenship or not. In accordance with this Convention, people with disabilities from non-English speaking backgrounds living in Australia:

- are entitled to measures designed to enable them to become as self sufficient as possible (*Article 5*);
- have the right to medical, psychological and functional treatment ... which will enable them to develop their capabilities and skills to the maximum and will hasten the process of integration or reintegration (*Article 6*);
- have the right to economic and social security and to a decent level of living (*Article* 7);
- are entitled to have their special needs taken into consideration at all stages of economic and social planning (*Article 8*);
- shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature (*Article 10*); and
- organisations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons (*Article 12*).

These rights are further reinforced through domestic legislation under the *Disability Discrimination Act* 1992. Therefore while language and cultural differences may impose significant barriers to the full enjoyment of human rights of people with disability, the right to non-discrimination places an obligation on Australia to ensure that these people enjoy the same standards of human rights as others in the community.



#### Summary

As a nation, Australia has a moral and legal obligation to recognise, promote and protect the human rights of people with disabilities from non-English speaking communities. International human rights instruments and Australian domestic law seek to provide people with disability from non-English speaking background communities:

- fundamental civil, political, economic, social and cultural rights;
- non-discriminatory treatment by the society as a whole;
- the opportunity to develop and maintain their own culture and language; and
- freedom from racism and other forms of discrimination.

Yet people with disabilities from non-English speaking backgrounds seem potentially at risk of breaches of their right to non-discrimination. The history of Australian migration confirms that language and cultural differences can be significant barriers to the full enjoyment of human rights. The recognition of the right to non-discrimination places an obligation on Australian social structures to ensure that people with disabilities from non-English speaking backgrounds enjoy substantive equality irrespective of these differences.

The ICCPR maintains that immigrants, as new arrivals in Australia, have a right to join Australian society and enjoy the freedom and protection accorded to other citizens. Similarly, the ICESCR recognises that all Australians, including people with disabilities from non-English speaking background communities, have a right to a basic standard of living in order to fully participate in the Australian community. The human rights contained within these international conventions and the Australian domestic legislation implementing them, are important for people with disabilities from non-English speaking background communities.

These human rights instruments provide a broad and valid framework against which, in the following chapters, this paper examines the extent to which people with disabilities from non-English speaking backgrounds enjoy recognition and protection of their human rights.



Chapter 3

## Attitudes and Misconceptions

This section summarises the current literature on attitudes and perceptions towards disability among people from non-English speaking background communities in Australia. The section also contains case examples that illustrate discrimination issues faced by this group.

Until recently in Australia, community attitudes, fears and misconceptions about people with disabilities were reinforced by policies and practices aimed at institutionalisation rather than integration. These policies and practices often led directly or indirectly to stigmatising and isolating people with disability, instead of assisting them to lead full and productive lives. People with disabilities from non-English speaking communities may have been even further disadvantaged because of their race.

The combined effects of activism, changes in government policy & community educational campaigns (which have been predominantly in English) have challenged some deeply held attitudes, fears & misconceptions about disability in the broader Australian community. Nevertheless, the myths that persist fuel discrimination and continuing disadvantage.

Prejudicial attitudes and misconceptions regarding disability present in broad society are equally evident in non-English speaking background communities. At times they may even appear more entrenched. Lack of educational opportunities to address such attitudes; adherence to some traditional beliefs that negate the rights of people with disabilities; and the sheltered and isolated nature of some communities could all contribute to the preservation of myths about disability.

#### **Community attitudes towards disability**

People with disabilities are routinely marginalised, stigmatised and dehumanised regardless of their community affiliations. Depending on the disability and society's different perceptions of the disability, they may be:

• stereotyped as 'others', who are less than whole & seen as defective;



- regarded as 'eternal children' and a burden;
- expected to constantly prove competence;
- assumed to have limitations that the person does not in fact have;
- 'judged' according to the manner in which a disability was acquired;
- not viewed in a multi-dimensional way and therefore not accorded the same human rights as able-bodied people; and
- regarded as objects of shame who may be being punished for a perceived misdeed.<sup>59</sup>

But these actions or attitudes, however unfounded, unjust or unfair, do not constitute grounds for complaint under the three anti-discrimination Acts, the DDA, RDA or SDA. They do, however, assist in a general sense to understand why discrimination against people with disability occurs so easily and so inconspicuously.<sup>60</sup>

In Chapter 5 we will explore some of the strategies that have been recommended to address such problems.

#### Literature survey

In addition to broad community attitudes to disability, a number of studies have examined the attitudes and perceptions about disability within non-English speaking background communities.<sup>61</sup>

• In 1993, Westbrook and colleagues studied attitudes within five non-English speaking background communities towards people with disabilities. The study also included English speakers from the broader community. The study found that there were significant differences in the attitudes of the survey participants towards some forms of disability. However, the relative degree of stigma attached to disability by the participants was very similar. The study reported that for all participants belonging to the six community groups, people with psychiatric illness, intellectual disability, AIDS and cerebral palsy were the least accepted of the disability groups.<sup>62</sup>

59. Human Rights and Equal Opportunity Commission and the Commonwealth Department of the Attorney-General, 1994, *Acting Against Disability Discrimination: A Practical Manual for Using the Disability Discrimination Act*, Canberra.

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<sup>60.</sup> Ibid at 25.

<sup>61.</sup> This focus does not imply that misconceptions and prejudices about disability do not exist in the broader community. On the contrary, these attitudes are often mirrored in varying degrees in the general community and need to be combated at all levels.

<sup>62.</sup> Westbrook, M.T., Legge, V. and Pennay, M., 1993, 'Attitudes Towards Disabilities in a Multicultural Society', 36(5) *Soc Sci Med* 615-623. The study included people from the Chinese, Italian, German, Greek, Arabic and English speaking communities.

- In 1993, Pane interviewed women with disability from a number of non-English speaking background communities. Her interviews indicated that even though the women had individual experiences, they were universally of the view that their communities did not accept their disabilities. Instead, they were denied opportunities to mature and grow and were either over-protected or hidden away.<sup>63</sup>
- In 1995, Minas and colleagues reaffirmed the need for education programs in community languages aimed at demystifying and de-stigmatising mental health issues.<sup>64</sup> In 1998, the Australian Trans-cultural Mental Health Network recommended the development of a Mental Health National Community Education Agenda for people from non-English speaking background communities.<sup>65</sup> A 1998 Tasmanian study focusing on trans-cultural mental service delivery models reached the same conclusion.<sup>66</sup>
- A 1995 study focusing on the child-care needs of families from non-English speaking background communities who have children with disabilities reported that mothers who were the primary carers felt isolated from their own communities and did not feel welcome to attend community and family functions with their children.<sup>67</sup>
- In 1996, a study into the social support needs of Arabic-speaking carers of people with disability in Victoria reported that disability is sometimes regarded as a social stigma that renders the person with disability and their family invisible in the community.<sup>68</sup>
- In 1999, Meehan and Hanson conducted a study into the sexual and occupational health of women with disabilities from non-English speaking background communities. Their prelimi-

63. Pane, L.G., 1993, A Triple (Dis)Advantage: Women with Disabilities from Non-English Speaking Backgrounds, 3 ADR 57–65. The study drew on women with disabilities from Italian, Maltese, Polish, Chinese, Greek, Afghani and Bulgarian backgrounds. Not all were born in Australia 64. Minas, I. H., Ziguras, S., Klimidis, S., Stuart, G. W. and Freidin, S. P., 1995, Extending the Framework: A Proposal for a Statewide Bilingual Clinical Support and Development Program, Victorian Transcultural Psychiatry Unit, Melbourne. 65. Ziguras, S., Pennella, J., Stuart, G., and Jackson, A., 1998, Implementation of the Bilingual Case Management Program: Progress Report January 1997–March 1998, Victorian Transcultural Psychiatry Unit and University of Melbourne, Melbourne. 66. Bower, M., 1998, Transcultural Mental Health Service Delivery Models for Small and Dispersed Migrant Populations: A Tasmanian Study, Australian Transcultural Mental Health Network, Department of Psychiatry, University of Melbourne, Melbourne. 67. Evert, H., 1995, Assessing the Child Care Needs of Non-English Speaking Families Who Have a Child with a Disability, Action on Disability Within Ethnic Communities Inc., ('ADEC'), Melbourne. 68. Wositzky, K., 1996, The Social Support Needs of Arabic Speaking Carers, ADEC, Melbourne. sidelines

nary report indicated that the sexual and reproductive health needs of such women were not addressed by the relevant service providers and the medical profession. They also reported that such women are regarded as 'asexual' and were further isolated and excluded in their own communities.<sup>69</sup> This finding has also been reported elsewhere.<sup>70</sup>

The research clearly indicates that people with disabilities from non-English speaking background communities are often stigmatised and isolated because of attitudes and misconceptions prevalent in their own communities and in the broader community. In respect of the broader community, disadvantage is compounded by discriminatory attitudes towards disability and ethnicity. Again, this raises the issue of multiple disadvantage in cases where an intersection of variables (such as disability, class, ethnicity, gender and sexuality) determine a person's identity.

Specialist advocacy services provided a number of case examples to HREOC, suggesting fundamental denial of human rights across a range of areas. The selection of cases cited below is indicative of the nature of disadvantage experienced on a daily basis by people with disabilities from non-English speaking backgrounds.

#### Case Examples

Mr A is a 30 year old man of Arabic speaking descent with a psychiatric disability. He lives with his mother, brother and sister-in law. He pays board. Recently, Mr A found a job and would like to move out to live independently. The Department of Housing has granted him priority housing. However, his family regard him as incapable of looking after himself and living independently because of his disability. Every time he mentions his desire to leave home, his brother belittles him and threatens him physically. Because of the intervention of his family and a community worker, the Department of Housing has allegedly retracted its offer.

#### Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.

(Declaration on the Rights of Disabled Persons, Article 5)

69. Meehan, E. and Hanson, K., 1999, *Three D - A Preliminary Report on Sexual and Occupational Health of NESB Women with Disabilities*, Women in Industry and Community Health Inc., Melbourne.

 Rousso, M. Daughters with Disabilities: Defective Women or Minority Women in Fine, M. and Asch, A. (eds.), 1988, Women with Disabilities - Essays in Psychology, Culture and Politics, Temple University Press, Philadelphia. 5/

In this instance there is a failure to acknowledge a fundamental human right to lead an independent life. Attitudes towards disability are frequently underpinned by ignorance and prejudice that serves only to dehumanise and alienate the individuals concerned.

Ms B is a young woman of Chinese descent who has a physical disability. She leads a full and productive life. She is currently attending a tertiary course at a university. Recently, Mr X, a member of her cultural and linguistic community, told her that people with her condition were 'deformed' and were destined to die early. Hence, there was no point in her attempting to gain higher education.

Disabled persons have the right to ... 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.

(Declaration on the Rights of Disabled Persons, Article 6)

Everyone has the right to education... Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms.

(Universal Declaration of Human Rights, Article 26)

Sometimes, independence and basic human rights are compromised due to negative attitudes and stereotypes regarding disability.

Ms C is a young woman of Italian descent with a mild intellectual disability. She lives with her parents and her siblings. At a gathering, she met Mr C, a young man (without disability) from her own cultural background on a Visitor's Visa. She subsequently started a relationship with him and became pregnant. Ms C and Mr C would like to get married. Her family is, however, firmly opposed to this relationship as they believe that Mr C could not possibly be interested in someone with a disability and is only using her to gain residency in Australia. They want Ms C to have an abortion and stop seeing Mr C. As a result, Ms C is distraught and confused.

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.

(Declaration on the Rights of Disabled Persons, Article 3)

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In extreme cases, stigma associated with disability may result in an individual being denied a place in the community as well as proper medical care. This engenders a sense of shame and isolation for the whole family.

Mr X is a Khmer community health worker who visits a number of families regularly. He has known family D for many years and has visited them often. To the best of his knowledge, family D was only comprised of Mr and Mrs D and their two sons. However, he recently discovered that they also had a 5 year old daughter with severe disabilities. She had been hidden at home because the parents felt that their community was unlikely to accept her disability and would therefore stigmatise the family. As a result, the child had not received proper medical care and was in great distress when Mr X saw her. Mrs D normally looked after the child but she had been hospitalised. In desperation, Mr D asked Mr X to help him take care of the little girl.

States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.

(Declaration on the Rights of the Child, Article 3)

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services...

(Universal Declaration of Human Rights, Article 25)

Everyone has the right to live in dignity, free of harassment. Repeated acts of harassment and discrimination, as outlined in the following case, may be in breach of the RDA and the DDA.



Ms E is a young woman of Chinese descent with physical disability. She is a tertiary student and because of the lack of accessible public transport, lives on campus. Ms E is the only person from a non-English speaking background living on campus with a visible disability. She has repeatedly been the subject of harassment by some able bodied students. Her room has been broken into several times, her nametag removed from the door and offensive graffiti alluding to her ethnicity and disability has been scrawled on the door.

It is unlawful for a person to do any act involving a distinction, exclusion, restriction or preference based on race, colour, descent or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of any human right or fundamental freedom in the political, social, cultural or any other field of public life.

(Racial Discrimination Act 1975, Section 9)

It is unlawful for a person to do an act, otherwise that in private, if the act is reasonably likely in all the circumstances, to offend, insult, humiliate or intimidate another person or a group of people; and the act is done because of the race, colour or national or ethnic origin of the other person of some or all of the people in the group.

(Racial Discrimination Act 1975, Section 18C(1))

The above research and the case examples indicate continuing breaches of the human rights of some people with disabilities from non-English speaking communities. These individuals are entitled to fully enjoy their human rights on par with other members of the community. Negative stereotypes and misconceptions contribute to further isolation and stigmatising of such individuals. Public educational campaigns need to target such attitudes at the grass roots level. To this end, the Conclusions to this paper offers some useful strategies.



Chapter 4

# Consultation, Participation & Culturally Appropriate Services

For people with disabilities from non-English speaking background communities, access to Commonwealth/State Disability Agreement (CSDA) funded services is fraught with barriers. This section outlines these barriers, discusses case examples and good practice examples.

The *Commonwealth Disability Strategy*<sup>71</sup> and CSDA generally acknowledge the importance of consultation with people with disabilities and their carers and their participation in advisory and review bodies and processes. For CSDA funded services to meet the needs of people with disabilities from non-English speaking backgrounds, it is also necessary to encourage and facilitate their participation in all stages of program planning, design, delivery and evaluation. The result should be culturally appropriate and accessible services that target the people most in need.

The *Charter of Public Service in a Culturally Diverse Society*<sup>72</sup> is particularly important to people with disabilities from non-English speaking background communities. The *Charter* has been endorsed by Commonwealth, State and Territory Governments and by the Australian Local Government Association. The foreword to the *Charter* states that:

[The Charter] represents a nationally consistent approach to the delivery of culturally responsive government services.<sup>73</sup>

The *Charter* lists consultation and participation as integral strategies to achieving effective communication (one of the charter principles) that should enhance the delivery of services. The Charter elaborates further:

<sup>71.</sup> Office of Disability, 1994, Commonwealth Disability Strategy - A Ten Year Framework for Commonwealth Departments and Agencies, Canberra. Consultation is a core strategy under the Commonwealth Disability Strategy, a ten year framework which provides direction to Commonwealth organisations to implement procedures which ensure that services, facilities and programs are accessible to people with disabilities. The Commonwealth Disability Strategy requires that all Commonwealth agencies consult with people with disabilities in the design and implementation of policies and programs. An evaluation of the Strategy is currently being finalised. (Information adapted from the Office of Disability website at www.facs.gov.au/disability/ood).

<sup>72.</sup> Department of Immigration and Multicultural Affairs (DIMA), 1998, *Charter of Public Service in a Culturally Diverse Society*, DIMA, Canberra.

<sup>73.</sup> Ibid at Foreword.

**Consultation:** Agencies consult with people from diverse linguistic and cultural backgrounds at all stages in program planning, design, delivery and evaluation, and provide feedback to customers about the outcomes of these consultations. Agencies also consult with other providers and levels of government, as appropriate, to ensure coordination of services appropriate to clients' needs.

**Participation:** Where appropriate, agencies include people from diverse linguistic and cultural backgrounds on decision-making and advisory bodies so that a broad range of views is brought to bear on all key decisions. In this regard, agencies make use of existing registers of people from diverse linguistic and cultural backgrounds to make appointments to these bodies.<sup>74</sup>

The Commonwealth Office of Disability is responsible for facilitating consultation with people with disabilities. This is achieved through a number of channels<sup>75</sup>:

- National Disability Advisory Council (NDAC): The NDAC acts as a Reference Group to the Minister for Family and Community Services by providing advice on disability related issues. In addition, it also facilitates consultation between the Commonwealth Government and consumers, carers and service providers within the disability sector. The Council's 14 members include people with disability, family members/carers and service providers.
- National Peak Disability Bodies: The Office of Disability funds 11 national peak disability bodies that as advocacy groups are responsible for representing the views of their respective members to the Government. NEDA<sup>76</sup> is one such advocacy body.

The Office of Disability has recently produced a practical guide for consulting with people with disability. The guide states that:

...if cultural practices and limited English skills are not taken into account there may be significant barriers restricting their access to information or participation in the consultation process.<sup>77</sup>

For any of these principles to have a practical and positive effect on service delivery beyond paying mere lip service, it is necessary for governments and service providers to implement these principles in their policies and practices.



In Chapter 5, we will discuss a number of strategies that could go some way toward addressing these issues.

## Literature survey

Apart from previously mentioned documents, a number of studies have discussed the importance of these principles for effective service delivery for people with disabilities from non-English speaking backgrounds.

- In 1992, Action on Disability within Ethnic Communities (ADEC) published the first of three reports<sup>78</sup> on developing accessible services for people with disabilities from non-English speaking background communities. The first report discussed the development of a model for increasing access to services by people with disabilities from this group. The second report focused on the development of partnership agreements with selected organisations for the implementation of the model within these organisations. The third report discussed the evaluation of the models within respective organisations. These reports emphasised the need for community consultation and participation and culturally appropriate services.
- A 1995 study commissioned by ADEC focused on the childcare needs of families from non-English speaking background communities who have children with disabilities. Some of the carers interviewed in this study reported that they were not consulted about what were the best care options for their children. Others reported that they were stereotyped because of their particular 'ethnic' background.<sup>79</sup>
- In 1995, Minas and colleagues<sup>80</sup> emphasised the need for bilingual staff and culturally appropriate services in the mental health area. They argued that these factors were necessary for the effective delivery of mental health services to people from

 Minas, I. H., Ziguras, S., Klimidis, S., Stuart, G. W. and Freidin, S. P., 1995, Extending the Framework: A Proposal for a Statewide Bilingual Clinical Support and Development Program, Victorian Transcultural Psychiatry Unit, Melbourne.

Fitch, S., Papanicolaou, E. and Maligeorgos, G., 1992, Report No. 1—Developing Accessible Services For People With a Disability and of Non-English Speaking Background: A Model, Action on Disability Within Ethnic Communities Inc. (ADEC), Melbourne; Papanicolaou, E., 1994, Report No. 2—Developing Accessible Services For People With a Disability and of Non-English Speaking Background: Implementation of the Access Model With Four Disability Services, ADEC, Melbourne; Papanicolaou, E., 1994, Report No. 3 -Developing Accessible Services for People With a Disability and of Non-English Speaking Background: An Evaluation of the Implementation of the Access Model, ADEC, Melbourne.
 Evert, H., 1995, Special Children Special Needs—Assessing the Child Care Needs of Non-

English Speaking Families Who Have a Child With a Disability, ADEC, Melbourne.

non-English background communities. They also noted the chronic shortage of bilingual professional staff in this field.

- A 1996 study by Wositzky<sup>81</sup> about the social support needs of Arabic-speaking carers of family members with disability discussed the lack of flexible and culturally appropriate respite care and Home and Community Care (HACC) services. Service providers interviewed also noted the unavailability of Arabic-speaking disability advocacy workers.
- In 1996, the Demand Study<sup>82</sup> commissioned for the Yeatman Review of CSDA noted that people from non-English speaking background communities were less likely to be using CSDA services or to report unmet need for help. The study speculated that, among other things, this was likely to be related to the lack of appropriate cultural services and available information about the services.
- In 1997, Velotti<sup>83</sup> in a study on needs and perceptions of culturally appropriate day options, interviewed a number of people with disabilities and their carers from non-English speaking background communities. She found:
  - a clear need for culturally sensitive and relevant respite care;
  - the carers' preferred to be consulted about their needs; and
  - a clear need for information to be made available through appropriate linguistic and cultural channels.

The literature on this topic clearly indicates that culturally appropriate services are integral to accessible service delivery and can enhance the quality of life of those with disability from non-English speaking backgrounds and their carers. The following case histories illustrate some of these points.



<sup>81.</sup> Wositzky, K. 1996, *The Social Support Needs of Arabic Speaking Carers*, ADEC, Melbourne.

83. Velotti, D. M., 1997, Disability Within Families From Non-English Speaking Backgrounds: A Focus on Needs and Perceptions of Culturally Appropriate Day Options, The Multicultural Advocacy and Liaison Service of SA (MALSA), Adelaide.

<sup>82.</sup> Madden, R., Wen, X., Black, K., Malam, K. and Mallise, S. 1996, *Commonwealth/State Disability Agreement Evaluation: Supporting Paper 2—The Demand Study*, AIHW, AGPS, Canberra.

# **Case histories**

Mr F is a 56 year old man of Arabic descent. He has an intellectual disability as a result of a brain injury he recently received and has been recovering in a rehabilitation hospital. As he is a practising Muslim, his family requested that specific dietary requirements be observed. This included no pork and halal meat if possible. His family has observed that he had been fed pork on a few occasions and had registered their concern with the hospital authorities. The family informed the advocacy service that an official from the hospital had told them that these were the rules and if they were not happy with those rules, they should 'go back to wherever they had come from'.

Everyone shall have the right to freedom of thought, conscience and religion. This right shall include freedom to have or adopt a religion or belief of his choice, and freedom, either individually or in a community with others and in public or private, to manifest his religion or belief in worship, observance, practice and teaching.

(International Covenant on Civil and Political Rights, Article 18)

In a diverse country like Australia, there is no justification for reasonable dietary requirements not being met. In this case, lack of consultation and failure to meet a simple request caused unnecessary distress to the patient and his family. In addition, offensive comments may potentially be actionable under section 13 (Provision of Goods and Services) or section 18 (Offensive Behaviour because of Race, Colour, National or Ethnic Origin) of the RDA.

In another, not dissimilar case, inappropriate attention to an individual's needs resulted in inadequate care and unfair treatment. Problems were exacerbated by the failure to use interpreters to ensure that the care provided was adequate and appropriate.

Mrs G is 35 years old and has recently migrated to Australia from Vietnam. She works full time and has a son with disability who attends a special school. He has told her that he does not like the food served at school and therefore does not eat it. To address this problem, she sent some of his favourite Vietnamese food with him to school. However, as he could not feed himself, he was unable to eat it, and so he remained unfed. Mrs G cannot communicate effectively with the staff. Her usual mode of communication is through an exercise book in which she writes down her concerns

continued next page



in basic English and the staff reply. Mrs G feels that her concerns are being ignored and she is not being consulted.

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

(International Covenant on Civil and Political Rights, Article 26)

In those States in which ethnic, religious or linguistic minorities exist, persons belonging to such minorities shall not be denied the right, in community with the other members of their group, to enjoy their own culture, to profess and practise their own religion, or to use their own language.

(International Covenant on Civil and Political Rights, Article 27)

In some cases, lack of English proficiency, reliance on interpreters or translated material and lack of culturally appropriate services fosters isolation and alienation.

> Family H consists of two parents over 70 years old and their son who is 42 years old with multiple disabilities. They are of Italian descent. Their story in the mother's words follows:

> I have been caring for my son on my own for many years. My husband is ashamed of him and he has never helped me. Now he is sick and I must look after them both. This is not easy and I have had many problems getting the help I need to do everything.

> Many times they (the service providers) have come to offer me help and I am very happy with what they give but later they tell me money is cut and the service must go. No one asks me before they make the decision and I am told there will be no more. This has been very confusing and difficult for me. Especially now that I have arthritis in my hands and a sore back. I need more help...

> We have used weekend respite... but I have found that it is too costly for transport. As I speak Italian, it is better that the worker that comes speaks Italian. I did not go to school back home because we continued next page



were poor, so it is better that someone comes to explain things to me rather than giving me papers to read. It has been very helpful to have an Italian respite worker because we can talk and many times he has told me important information.

The States Parties to the present Convention... [bear] in mind the great contribution of women to the welfare of the family and to the development of society, so far not fully recognized, the social significance of maternity and the role of both parents in the family and in the upbringing of children, and aware that the role of women in procreation should not be a basis for discrimination but that the upbringing of children requires a sharing of responsibility between men and women and society as a whole.

(Convention on the Elimination of Discrimination Against Women, Preamble)

Everyone, as a member of society, ... is entitled to realisation...of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

(Universal Declaration of Human Rights, Article 22)

## Good practice examples<sup>84</sup>

The examples outlined above highlight the breaches of human rights that exist in some areas of service delivery. They clearly demonstrate that some service providers need to adopt an approach that is more sensitive and responsive to the different needs of individuals. Fortunately, not all service providers fit this description. The following two good practice examples provide models that could be adapted by other service providers.

#### **Consumer participation:**

Western Region Outreach Service in Victoria (WROS)

During 1992–1993,WROS set up an advisory group working with clients of Vietnamese background. WROS is situated in a region of Melbourne with a high Vietnamese population. WROS provided a good practice example by:

• identifying the need to specifically target the Vietnamese

 Adapted from Papanicolaou, E., 1994, Report No. 2–Developing Accessible Services For People With a Disability and of Non-English Speaking Background: Implementation of the Access Model With Four Disability Services, ADEC, Melbourne.

community in order to promote its services and to learn more about the Vietnamese community itself; and

• establishing the Vietnamese Advisory Group to encourage Vietnamese people with psychiatric disabilities, Vietnamese workers and others with knowledge of the Vietnamese community and psychiatric disability, to provide direction to WROS.

Forming specific advisory groups for clients from non-English speaking background communities may be an effective model for increasing participation and consultation.

#### Appropriate staff and working practices:

Department of Health and Community Services (H&CS), Southern Metropolitan Region, Disability Services Program

The project commenced in late 1991 and continued to late 1993.

H&CS provided a good practice example by:

- surveying all relevant staff working in teams (ie. Client Services, Behaviour Intervention Support, Residential Services, House Supervisors and Disability Program) to obtain information regarding specific training needs; and
- identifying and acknowledging available staff skills and exploring ways to utilise these skills in the most effective and efficient way.

The project evaluation survey found that while most workers had at some point worked with clients from non-English speaking backgrounds, they generally were not confident about their skills in working with these clients, even when they had received cross-cultural training.

The above two strategies are likely to facilitate access to disability services for clients of non-English speaking backgrounds. However, they need to operate in conjunction with a number of other strategies such as the recruitment of bilingual staff, the availability of interpreters and trained staff to use them and effective information promotion and dissemination to such clients.

The conclusions section of this paper offers further strategies as a positive contribution towards addressing these problems.

Chapter 5

# Communication & Access to Information

This section summarises the available literature on barriers to accessing information for people with disabilities from non-English speaking background communities. It also contains case examples and good practice examples. The section also briefly discusses the operation of the Translating and Interpreting Service (TIS) which is funded by the Department of Immigration and Multicultural Affairs (DIMA).

The inability to communicate effectively in English has been consistently identified as a major barrier to accessing services for people from non-English speaking background communities.<sup>85</sup>

Advocacy organisations representing people with disabilities have reported that language difficulties are an initial barrier to accessing services for people with disabilities from non-English speaking backgrounds.<sup>86</sup>

For some people with disabilities and their carers from non-English speaking background communities who are not fluent in English, access to easily understood information about services and benefits in community languages and the availability of interpreters go some way towards enhancing their quality of life. Conversely, lack of awareness or failure to promote such information and absence of interpreters or bilingual staff could further isolate and marginalise them.

# Literature survey

• In a 1992 study of the use of psychiatric disability services by people with disability in Victoria, Ziguras found that there was a very long waiting list for interpreters for some languages, in particular for those from small and emerging communities.<sup>87</sup> In the same report he stated that:

49

<sup>85.</sup> Supra note 37 at 190.

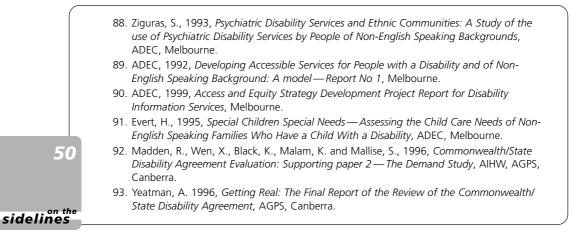
<sup>86.</sup> ADEC's 1997–1998 Annual Report states that 39% of their clients required an interpreter for all contacts, with a further 30% requiring interpreter assistance for formal processes such meetings with Centrelink and other service providers.

<sup>87.</sup> HREOC defines small and emerging communities as those who have 10,000-20,000 members and have settled in Australia less then ten years ago.

Psychiatric non-governmental organisations felt that ethnic communities knew very little about their services, and would not know how to get access to them.<sup>88</sup>

- ADEC in a 1992 report noted that the lack of availability of interpreters or reliance on family members who are often children, compounds the anxiety of many service users and prevents them from approaching services in the first place.<sup>89</sup> In a 1999 study, ADEC identified the lack of promotion of the availability of interpreters as a further barrier to access.<sup>90</sup>
- In a 1995 study commissioned by ADEC on the child care needs of families from non-English speaking background communities who have children with a disability, Evert reported an under-utilisation of federally funded children's services. Parents and service providers attributed this under-utilisation, among other things, to lack of information in community languages about child care centres.<sup>91</sup>
- In 1996, the Demand Study commissioned for the Review of the CSDA reported a lack of knowledge regarding CSDA respite services among carers for people with disabilities. The report also commented on the need for the provision of information about CSDA funded services in appropriate community languages for people with disability from non-English speaking background communities.<sup>92</sup> Professor Yeatman in her final report for the Review of the CSDA recommended that:

There be widely accessible and user friendly information in English and the main community languages about the range of services available under the auspices of the CSDA, how to access them, and the eligibility/priority of access criteria for access.<sup>93</sup>



- In a 1996 study by Wositzky about the social support needs of Arabic speaking carers of family members with disability commissioned by ADEC, carers reported that they had not received appropriate information regarding the available services in Arabic and the service providers had not used TIS interpreting services to communicate with them.<sup>94</sup>
- In 1996, the Australian Law Reform Commission (ALRC)<sup>95</sup> published a report of the review into the provision of disability services by the Commonwealth or funded by it. The ALRC received a number of submissions, which stated that the most important issue for people from non-English speaking background communities was lack of information about available disability services. Suggestions for improving information delivery included:
  - implementing a special disability information strategy in consultation with the relevant communities;
  - providing more written information, audio-tapes and videos in community languages;
  - using 'ethnic' radio;
  - producing major policy documents in languages other than English;
  - promoting the use of Interpreter Services; and
  - requiring the Department [responsible Commonwealth agency] and services to employ bilingual and non-English speaking background workers and to provide a list of ethno-specific services.
- In a 1997 study commissioned by Multicultural Advocacy Liaison Service of SA (MALSA Inc), Velotti reported on the needs and perceptions of culturally appropriate day options for people with disabilities and their carers from non-English speaking backgrounds. The study found there were a limited number of available interpreters in rural and remote areas, a lack of promotion regarding the availability of TIS and reliance on family and friends as interpreters by service providers.<sup>96</sup>
- In a report to DIMA in 1998, ADEC highlighted the communication

<sup>94.</sup> Supra note 81.

<sup>95.</sup> Australian Law Reform Commission 1996, *Making Rights Count: Services for People with a Disability*, ALRC, Sydney.

Disability Within Families from Non-English Speaking Backgrounds: A Focus on Needs and Perceptions of Culturally Appropriate Day Options, 1997, MALSA, Adelaide.

difficulties arising from the lack of interpreters for clients who have developed psychiatric disabilities as a result of torture and trauma.<sup>97</sup>

- In 1998, a study for the Trans-cultural Mental Health Network identified the under-utilisation and inappropriate use of interpreters among the factors effecting the quality of care.<sup>98</sup> This is significant as some people with psychiatric illness might also have a range of disabilities.
- A 1998 survey profiling the deaf and hearing-impaired community of NSW reported that AUSLAN was the preferred language of communication for respondents from non-English speaking background communities.<sup>99</sup>
- A 1999 Victorian pilot study by Women in Industry and Community Health Inc. found that six out of 21 women with a disability were unable to access an interpreter service in the health service they used. Five women were not certain if an interpreter was available in the health service they used.<sup>100</sup>

# **Translating and Interpreting Service (TIS)**

DIMA funds the nationwide Translating and Interpreting Service (TIS). TIS<sup>101</sup> provides the following services free of charge to people from non-English speaking background communities:

- telephone interpreting to individuals wishing to speak with government or certain community organisations;
- limited face-to-face interpreting to individuals, medical practitioners and community organisations on migrant/refugee settlement-related matters; and
- extract translations of personal documents for migrants/refugees during their first two years of residence in Australia.

Access to free on-site interpreting through TIS is, however, limited by resource quotas.<sup>102</sup> TIS does not provide services for sign-language

	97. ADEC, 1998, Advocacy for Survivors of Torture and Trauma Program (ASTT)—12 month Project report for the Department of Immigration and Multicultural Affairs.
	98. Bower, M., Trans-cultural Mental Health Service Delivery Models for Small and Dispersed Migrant Populations: A Tasmanian Study, 1998, Australian Trans-cultural Mental Health Network, Department of Psychiatry, the University of Melbourne, Melbourne. See also Minas et al, 1995, Extending The Framework: A Proposal for State wide Bilingual Clinical Support and Development Program, Victorian Trans-cultural Psychiatry Unit, Melbourne.
	<ol> <li>Bonser, P. and Burns, L., 1998, Hands Up NSW— A Profile of the Deaf Community1998, Deaf Society of NSW, Sydney.</li> </ol>
52	<ol> <li>Meehan, E. and Hanson, K, 1999, A Preliminary Report on Sexual and Occupational Health of NESB Women with Disabilities, Women in Industry &amp; Community Health Inc., Melbourne.</li> </ol>
	101. Adapted from Department of Immigration and Multicultural Affairs (DIMA) <i>Fact Sheet</i> 67: Translating and Interpreting Service.
sidelines	102. DIMA, 1998, Annual Report 1997–1998, on-line version at www.immi.gov.au.

users (eg. AUSLAN) or for any of the Aboriginal and Torres Strait Islander languages.

TIS also provides services on a fee-for-service basis<sup>103</sup> for individuals, Commonwealth and State/Territory government agencies, community organisations and private sector businesses and organisations for commercial transactions.

DIMA's quota-limited on-site interpreting services are dedicated to either 'settlement-related' or 'Medicare-funded' matters. Interpreting associated with Commonwealth or State/Territory government disability agencies would normally be the responsibility of that agency.<sup>104</sup>

All Commonwealth Government-funded service delivery to clients is subject to the principles of the Charter of Public Service in a Culturally Diverse Society. The Charter also applies when service delivery is contracted out and provided to clients by a third party. To facilitate access to services for people from non-English speaking background communities, the Charter stresses the need for the use of interpreters with clients.<sup>105</sup> For clients with disabilities from this group who are the recipients of the CSDA services that are a Commonwealth responsibility, the principles of the Charter should apply. This means in theory, interpreters should be provided to facilitate access to services in accordance with the principles of the Charter. However, due to DIMA's quota and budgetary restrictions, access to TIS services for community organisations relating to non 'settlement, health or welfare-related activities' is currently not feasible.<sup>106</sup> This appears to be in conflict with the principles of the *Charter* and is likely to cause considerable hardship to those clients with disabilities who need interpreters and can't access them.

NEDA has expressed concern about the possibility of considerable costs being imposed on its affiliated bodies for interpreting services associated with their non settlement-related advocacy function.<sup>107</sup> NEDA claims that if Commonwealth, State/Territory agencies do not

103. Since 1991, DIMA has applied user-charges to recover some of the cost of its translating and interpreting services.

- 105. DIMA, 1998, Responding to Diversity Charter of Public Service in Culturally Diverse Society, DIMA, Canberra.
- 106. Based on advice provided by DIMA to NEDA on 16 July 1998 which in part reads: 'Given the nature and functions of NEDA and its associates, TIS considers that from now on, TIS should admit the interpreting needs of Non-English speaking clients of any of NEDA, ADEC, MALSA, EDAC, MDAA and ECDN that are associated with its non-government, non-profit community based health or welfare activities for settlement-related purposes, to be provided "free".'
- 107. NEDA, 1998, Annual Report, 1997-1998, Canberra, at 26.

<sup>104.</sup> Based on communication between NEDA and Translating and Interpreting Service (TIS) section of DIMA, 20 July 1999.

fund the provision of on-site interpreters for people with disability, NEDA's affiliated bodies would have to pay for such interpreting services for their clients.<sup>108</sup> NEDA is of the view that:

The additional cost to community organisations of using TIS to provide information or services to people from a non-English speaking background may lead to a reduction in community services for them, or the possible provision of inappropriate information or services because of a lack of effective interpreting services.<sup>109</sup>

Responding to an individual's needs requires proper consultation and care and indicators like ethnicity are not necessarily reflective of a person's English language skills or the kind of service they require. The following case highlights an individual whose preferred method of communication was sign language, had he been consulted in this regard. His access to the service was hampered by the failure to provide an AUSLAN interpreter.

Mr I is a 20 year old man with a physical and sensory disability. He is of Vietnamese background and lives independently in metropolitan Adelaide.

He says: Many times when I go out to use services they book a Vietnamese interpreter but I need a sign language interpreter and I think they should ask me or find out what I need and not assume because I am Vietnamese that I need a Vietnamese interpreter.

The States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

(International Covenant on Economic, Social and Cultural Rights, Article 12)

In some circumstances, eligibility for the payment of Special Benefits are dependent on verification of a person's medical history. In the case

108. An example provided by NEDA relates to a situation where an interpreter was required by the carers of a person with disability. The carers could not speak English and were finding it difficult to maintain their carers' role because of health reasons. The advocate provided by the Multicultural Advocacy Liaison Service of SA (MALSA) — a NEDA affiliated advocacy organisation — required an on-site interpreter to assess the needs of the person with disability and his carers, explain the intricacies of the service provision and their entitlements and organise service provision. Since, this was not classified as a settlement-related service, MALSA had to pay a charge of \$65.00 in order to secure an interpreter to communicate with their client. DIMA has advised the Commission that as this was not a 'settlement'-related matter, MALSA was not entitled to receive free on-site or phone interpreting services through TIS.



109. Supra note 107 at 26.

of refugees, who have come to Australia under humanitarian programs, many do not have access to their medical histories in light of the circumstances of their departure from their home countries.

Members of family J came to Australia as refugees two years ago and settled in Melbourne. Mr J had experienced life in a concentration camp where he had undergone constant beatings, starvation and persecution. As a result Mr J has severe post traumatic stress disorder, suffers from panic attacks, has sight only in one eye, suffered a heart attack two years ago, has significant short term memory loss and is prone to wandering.

As Mr J required full time care, Mrs J had been trying unsuccessfully to obtain the carer's pension because among other things she appeared to lack the required official papers. As she speaks little English, she could not communicate effectively with the relevant service providers, medical professionals and government bodies without an interpreter. She requested help from the Advocacy for Survivors of Torture and Trauma Program (run by ADEC). Eight weeks of advocacy, information searches, meetings with doctors and Commonwealth government agencies resulted in Mrs J being eligible for the carer's pension and receiving it.

Everyone has the right to a standard of living adequate for the health and well being of himself and of his family, including... necessary social services...

(Universal Declaration of Human Rights, Article 25)

The States Parties to the present Covenant recognise the right of everyone to social security...

(International Covenant on Economic, Social and Cultural Rights, Article 9)

Another problematic area is the use of friends and family as interpreters for people with disabilities from non-English speaking backgrounds. This has the potential to create confusion and misunderstandings, given that they are not trained professional interpreters. Also, professional interpreters are bound by ethical obligations that prevent the disclosure of confidential information about clients. Friends and family are not bound by the same rules. Indeed in many situations there will be a real reluctance to discuss intimate details in the presence of a relative or friend. It is incumbent upon the medical practitioner or the service provider to ensure that proper interpreter

services are made available to all patients who are not comfortable in English. Where this is not the case, poor service and even misdiagnosis or mistreatment may result. This possibility is highlighted in both of these cases:

Mr K was referred to a psychiatrist by his treating doctor for a specialist assessment to support a claim for the disability support pension (as required by the Commonwealth agency). The psychiatrist was not prepared to use an interpreter because he believed the cost of an interpreter was allegedly not covered under Medicare. Hence Mr K took a friend along for assistance.

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,... language... or any other situation applying either to the disabled person himself or herself or to his or her family.

(Declaration on the Rights of Disabled Persons, Article 2)

Mr L needed to have an artificial leg fitted by a service provider. Due to language barriers, he had not been able to communicate with the staff and was feeling a great deal of discomfort. The service provider refused to engage an interpreter because of the extra cost involved. In order to assist Mr L, ADEC paid for an interpreter so Mr L could communicate with the staff. Consequently, his artificial leg was adjusted to fit him properly.

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

(Declaration on the Rights of Disabled Persons, Article 8)

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# Good practice example

While some service delivery is clearly inappropriate and inadequate, there are organisations whose good practices can serve as a model for others to follow.<sup>110</sup> One such example is the Noah's Ark Toy Library and Family Resource Centre (NATL).<sup>111</sup>

## Signage in community languages and changes to the reception area:

Noah's Ark Toy Library and Family Resource Centre

NATL provided a good practice example by:

- displaying sandwich boards outside each of the NATL centres with relevant information in community languages;
- displaying information posters about the organisation in community languages inside;
- translating information brochures, maps and membership forms into community languages;
- providing articles in community languages to community newspapers and including relevant articles in community languages in the NATL newsletter and NATL libraries;
- ensuring telephone systems were compatible with the use of TIS services;
- placing language maps near telephones for prompt identification of languages spoken by clients; and
- training staff to use TIS effectively.

<sup>110.</sup> The good practice examples have been adopted in abbreviated form from Papanicolaou, E., 1994, Report No 2 — Developing Accessible Services for People with a Disability and of Non-English Speaking Background: Implementation of the Access Model With Four Disability Services, ADEC, Melbourne.

<sup>111.</sup> The Noah's Ark Toy Library and Family Resource is a Victoria based resource centre and toy library for children and teenagers (0–20 years) with special needs; and their parents, siblings, extended families, teachers, care givers and professionals in the field. The core service of Noah's Ark is toy lending, however associated services such as play groups, counselling and therapy, are integral to the organisation.

# Conclusion

This paper has identified a range of key issues that prevent people with disabilities from non-English speaking backgrounds from enjoying their human rights to the same standard as other Australians. Governments, service providers, community and health workers and employers all have a role to play in addressing these issues.

People with disabilities from non-English speaking backgrounds have a legitimate expectation that Australian society should take seriously their claims to be recognised as equal members of the community.

Several important recurring themes are evident throughout this issues paper. They are the need to raise general community awareness about disability; the need to increase readily available and accessible information; the need to improve education about disability across the society as a whole; the importance of advocacy and the imperative of designing more culturally appropriate service delivery. These themes are treated separately below with some suggested strategies to improve barriers to access and enhance service provision.

The following strategies are offered as a starting point as measures that might go some way towards adressing the disadvantages experienced on a daily basis by people with disability from non-English speaking backgrounds. People with disabilities, without distinction based on race, colour, sex, language, religion, political or other factors have an inherent right to respect for their human dignity. They are entitled to measures designed to enable them to become as self-reliant as possible<sup>112</sup>, and they are entitled to have their special needs taken into consideration at all stages of economic and social planning.<sup>113</sup>

# Strategies for Awareness Raising and Education

People with disabilities from non-English speaking background communities, advocacy groups and expert commentators have emphasised the importance of educational strategies to combat negative stereotypes of people with disabilities in general and from

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112. Article 5, Declaration on the Rights of Disabled Persons.113. Article 8, Declaration on the Rights of Disabled Persons.

non-English speaking background communities in particular. There is an imperative for governments and service providers to provide targeted education aimed at the general public as well as a range of specific communities. The following is a summary of strategies advocated or implemented by governments, advocacy groups, community organisations and expert commentators in Australia.

- Provide information in relevant community languages about disability issues including mental health in a variety of media (print, radio, TV, Internet); include positive images of people with disability from non-English speaking background communities in promotional information.
- Promote the need for, and develop a national mental health community education agenda aimed at people from non-English speaking background communities.
- Provide cross-cultural training for staff working with people with disability from non-English speaking background communities.
- Provide leadership aimed at dispelling disability myths and prejudices at community level by challenging attitudes which isolate and exclude people with disabilities from non-English speaking background communities from participating in the broader community as well their own.
- Promote anti-discrimination measures aimed at stamping out racial and disability discrimination.
- Consult with specialist advocacy organisations and other relevant peak bodies in the development and implementation of any such strategies.

## Strategies for Improving the Cultural Appropriateness of Service Delivery

People with disabilities from non-English speaking background communities, government agencies, specialist advocacy organisations and expert commentators have continually emphasised the importance of consultation, participation and culturally appropriate services for improved service delivery in this area. Indeed this need was clearly identified by government in Recommendation 7 of the *National Disability Program Review*.

The following summarises some suggested strategies for governments and service providers that should be adopted as a matter of priority.

• Employ bilingual or multilingual workers, select staff experi-



enced in working with the prospective client group.

- Train workers from mainstream services in the proper use of interpreters and translators.
- Design and implement disability awareness information campaigns in community languages through print and electronic media.
- Provide cross-cultural training for workers in mainstream services to raise their awareness of particular needs of the prospective client group.
- Equip workers with interviewing, networking, and effective communication skills.
- Include people with disabilities from non-English speaking background communities and/or their carers and families in government and community advisory bodies.
- Involve people with disabilities from non-English speaking background communities in consultative forums dedicated to program design, implementation and evaluation.
- Monitor service delivery standards and report outcomes.
- Adopt charters of service integrating principles of cultural diversity.
- Monitor and evaluate the implementation of *Charter of Public Service in Culturally Diverse Society* regarding CSDA services.
- Develop and implement codes of professional practice for those working with people with disabilities from non-English speaking background communities.

It is important to note that specialist advocacy organisations such as NEDA and its member organisations can contribute a great deal of knowledge and expertise to the development and implementation of such strategies and should be consulted prior to any major initiatives.

#### Strategies for Improved Communication

While research in this area is relatively limited, there are a number of reports that have consistently identified either lack of availability and/or awareness of interpreters as a major barrier for people with a disabilities from non-English speaking background communities. In addition, lack of access to relevant information in community languages and/or promotion of such resources further isolate and marginalise people with disabilities in this group. This seriously hampers their ability to access the range of support services provided under the CSDA as well as other services such as financial assistance, health care, aged care, education, housing and child-care.



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There is an ongoing need for governments and service providers to implement strategies that address barriers to communication. The following is a summary of useful strategies recommended by advocacy organisations, governments and community organisations.

#### Interpreters

- Develop written guidelines for the use of interpreters and circulate to staff.
- Promote the availability and use of interpreters in relevant community languages and/or sign language eg. AUSLAN, train staff in the use of interpreters and in accessing TIS services and ensure phone equipment is capable of accommodating TIS services.
- Budget for the provision of interpreter services.
- Investigate alternative sources of funding for interpreting apart from TIS and state agencies.
- Include costs associated with interpreter services within unit costing models.

#### **Promotion and Delivery of Information**

- Consult communities regarding the preferred means of promotion and delivery of information.
- Promote & deliver information about disability issues including mental health through a variety of media (print, radio, TV, Internet).
- Include positive images of people with disabilities from non-English speaking background communities in promotional information. In particular provide information:
  - in large print or downloadable formats in community languages on websites;
  - in Braille as necessary; and
  - through community newspapers and radio stations.
- Display the information at community centres, government agencies, health care Providers, libraries and any other premises where people with disabilities from non-English speaking backgrounds access information.

In the interests of addressing the social inequality and lack of fundamental rights of this group, there are a significant number of issues raised in this paper that require further investigation and urgent attention by governments, policy makers and service providers alike.

This issues paper is offered as a positive contribution towards that overall effort.

# Abbreviations

ABS	Australian Bureau of Statistics
ADEC	Action on Disability within Ethnic Communities, Victoria
AIHW	Australian Institute of Health and Welfare
ALRC	Australian Law Reform Commission
ATMHN	Australian Trans-cultural Mental Health Network
CEDAW	Convention on the Elimination of all Forms of Dicrimination Against Women
CERD	Convention on the Elimination of all Forms of Racial Discrimination
CRS	Commonwealth Rehabilitation Service
CROC	Convention on the Rights of the Child
CSDA	Commonwealth/State Disability Agreement
CSDA funded Services	Service providers receiving funding from State and Territories and/or Commonwealth governments for a service or services covered by the CSDA
DIMA	Department of Immigration and Multicultural Affairs (Cth)
DDA	Disability Discrimination Act 1992 (Cth)
DDRAG	Disability Data Reference and Advisory Group
DFCS	Department of Family and Community Services, Commonwealth
DSA	Disability Services Act 1986 (Cth)
ECDN	Ethnic Communities Disability Network, Queensland
EDAC	Ethnic Disability Advocacy Centre, WA
FECCA	Federation of the Ethnic Communities' Councils of Australia
HACC	Home and Community Care
Н&СЅ	Department of Health and Community Services, Victoria
HREOC	Human Rights and Equal Opportunity Commission
HREOCA	Human Rights and Equal Opportunity Commission Act 1986 (Cth)
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICIDH	International Classification of Impairments, Disabilities and Handicaps (WHO)
MALSA	Multicultural Advocacy and Liaison Service of SA Inc
MDAA	Multicultural Disability Advocacy Association, NSW
NATL	Noah's Ark Toy Library and Family Resource Centre
NCSDD	National Community Services Data Dictionary
NDAC	National Disability Advisory Council
NEDA	National Ethnic Disability Alliance (members are ADEC, MALSA, MDAA,
	EDAC and ECDN)
NESB	Non-English speaking background
NMDS	National Minimum Data Set
OOD	Commonwealth Office of Disability
RDA	Racial Discrimination Act 1975 (Cth)
SDA	Sex Discrimination Act 1984 (Cth)
SSA	Social Security Act 1991 (Cth)
TIS	Translating and Interpreting Service (DIMA)
UDHR	Universal Declaration of Human Rights
UNESCO	United Nations Educational Scientific and Cultural Organisation
WHO	World Health Organisation
WROS	Western Region Outreach Service in Victoria

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# Definitions of Disability

# International classification of impairments, disabilities and handicaps (ICIDH)

In 1980, the World Health Organisation (WHO) published the International Classification of Impairments, Disabilities and Handicaps (ICIDH-1) as a guide for the classification of diseases. The ICIDH-1 is regarded as a conceptual framework for disability that includes three dimensions-impairment, disability and handicap.

In 1993, the WHO agreed to revise ICIDH-1 across all three dimensions. Accordingly, the revised International Classification of Impairments, Disabilities and Handicaps (ICIDH-2) has used the following criteria to define disablements:

- losses or abnormalities of bodily function and structure (impairments);
- limitations of activities (disabilities); and
- restrictions in participation (formerly called handicaps).

The ICIDH-2 adopted a conceptual model in which functioning and disablement are regarded as:

Outcomes of an interaction between a person's physical or mental condition and the social and physical environment.<sup>114</sup>

#### **Definitions of disability in Australia**

Madden and Hogan in their discussion paper on definition of disability in Australia discuss the conceptual framework for the use of definitions and terminology. They state that:

Terminology provides a name to a concept–an idea or a way of thinking about a particular entity, relationship or situation– and the description of the concept may be formalised into a definition.<sup>115</sup>

115. Madden, R. and Hogan, T., 1997, *The Definition of Disability in Australia; Moving Towards National Consistency*, AIHW, Canberra.

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<sup>114.</sup> WHO website at http://www.who.int/msa/mnh/ems/icidh/brochure.

#### Definitions used by activists and advocates

There are a number of definitions of disability currently in use in Australia.<sup>116</sup> These definitions are:

- definitions used by activists and advocates;
- broad inclusive definitions for anti-discrimination measures and population research;
- definitions for generic or mainstream services;
- definitions for income support; and
- definitions for disability support services.

#### **Broad inclusive definitions**

Fine and Asch in their book *Women with Disabilities*<sup>117</sup> have discussed the use of disability terminology as a political and rhetorical tool. They have argued that during the past two decades, activists and scholars in this area have insisted that disability (the biological condition) be conceptually separated from the handicap (the social ramifications) of the condition.

# Anti-discrimination legislation

#### **Disability Discrimination Act 1992 (DDA)**

The definition of disability under the DDA is very broad. The definition is not intended to change the day-to-day concept of disability, but has been made as broad as possible to ensure any person who is treated less favourably on the basis of a past, present, future, real or imputed disability has access to remedies under the Act.

Section 4 of the DDA defines disability as:

- (k) total or partial loss of the person's bodily or mental functions; or
- (l) total or partial loss of a part of the body; or
- (m) the presence in the body of organisms causing disease or illness; or
- (n) the presence in the body of organisms capable of causing disease or illness; or
- (o) the malfunction, malformation or disfigurement of a part of the person's body; or
- (p) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or



116. Some of the definitions are adopted from Madden and Hogan, supra note 4 at 29.

117. Asch, A. and Fine, M., 1988, *Introduction: Beyond Pedestals* in Fine, M. and Asch, A. (eds.), *Women with Disabilities*—*Essays in Psychology, Culture and Politics*, Temple University Press, Philadelphia.

- (q) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour; and includes a disability that:
- (r) presently exists; or
- (s) previously existed but no longer exists; or
- (t) is imputed to a person.

This definition is wider than many of the 'impairment-based' definitions in State or Territory equal opportunity legislation. Madden and Hogan have characterised it as:

An unstructured mixture of the ICIDH and the International Classification of Diseases ideas.<sup>118</sup>

#### **Population research**

# Survey of Disability, Ageing and Carers–Australian Bureau of Statistics (ABS)

The Australian Bureau of Statistics (ABS) in the 1998 Disability, Ageing and Carers survey<sup>119</sup> has defined a person as having a disability if she/he has one of the following 17 conditions, that has lasted or is likely to last for 6 months or more:

- loss of sight (not corrected by glasses);
- loss of hearing (with difficulty communicating or use of aids);
- loss of speech;
- chronic or recurring pain that restricts everyday activities;
- breathing difficulties that restrict everyday activities;
- blackouts, fits or loss of consciousness;
- difficulty learning or understanding;
- incomplete use of arms or fingers;
- difficulty gripping;
- incomplete use of feet or legs;
- a nervous or emotional condition that restricts everyday activities;
- restriction in physical activities or physical work;
- disfiguration or deformity;
- needing help or supervision because of a mental illness or condition;
- head injury, stroke or other brain damage, with long-term

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<sup>118.</sup> *Supra* note 4 at 30.

<sup>119.</sup> ABS, 1998, *Disability, Ageing and Carers: Summary of Findings*, Catalogue Number 4430.0, ABS, Canberra.

effects that restrict everyday activities;

- treatment for any other long-term condition, and still restricted in everyday activities; or
- any other long-term condition that restricts everyday activities.

The definitions used in the ABS *Disability, Ageing and Carers* surveys are generally intended to be consistent with the definitions of the ICIDH-1 and its successor ICIDH-2.

#### **Definitions used for generic services**

A number of Commonwealth Acts define disability for generic services. An example is the definition of target group under Part III of the *Disability Services Act* 1986 (DSA), which outlines the provision of services by the Commonwealth Rehabilitation Service (CRS).

Section 18 of the DSA defines the target group for the purpose of Part III as persons who:

- (a) have attained 14 years of age but have not attained 65 years of age; and
- (b) have a disability that:
  - (i) is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments; and
  - (ii) results in a substantially reduced capacity of the person:
    - (A) to obtain or retain unsupported paid employment; or
    - (B) to live independently.

#### Definitions used for income support

Income security is a Commonwealth responsibility, which is administered by Centrelink.<sup>120</sup> Centrelink is a statutory authority responsible through its Board, to the Minister for Social Security. It was established under the *Commonwealth Service Delivery Agency Act* 1997 that came into effect on July 1 1997. Centrelink offices provide the following<sup>121</sup>:

• all services formerly provided by DSS offices, as well as child care and student assistance payments and services;

registration and acceptance of all new applicants for income support and employment assistance;
 120. Centrelink is the operating name of the Commonwealth service delivery agency.
 121. This information was obtained from the Centrelink Website at www.centrelink.gov.au.

- referrals for employment assistance; and
- specialist labour market assistance services for disadvantaged groups, including Aboriginal and Torres Strait Islanders, sole parents, people with disabilities, migrants and young people.

A number of Acts confer functions on Centrelink, one of which is the *Social Security Act* 1991 (SSA). The main disability-related terms and definitions from this Act are as follows:

## Carer payment definitions

#### Section 197 of the SSA-Definitions

Disabled adult means a person aged 16 or more who:

- (a) has a physical, intellectual or psychiatric disability; and
- (b) is likely to suffer from that disability permanently for an extended period.

A child is a profoundly disabled child if:

- (a) if the child has either:
  - (i) a severe multiple disability; or
  - (ii) a severe medical condition; and
- (b) the child, because of that disability or condition, needs continuous personal care for:
  - (i) 6 months or more; or
  - (ii) if the child's condition is terminal and the child's life expectancy is less than 6 months—the remainder of child's life; and
- (c) the child's disability or condition includes 3 or more of the following circumstances:
  - (i) the child receives all food and fluids by nasogastric or percutaneous enterogastric tube;
  - (ii) the child has a tracheostomy;
  - (iii) the child must use a ventilator for at least 8 hours each day
  - (iv) the child:
    - (A) has faecal incontinence day and night; and



- (B) if under 3 years of age, is expected to have faecal incontinence day and night at the age of 3;
- (v) the child:
  - (A) cannot stand without support; and
  - (B) if under 2 years of age, is expected to be unable to stand without support at the age of 2;
- (vi) a medical practitioner has certified that the child has a terminal condition for which palliative care has replaced active treatment;
- (vii) the child:
  - (A) requires personal care on 2 or more occasions between 10pm and 6am each day; and
  - (B) if under 6 months of age, is expected to require care as described in sub-subparagraph (A) at the age of 6 months.

*Higher ADAT score adult* means a disabled adult who is a care receiver because paragraph 198(2)(a) applies.

*Lower ADAT score adult* means a disabled adult who is a care receiver because paragraph 198(2)(d) applies.

#### Section 198(2) of SSA—Constant care of disabled etc. persons

The person must personally provide constant care for:

- (a) either:
  - (i) if the person is the only person providing the constant care—a disabled adult (the care receiver) who has been assessed and rated, and given a score of at least 25, under the Adult Disability Assessment Tool; or
  - (ii) if not-a disabled adult (the care receiver) who has been assessed and rated, and given a score of at least 80, under the Adult Disability Assessment Tool; or
- (b) a profoundly disabled child (the care receiver) aged under 16; or
- (c) 2 or more disabled children (the care receivers) aged under 16; or
- (d) a disabled adult and a dependent child of the adult (the care receivers), where:



- (i) the disabled adult has been assessed and rated, and given a score of at least 20, under the Adult Disability Assessment Tool; and
- (ii) the child is aged under 16; and
- (iii) if the child is aged 6 or more-carer allowance is payable for the child.

Section 38C of the SSA provides for the new method of assessing an adult's disability, called the Adult Disability Assessment Tool:

38C(1) The Secretary may, by determination in writing:

- (a) devise a test for assessing the disability, emotional state, behaviour and special care needs of a person aged 16 or more; and
- (b) provide a method for rating the person by giving him or her, on the basis of the results of the test, a score in accordance with a scale of the kind described in subsection (2).
- 38C(2) The scale referred to in subsection (1) is a scale that provides for a range of scores that indicate the different levels of physical, intellectual or psychiatric disability of persons.
- 38C(3) The determination is, in this Act, referred to as the Adult Disability Assessment Tool.

Section 198(2) of the SSA states the qualifications for carer payment:

The person must personally provide constant care for:

- (a) either:
  - (i) if the person is the only person providing the constant care-a disabled adult (the care receiver) who has been assessed and rated, and given a score of at least 25, under the Adult Disability Assessment Tool; or
  - (ii) if not—a disabled adult (the care receiver) who has been assessed and rated, and given a score of at least 80, under the Adult Disability Assessment Tool; or
- (b) a profoundly disabled child (the care receiver) aged under 16; or
- (c) 2 or more disabled children (the care receivers) aged under 16; or
- (d) a disabled adult and a dependent child of the adult (the care receivers), where:



- (i) the disabled adult has been assessed and rated, and given a score of at least 20, under the Adult Disability Assessment Tool; and
- (ii) the child is aged under 16; and
- (iii) if the child is aged 6 or more-carer allowance is payable for the child.

#### **Disability support pension**

The following is a simplified version of section 94(1) of the SSA:

A person is qualified for disability support pension if:

- 1. the person has a physical, intellectual or psychiatric impairment; and
- 2. the person's impairment is of 20 points or more under the Impairment Tables<sup>122</sup>; and
- 3. the person has a continuing inability to work;
- 4. the person has turned 16; and
- 5. is an Australian resident, or living in Australia at the time of the claim (must have 10 years qualifying residence unless inability to work commenced while an Australian resident or arrived as a refugee).

Section 94(2) of the SSA contains the following definition:

A person has a 'continuing inability to work', because of an impairment if the Secretary<sup>123</sup> is satisfied that:

- (a) the impairment is of itself sufficient to prevent the person from doing any work within the next 2 years; and
- (b) either:
  - (i) the impairment is of itself sufficient to prevent the person from undertaking educational or vocational training or on-the-job training for the next 2 years; or
  - (ii) if the impairment does not prevent the person from undertaking educational or vocational training or on the job training, such training is unlikely (because of the impairment) to enable the person to do any work within the next 2 years.



122. Impairment tables are designed to assess impairment in relation to work and consist of system based tables that assign ratings in proportion to the severity of the impact of the medical conditions on normal functions as they relate to work performance. These tables are contained in a schedule to the *Social Security Act* 1991 and are also available from Centrelink.123. See section 23(1) of the SSA.

#### Definitions used for disability support services

In 1991, the Australian Heads of Government signed the Commonwealth/ State Disability Agreement (CSDA). The CSDA provides a national framework to underpin the provision of specialist disability services across Australia and sets out how responsibilities are shared between the Commonwealth and State and Territory Governments.

The CSDA required that all jurisdictions develop legislation for provision of disability services. Madden and Hogan are of the view that the CSDA definitions provide a reference point for the development of State disability services legislation, and a common approach could be seen when comparing the various state legislation.<sup>124</sup>

#### **CSDA** definition

'People with disabilities' means people with a disability attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of the following:

- self care/management;
- mobility;
- communication; and
- requiring ongoing or episodic support.

#### Disability Services Act 1986

'Persons with a disability' are defined as having a disability that:

- (a) is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments;
- (b) is permanent or likely to be permanent; and
- (c) results in:
  - (i) a substantially reduced capacity of the person for communication, learning or mobility; and
  - (ii) the need for ongoing support services.



#### State disability services legislation

For the sake of brevity, only one example is cited.

#### Disability Services Act 1992 (QLD)

Part 3 of this Act contains the following definitions:

- (1) A person with a disability:
  - (a) that is attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment or a combination of impairments; and
  - (b) that results in
    - (i) a substantial reduction of the person's capacity for communication, social interaction, learning or mobility; and
    - (ii) the person needing support.
- (2) The disability must be permanent or likely to be permanent.
- (3) The disability may be, or may not be, of a chronic episodic nature.



# Disability Discrimination Act 1992 and the Racial Discrimination Act 1975

Both Acts are available in full on the Commission's website at http://www.hreoc.gov.au

# **Disability Discrimination Act 1992**

The Disability Discrimination Act 1992 has as its major objectives to:

- eliminate discrimination against people with disabilities;
- promote community acceptance of the principle that people with disabilities have the same fundamental rights as all members of the community; and
- ensure as far as practicable that people with disabilities have the same rights to equality before the law as other people in the community.

## **Racial Discrimination Act 1975**

The *Racial Discrimination Act* 1975 gives effect to Australia's obligations under the *International Convention on the Elimination of All Forms of Racial Discrimination*.

Its major objectives are to:

- promote equality before the law for all persons, regardless of their race, colour or national or ethnic origin; and
- make discrimination against people on the basis of their race, colour, descent or national or ethnic origin unlawful.



# National Ethnic Disability Alliance

The National Ethnic Disability Alliance (NEDA) is a national disability consumer organisation that maintains a primary focus on disability issues among people with disability from non-English speaking backgrounds. It was established in 1994.

NEDA incorporates a number of affiliated members. These are:

- Action on Disability within Ethnic Communities (ADEC), VIC
- Multicultural Advocacy Liaison Service of SA Inc (MALSA), SA
- Multicultural Disability Advocacy Association (MDAA), NSW
- Ethnic Disability Advocacy Centre (EDAC), WA
- Ethnic Communities Disability Network (ECDN), QLD

NEDA is one of the 10 national peak disability consumer bodies funded by the Commonwealth Office of Disability. It is also a member of the National Caucus of Disability Consumer Organisations<sup>126</sup> (the National Caucus) established in August 1995.

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125. The functions of National Caucus are to share information and network among its members and collective campaign action and representation to government on issues affecting people with disability.

National Disability Advocacy Program Review Report

# **Summary of Recommendations**

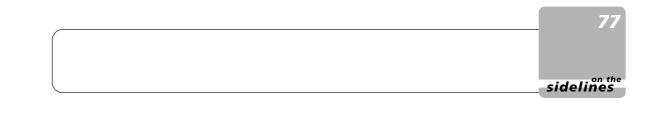
- 1. The goal of the Commonwealth's National Disability Advocacy Program: To enable people with disabilities to achieve and maintain their rights as citizens and to improve their access to and participation in community life, taking into account the family context.
- 2. The objectives of the Commonwealth's National Disability Advocacy Program be:
  - to prevent abuse, discrimination or negligent treatment of people with disabilities;
  - to promote and enhance the rights of people with disabilities;
  - to encourage people with disabilities to make informed choices;
  - to increase economic and social participation for people with disabilities in the community;
  - to assist people with severe disabilities to participate equitably in community life;
  - to increase the knowledge and understanding of people with disabilities;
  - to improve communication between people with disabilities, their families and carers about the rights of people with disabilities;
  - to improve communication between people with disabilities and other members of the community; and
  - to recognise, value and include families and carers, where appropriate, in the support system for people with disabilities.



- 3. In cooperation with advocacy services and people with disabilities, strategies for achieving the goal and objectives of the Commonwealths' National Disability Advocacy Program be developed and incorporated into revised contractual arrangements. That a Code of Practice for the National Disability Advocacy Program be developed and incorporated into revised contractual arrangements.
- 4. The Commonwealth, in consultation with advocacy organisations, the Commonwealth/State Disability Services Sub-Committee and the National Community Services Information Management Group collect nationally consistent advocacy data (both qualitative and quantitative) on a regular basis.
- 5. The development of performance indicators, and outcome and output measures for advocacy services funded by the Commonwealth be undertaken in cooperation with advocacy service providers and people with disabilities.
- 6. A range of suitable funding systems with links to performance indicators and output and outcome measures be investigated and developed.
- 7. Strategies to address the needs of people with disabilities from Aboriginal and Torres Strait Islander backgrounds, diverse cultural and linguistic backgrounds and rural and remote communities be developed in consultation with advocacy services.
- 8. Two categories of advocacy be adopted for the National Disability Advocacy Program-individual and systemic.
- 9. A more equitable distribution of Commonwealth funding within States/Territories be examined further, taking account of advocacy policy and funding direction of State/Territory governments.
- 10. The primary focus of the program be individual advocacy, with a small proportion of systemic advocacy at the local and regional level as agreed in revised contractual arrangements.



- 11. A number of state-based systemic organisations and national advocacy organisations be funded.
- 12. The program include a component of funding for advocacy development for training activities and networking through self-help groups.
- 13. In establishing the new framework for the Commonwealth's National Disability Advocacy Program, there would need to be active coordination with State and Territory governments.
- 14. A formal mechanism be established to represent the interests of families with members with disabilities.



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