

EXECUTIVE SUMMARY

People from a non-English speaking background (NESB) with disability are one of the most disadvantaged and marginalised groups in society. The issues and needs of people from NESB with disability and their families and carers have not been understood or addressed by governments, the community sector and the general population.

The purpose of this document is to increase the knowledge about, and achieve outcomes in relation to, the issues and needs of people from NESB with disability and their families. In order to do this, *Less Talk, More Action* outlines concrete strategies and suggests the formation of meaningful partnerships between government departments, service providers and ourselves to work collaboratively towards achieving equitable outcomes for people from NESB with disability and their families.

Dispelling some of the commonly held myths, also known as stereotypes, is an important part of increasing knowledge. It is also imperative that the historical, social and political context is understood because it has shaped the current realities of many people from NESB with disability. It is our understanding that people from NESB with disability make up 3.5 per cent of the NSW population (in real numbers this means about 218 thousand people plus their families, carers and friends) which accounts for a substantial section of the community.

The section titled *The Talk* provides a summary of the NSW Government's current policies and legislation that are most relevant to people from NESB with disability. The policies and legislation provide a framework which the NSW Government has agreed to work in. It is our belief that the realities experienced by people from NESB with disability need to be measured against these policies.

Current Realities does exactly this and in this section we highlight the five main issues facing people from NESB with disability. These five issues are:

- ▶ **Anglo-Australian service provision:** 3 out of 4 people from NESB with disability miss out because of their ethnicity.
- ▶ **Whole of Government 'Ping Pong':** A whole-of-government approach to disability on one hand, and to ethnicity on the other, has led to government departments, service providers and Ministers shuffling responsibility from one to the other. People from a NESB with disability continually fall through this gap.
- ▶ **Lack of Accessible Information:** People from NESB with disability are unable to participate in the community because access to information, which in effect means access to opportunities, has been denied by successive governments.
- ▶ **Financial Vulnerability:** People from NESB with disability are poorer than their Anglo-Australian counterparts largely because of the discriminatory policies (both racial and disability) and practices of the Federal Government.
- ▶ **Carer / Family 'Burn Out':** The major impact of migration is diminished family and support networks. Together with the factor mentioned above, this leads to excessive burdens being carried by families and carers from NESB.

The Multicultural Disability Advocacy Association of NSW (MDAA) strongly believes that what is desperately needed now is for the gap between *The Talk* and the *Current Realities* to be closed.

Less Talk, More Action offers a model for culturally diverse service provision and suggests broad strategic directions which can assist governments and government departments, as well as service providers in moving towards *More Action*.

Less Talk, More Action focuses on achieving outcomes for people from NESB with disability. We argue that meaningful outcomes can be achieved through a real commitment by the NSW Government and its respective departments to the implementation of *The Talk*, the policies and legislation.

Less Talk, More Action suggests that what is also needed is a demonstration of that commitment through the development and implementation of concrete strategies. People from NESB with disability and their families are ready to make that commitment and move together in partnership.

CHAPTER 1. Introduction



DISPELLING THE MYTHS

Myths and stereotypes play an important part in maintaining and perpetuating current inequities. Naming these myths and understanding how they operate to marginalise and stigmatise people from a NESB with disability, is an important step in dispelling them.

Below is a reality check on three of the more commonly held myths.

MYTH 1	REALITY
There are hardly any people from a NESB with disability in Australia, because they are not allowed into the country.	Despite restrictive immigration policies the prevalence of disability amongst people from NESB is comparable to the Anglo-Australian community.

MDAA argues that the prevalence of disability amongst people from NESB is at least comparable to Anglo-Australians. Unfortunately, at this point in time, there is no hard data available about the incidence of disability in NESB communities. However, there is some evidence which suggests that there is the possibility of a higher incidence of disability amongst NESB communities.

Suggested reasons for a higher incidence of disability include:

- ▶ The concentration of many NESB migrants in jobs and industries (unskilled or semi-skilled labourers) where the incidence of industrial accidents is high
- ▶ The higher incidence of marriage between relatives in some communities which increases the risk of genetically-based disability
- ▶ Unfamiliar and inaccessible health systems and early intervention programs, resulting in late diagnosis and delayed treatment of children with a disability, increases the likelihood of a condition deteriorating
- ▶ Potential for post-traumatic stress disorder and other psychiatric and physical disabilities resulting from the refugee / migration experience.

Despite the intention of the *Migration Act* to restrict the entry of 'handicapped' people into Australia, people from a NESB with disability make up about 4.6 percent of the national population and 3.5 per cent of the NSW population. **(For more information, see Appendix 2: Statistics)**

In general, a health assessment is used to screen out immigrants with disability. There are **some** exceptional circumstances allowing some people with disability to enter, such as humanitarian grounds or being reunited with family.

Specific sections within the *Migration Act* (sections 351, 391, 417, 454) give the Australian Minister for Immigration and Multicultural Affairs discretionary power to grant admittance into Australia and in 1999, a new set of guidelines outlining exceptional circumstances were signed off by the Minister. **(For more information, see Appendix 1: Ministerial Discretion)**

It is our experience that this process does not allow for consistency or fairness and encapsulates the 'squeaky wheel' syndrome which means that sometimes the loudest or the most desperate, provided they are aggressive enough, get what they want, whilst others miss out. This process also flies in the face of the Federal Government's publicly stated commitment about valuing people with disability.

In fact, the exemption of the *Migration Act* from the *Disability Discrimination Act* epitomises the two-tiered value system afforded to people with disability living in Australia on the one hand, and potential migrants with disability on the other.

The current immigration practices have their greatest impact on families. It is not uncommon for families to immigrate, leaving behind the family member with the disability with a relative. Once settled, they apply for this member to immigrate to Australia. This process is proving to be extremely traumatic for the family, especially for the individual who has been left behind.

ABDUR

The Sultani family are refugees from Afghanistan. They came to Australia in 1994 and were granted a Protection Visa. They had to leave behind in the care of his elderly grandmother in Afghanistan their 11 year-old son, Abdur, who has Down syndrome. Abdur has been deeply traumatised by the separation from his family and has difficulties coping on a daily basis.

The family has lodged an application with the Department for Immigration and Multicultural Affairs (DIMA). Unfortunately, the Department will not make a decision because there is a pending case in the Supreme Court on a similar matter. The Department is of the opinion that if they make a favourable decision, this will open the 'floodgates' with other cases.

Meanwhile, in Afghanistan, Abdur's grandmother is getting older and is finding it harder and harder to care for Abdur as he has developed 'challenging behaviours', (tried to commit suicide and has become violent) most likely as a result of the lengthy separation from his family.

Alternatively, people with disability immigrate to Australia with their family on a Visitor Visa and then try and stay on with a Bridging Visa. What this means is that the individual and the family has no access to services or intervention programmes. Meanwhile, their condition can significantly deteriorate. This places an enormous strain on the individual and their families.

MYTH 2	REALITY
Disability is the major concern – being from a NESB does not matter.	For people from NESB with disability, disability and ethnicity are inter-related.

If ethnicity did not matter, the provision of services to people from NESB with disability would be comparable to Anglo-Australians. The fact that there are so many Anglo-Australians and so few people from NESB in services shows that ethnicity does matter. It is our experience that issues of ethnicity and disability are interdependent and one cannot be valued over the other.

SIEW- CHIN

Siew-Chin is a young woman of Chinese descent with a physical disability. She is a tertiary student and because of the lack of accessible public transport, she lives on campus. Siew-Chin is the only person from a non-English speaking background with a visible disability living on campus.

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.

Some students do not refer to her by name but call her 'crippled nip'.

MAHAN

Mahan and her family came to Australia as refugees from Iran. She is 23 years old and works in a sheltered workshop. She is the only NESB worker in the workshop and is harassed and tormented on a daily basis by her co-workers because she does not speak English.

Despite the fact that her work mates have intellectual disability, just like her, she is still singled out and called 'stupid' and 'slow'. Hierarchies exist everywhere, even in the sphere of disability.

Mahan aspires to become an actress. It seems her dream will never become a reality because of the hostile environment she is subjected to and the lack of opportunities this presents.

(For more information, see the section of this Paper titled *Anglo-Australian Service Provision*)

MYTH 3	REALITY
<p>People from a NESB do not need support because they look after their own.</p>	<p>People from NESB with disability face discrimination from their own communities. People from NESB with disability need support.</p>

The prejudicial attitudes and misconceptions regarding disability present in Anglo-Australian communities are equally evident in NESB communities. Whilst there are differences in the perception of disability amongst different ethnic groups, the relative degree of stigma attached to disability appears similar across NESB and Anglo-Australian communities.

MARIA

Maria is a young woman of Mexican descent who has a physical disability. She leads a full and productive life. She is currently attending a tertiary course at a university. Recently, Jose, a respected and well-known member of the Mexican community, told her that people with her condition were 'deformed' and were destined to die quickly. Hence, there was no point in her attempting to gain higher education.

OMAR

Omar is an Arabic community health worker who visits a number of families regularly. He has known the Sulaiman family for many years and has visited them often. To the best of his knowledge, the Sulaiman family only consists of Mr and Mrs Sulaiman and their two sons.

However, he recently discovered that they also have a 5 year old daughter with severe disabilities. She has been hidden away 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 Omar saw her. Mrs Sulaiman normally looks after the child but she had been hospitalised. In desperation, Mr Sulaiman asked Omar to help him take care of his daughter.

GABRIELA

Gabriela is Lebanese and comes from a large family of 9 children. She was recently diagnosed with a bi-polar disorder which the psychologist believes she must have had since she was a teenager. Gabriela reported that at the age of 14, her uncle sexually assaulted her but nobody in the family would believe her. Being the youngest in the family, she was expected to help her elderly mother do the household chores. Her parents are separated.

She has been physically abused by her elder siblings, especially her brothers who expect her to serve them. She has said that she never had a happy childhood and resorted to using drugs and alcohol as a means of escape. She ran away from home and married at an early age to escape her family situation.

Experience of disability varies as much within families as it does within cultures. The factors which have been found to affect family responses to disability across cultures include:

- ▶ Levels of education
- ▶ Access to information in community languages
- ▶ Socio-economic status
- ▶ Length of residence
- ▶ Access to medical information
- ▶ Ways of dealing with such issues as blame, honour, shame, status, marriageability and religious beliefs resulting in acceptance or guilt and the expectation of extended family rather than institutional care
- ▶ Rural or urban upbringing.

By and large, NESB communities have missed out on education campaigns about disability because those conducting the campaigns have failed to target and reach NESB communities. At the same time, there have been consultations with people from NESB with disability, but unfortunately the consultations have not resulted in the development of concrete strategies.

People from NESB with disability and their carers are often stigmatised and isolated because of attitudes and misconceptions prevalent in their own communities and in the Anglo-Australian community. Many migrant families with a member with a disability tend to socialise less, and have fewer contacts with other people, often only with people who accept disability.

Beneath this isolation lies a migration process which is a traumatic and isolating experience. Relatives, friends, social and support networks are no longer available and are difficult to establish in a new country.

There is also a high level of mistrust towards governments amongst many migrant communities, often based on negative experiences with governments in their country of birth.

The lack of support networks has a particularly adverse impacts on women carers, especially those in communities where there is an enormous stigma attached to disability.

(For more information, see the section of this Paper titled *Anglo-Australian Service Provision and Family / Carer Burnout*)

NESB + Disability: The Statistics

At present, there are no statistics available about the incidence of disability within NESB communities. MDAA has used available data from the:

- ▶ Australian Bureau of Statistics (ABS)
- ▶ NSW Ageing and Disability Department (ADD)
- ▶ Department of Family and Community Services (FaCS)

to extrapolate the following.

State (NSW)

The 1998 statistics show that:

- ▶ 15% of the population in NSW has a disability [**ABS, 1998 *Disability, Ageing and Carers: Summary of Findings***].

The ABS statistics also show that:

- ▶ 42% of the population were either born overseas (English speaking + non-English speaking countries) or have one or both parents born overseas (English speaking + non-English speaking countries)
- ▶ 57% of those born overseas or with one or both parents born overseas come from a non-English speaking background [**ABS, 1996 Census**].

Using this information, MDAA estimates that 24% of the population of NSW are people from a NESB. Thus, approximately 24% of all people with a disability living in NSW are from a NESB.

Therefore, MDAA concludes that approximately **3.5% of the population** or 217,396 people in NSW are from a NESB with a disability.

(See Appendix 2: Statistics for more information)

Commonwealth (Australia)

The 1998 statistics show that:

- ▶ 19% of the population in Australia has a disability [**ABS, 1998 Disability, Ageing and Carers: Summary of Findings**].

The ABS statistics show that:

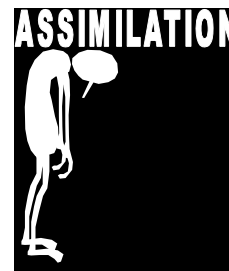
- ▶ 41% of the population were either born overseas (English speaking + non-English speaking countries) or have one or both parents born overseas (English speaking + non-English speaking countries)
- ▶ 60% of those born overseas or with one or both parents born overseas come from a non-English speaking background [**ABS, 1996 Census**].

Using this information, MDAA estimates that 24.6% of the population of Australia are people from a NESB. Thus, approximately 24.6% of all people with a disability living in Australia are from a NESB.

Therefore, MDAA concludes that approximately **4.6% of the population** or 902,082 people in Australia are from a NESB with a disability.

(See Appendix 2: Statistics for more information)

CHAPTER 2: The Historical, Social & Political Context



In order to understand the difficulties experienced by people from NESB with disability an understanding of the historical, social and political context is imperative.

Immigration

Since 1945, almost 5.7 million people have come to Australia as new settlers. The make-up of Australia's population has changed dramatically over the past 200 years – from a purely Aboriginal population to a predominantly Anglo-Celtic one by 1900, to its present make-up of about:

- ▶ 74 per cent Anglo-Celtic
- ▶ 19 per cent European
- ▶ 4.5 per cent Asian¹.

The catalyst for a large-scale migration program was the end of the second World War (WWII). Throughout Europe, millions of people were unable to return to their homes because of the devastation and destruction caused by the war. Meanwhile, in another part of the world, Australia was experiencing a chronic shortage of labour together with a growing belief that a substantial increase in population was needed for the benefit of the country's future.

In 1945 a federal Immigration Portfolio was created and by 1947 a post-war immigration boom was under way with a large and growing number of new arrivals. Agreements were reached with Britain, some European countries and with the International Refugee Organisation to encourage migrants to come to Australia, including displaced persons from the war-ravaged Europe. By 1950, almost 200,000 people had arrived².

A million more migrants arrived in each of the following 4 decades. Today in Australia:

- ▶ Four in ten people are migrants or the children of migrants
- ▶ One in four were born overseas
- ▶ 13.7 per cent were born overseas in non-English speaking countries
- ▶ People from 160 countries live in Australia³.

New Zealand and Britain are the largest source countries for migrants, but other regions – notably Asia – have become more significant.

¹ DIMA: Fact Sheet 11

² DIMA: Fact Sheet 11

³ ABS: Australian Social Trends, 1996

Social Integration Ideologies

Historically, Australia has attempted to create social cohesion through 3 social integration ideologies:

1. Assimilation
2. Integration
3. Multiculturalism.

Assimilation – 1901 to the mid 1960s

The origins of this ideology are reflected in the White Australia policy and implies an almost total absorption one ethnic group into another linguistic and cultural group. While the preference at the time was for British migrants, others were accepted on the basis that they should disregard, and become indistinguishable from, their cultures and languages. Hence, a migrant's success was measured largely by the degree of invisibility they had managed to achieve.

The policy effectively excluded all non-European immigration and unable to withstand the attitudinal changes evident in the Australian population after WWII. This was coupled with a recognition that if Australia was to become an international player, then there was no room for the criticism, especially in neighbouring Asian countries, that this was a racist country.

Integration – mid 1960s to 1972

The Liberal Country Party effectively ended the White Australia policy in 1966 by allowing the migration of 'distinguished' non-Europeans.

Integration does not imply the loss of an individual's identity, original language and culture. Amongst other things, this new integration policy recognised that large numbers of migrants, especially those whose first language was not English, were experiencing many hardships as they settled into Australian life and required more direct assistance.

It also recognised the importance of ethnic organisations in assisting the process of re-settlement. Expenditure on migrant assistance and welfare rose sharply in the early 1970s in response to these needs⁴.

Multiculturalism – from 1972

In descriptive terms, Australia is already multicultural – its population is derived from all parts of the world, which is a historical consequence of the white settlement process that began two centuries ago.

⁴ DIMA: Fact Sheet 8

As a public policy, Multiculturalism gained its footing in the 1960's and 70's (coinciding with Labor's social justice reforms during the Whitlam era) as an expression of a liberal democracy affirming and extending the rights of citizenship and the bounds of individual freedom. Multiculturalism, a policy based on rights and responsibilities, has been endorsed by Australian governments for managing a culturally diverse nation.

There are three overriding principles of Multiculturalism that can be summarised as:

- ▶ Loyalty to Australia – all Australians should have an overriding and unifying commitment first and foremost to Australia's interests and future
- ▶ Acceptance of the Australian system – all Australians are required to accept the basic structures and principles of Australian society: the Constitution, Australian laws, tolerance, equality, democracy, freedom of speech and religion, English as the national language and equality of the sexes
- ▶ Mutual respect – all Australians have the right to express their culture and beliefs that this involves a reciprocal responsibility to accept the right of others to express their views and values⁵.

The public policy of Multiculturalism encapsulates three distinct but inter-related dimensions:

- ▶ Cultural identity – the right of all Australians to express and share their individual and cultural heritage, including their language and religion
- ▶ Social justice – the right of all Australians to equality of treatment and opportunity and the removal of barriers of race, ethnicity, culture, religion, language, gender or place of birth
- ▶ Economic efficiency – the need to maintain, develop and utilise effectively the skills and talents of all Australians, regardless of background⁶.

In contrast to the former ideologies, Multiculturalism promotes the individuality of cultural groups which form a pluralistic society. Within this framework, individual citizens have the right and are given opportunities to maintain and develop their own culture and identity whilst maintaining a position of equal status with other citizens.

Cultural Diversity or Assimilation? 1972 to the present

In 1996 / 97 NSW received approximately 45 per cent of the total migration intake of Australia. 84 per cent of these arrivals are settlers from a NESB⁷.

According to the 1996 Census, 23 per cent of the total NSW population were born overseas, and 15.7 per cent were born in a NES country. The range of languages, cultures and religions that comes with this diversity presents a great challenge in meeting the needs of our diverse society.

Over 16 per cent of people over the age of 5 speak a language other than English. A range of 133 languages and 120 religions has been identified in NSW⁸.

⁶ Dept of the Prime Minister and Cabinet, Office of Multicultural Affairs: Sharing Our Future – National Agenda for Multicultural Australia, July 1989, p.vii.

⁷ DIMA: Settlement Planning Information, 1998

Although the majority of people from diverse cultural and linguistic backgrounds settle in the Greater Sydney area and the regional areas of Illawarra and Hunter, there are substantial numbers of people from NESB living outside those areas.

One of the greatest obstacles facing many vulnerable people in the community is the strong emphasis government now places on rationalist economics and competition principles rather than social cohesion.

For people from a NESB with disability, the political environment is even more hostile because this emphasis is coupled with the major parties' response to the populist thinking about ethnicity (as can be seen through the One Nation phenomenon).

The effect of this response has been a policy shift in both State and Commonwealth governments. For example:

- ▶ on a State level, NSW Premier Bob Carr has taken actions aiming to replace 'Ethnic Affairs Commission' with 'Community Relations Commission', thus losing the specific focus on ethnic communities to encompass all groups in the community (without increasing the Commission's budget - as of the 2000 / 2001 State Budget).
- ▶ on a Commonwealth level, the responses by the Coalition Government and the Labor opposition to the "recent swamping of Australia by illegal migrants who jump the waiting queues and are not genuine" have been similar. Interestingly over 90 per cent of those 'illegal migrants' have, in consequent DIMA assessments, been deemed genuine refugees.

Between 1989 and 1998 Australia on average granted only 7.9% of asylum seeker applications compared to comparable countries such as Canada (33%) and Denmark (18%).

In 1997 there were 22.4 million refugees worldwide. In 1997 / 98 Australia committed itself to having an intake of **12 thousand refugees**. This compares to 104 thousand into Germany and 24 thousand into Canada⁹.

⁸ EAC: The People of NSW Statistics for the 1996 Census, 1998

⁹ From Refugee Council of Australia, based on UN figures.

CHAPTER 3. THE TALK: Current Policy Framework



The historical, social and political context does not only impact directly on the lives of people from NESB with disability. It also shapes the making of policies and legislation affecting people from NESB with disability. Below are some of the central NSW Government policies and legislation that are particularly relevant to people from NESB with disability.

The policies and legislation make up the framework which the NSW Government has agreed to work within, and the realities of people from NESB with disability must be measured against these policies and legislation.

Relevant Policies for People from NESB with Disability

Building on Cultural Diversity – Ethnic Affairs Action Plan 2000 White Paper, 1996

NSW Government's approach to ethnic affairs is a whole-of-government approach. Ethnic affairs is a priority for the government and must be part of the core business of every Government agency. The Government will work with the community to keep it informed of their progress.

The role of the Government in ethnic affairs is to:

- ▶ Provide leadership in encouraging and valuing a culturally diverse society and in promoting social cohesion
- ▶ Ensure access to quality goods and services and an equitable distribution of those goods and services
- ▶ Ensure that policy, legal and planning frameworks support a culturally diverse society
- ▶ Encourage community development.

The Ethnic Affairs Action Plan 2000 lists major outcomes in three primary areas: Social Justice; Community Harmony; and Economic and Cultural Opportunities. The following are the Social Justice goals:

- ▶ Responsive and equitable policy – policy and program development will be responsive to linguistic, cultural, racial and religious diversity
- ▶ Participation in decision-making bodies – increased participation by members of ethnic communities at all levels of Government decision-making and on advisory and consultative bodies
- ▶ Cultural diversity in government services – increased understanding by Government service providers of

cultural diversity, particularly in essential service areas such as health, education, community welfare, housing, police and justice

- ▶ Cultural diversity in funded services – increased understanding by Government funded organisations of cultural diversity
- ▶ Culturally diverse workforce – increased valuing and productive use of cultural diversity within the public sector workforce
- ▶ Access to interpreters and translators – increased access to accredited interpreters and translators for customers of Government services [and government funded services]

- ▶ Access to local government – accessible programs and services delivered by local government
- ▶ Planning for cultural diversity – urban and regional planning will reflect the current and future needs of our culturally diverse community and ensure that housing, social and community infrastructure are accessible
- ▶ Improved settlement services – planning and provision of settlement services will be improved to ensure that new migrants are better supported.

To implement the action plan, agencies are required to:

- ▶ Implement legislation and Government policies related to ethnic affairs
- ▶ Report on progress and outcomes.
- ▶ Ensure ethnic affairs is integrated into their core business
- ▶ Work together with other agencies on joint initiatives.

NSW Charter of Principles for a Culturally Diverse Society, 1994

This Charter, which is part of the amended *Ethnic Affairs Commission Act 1994*, was endorsed by the NSW Cabinet in 1993 and again supported by the NSW Government in 1995, is based on the following principles:

- ▶ All individuals in NSW should have the greatest possible opportunity to contribute to, and participate in, all levels of public life
- ▶ All individuals and public institutions should respect and accommodate the culture, language and religion of others within an Australian legal and institutional framework where English is the primary language
- ▶ All individuals should have the greatest possible opportunity to make use of, and participate in, relevant activities and programs provided and / or administered by NSW government institutions
- ▶ All NSW public institutions should recognise the linguistic and cultural assets in the NSW population as a valuable resource and utilise and promote this resource to maximise the development of the state.

This charter states that it will be applicable and “reflected in all Government policies, activities, and in its dealings with the non- government sector”.

Furthermore, as pointed out in the Handbook for Chief Executives and Senior Managers. “...the Charter of Principles lends itself to a number of equity planning issues facing public sector agencies today, in the sense that it is about principles which should govern the full participation of the entire community in public life...”.

One of the stated outcomes of implementing this Charter is “the benefits that flow from organisational responsiveness to the changing society that the agency serves”.

NSW Social Justice Directions Statement: Fair go, Fair share, Fair say, 1996

The Government’s social justice strategy is based on the four interrelated principles of:

1. Equity
2. Access
3. Participation
4. Rights.

This statement sets out the Government’s broad approach to social justice and states the Government’s commitment to ensuring that:

- ▶ There is fairness in the distribution of resources
- ▶ Rights are recognised and promoted
- ▶ Access to economic resources and services which are essential in meeting the basic needs of people and improve their quality of life
- ▶ People have better opportunities for genuine participation and consultation about decisions affecting their lives.

NSW Disability Services Act, 1993

The NSW *Disability Services Act* 1993 (DSA), regulates the provision of services to people with disability with some of the following aims:

- ▶ Achievement of maximum potential
- ▶ Furthering integration
- ▶ Achievement of positive outcomes
- ▶ Promotion of a positive image
- ▶ Achievement of increased independence.

In relation to people from NESB with disability, the Principles and Applications of Principles specifically state that:

- ▶ “Services and programs of services must apply the principles set out in clause 1. In particular, they must be designed and administered so as to achieve the following:
 - (e) to meet the need of persons with disabilities who experience an additional disadvantage as a result of their gender, ethnic origin or Aboriginality
 - (m) to recognise the importance of preserving the family relationships and the cultural and linguistic environment of persons with disabilities.
- ▶ “Persons with disabilities have the right to choose their own lifestyle and to have access to information, provided in a manner appropriate to their disability and cultural background necessary to allow informed choice”.

NSW Disability Policy Framework, 1998

Under **Section 9** of the DSA, the NSW Ageing and Disability Department is responsible for ensuring that all departments and agencies develop Disability Action Plans. The NSW Government Disability Policy Framework was developed to assist these departments and agencies with their disability action plans. The three objectives of the Framework are:

1. The achievement of a planned, coordinated and flexible approach to policy and service provision in NSW for, and with, people with disability and their carers
2. The creation and promotion of opportunities, services and facilities which enable people with disability
3. Provision of ways for State Government service providers to measure and report on their progress in increasing access for people with disability.

There is a specification – under all three objectives – that in all situations it will be necessary to incorporate initiatives to address specific needs related to gender, culture, language, religion, sexuality, geographical location and socio-economic circumstances.

Culture is certainly a major issue highlighted in this document and makes up one of the principles. Principles of the Framework include:

- ▶ People with disability are full and valued members of the community
- ▶ People with disability will have access to services provided to the general community
- ▶ In the provision of service to people with disability, the focus will be on the whole-of-life needs of individuals in their own communities
- ▶ Better outcomes for people with disability will result from cooperation among service providers with the active participation of people with disability
- ▶ Services will support and be sensitive to, the diversity of people with disability
- ▶ The unique needs of people with disability of Aboriginal and Torres

Strait Islander background will be recognised

- ▶ The legal rights of people with disability will be recognised and protected.

Appendix 3 provides a more detailed analysis of the “NSW Disability Policy Framework” and the “Building on Cultural Diversity” documents.

MDAA is currently undertaking a policy analysis of major policy, legislation, planning, reporting on intended and actual outcomes for people from NESB with disability. This publication will be available shortly.

CHAPTER 4. CURRENT REALITIES



The policies and legislation discussed in the previous chapter are important in setting the broad aims and objectives for an equitable and accessible community. So far, they have largely failed to deliver outcomes to people from NESB with disability.

Human Service Delivery in Australia

The Australian social, political and historical context has a significant impact on the current realities experienced by people from NESB with disability. This context has also led to the development of four distinct orientations to human service delivery in Australia.

These are:

- ▶ **Assimilative and Universal** – services assume a shared value system and make no attempt to identify and respond to cultural differences
- ▶ **Assimilative and Ethnic Targeted** – service delivery assumes common needs but provides some facilitating services such as interpreters and multi-lingual information
- ▶ **Pluralist** – services are developed, maintained and responsive to the needs of individuals in culturally appropriate ways
- ▶ **Ethnic** – a service or agency solely geared towards one ethnic group.

Mainstreaming

Whilst Australia has adopted multiculturalism as the official policy since 1985, service delivery in the disability services sector is predominantly reflective of the *Assimilative and Universal* and *Assimilative and Ethnic Targeted* orientations rather than the pluralist approach. In disability services, the provision of services to people from NESB with disability is assumed to largely occur through 'mainstream' services.

The disability service sector is divided into three components:

1. ethno-specific (only three in NSW)
2. multicultural (only three in NSW) and
3. mainstream services (almost all disability services in NSW).

However, as we will demonstrate, mainstream services do **not** provide for the community, as they almost exclusively service people from an Anglo-Australian background and operate from Anglo-centric service models.

These so-called mainstream services are in fact **ethno-specific services, as they service almost exclusively people from Anglo-Australian backgrounds.**

The notion of a mainstream as currently used is an exclusionary notion, based on the assumptions that 'mainstream' equates with Anglo Australian. This contradicts the principles and goals laid out in all of NSW government policies and legislation.

MDAA argues that the whole idea of mainstreaming needs to be reconsidered if the current barriers are to be removed. Services need to be delivered to the whole of the community, not just to Anglo-Australians, who are after all, only one of the many ethnic groups living in NSW.

Barriers Experience by People from NESB with Disability

Lack of accessible information and knowledge about essential services

- ▶ Lack of culturally appropriate services
- ▶ Discrimination in service provision
- ▶ Complexities of disability when coupled with a NESB means that some service providers relegate people to the 'too-hard basket'
- ▶ Myths, misconceptions and negative stereotypes about disability and ethnicity in the general community
- ▶ Prejudice against people with disability from members of their own communities
- ▶ Increasingly hostile political environment, especially in light of the call for the demise of multiculturalism as a public policy.

The **five most significant barriers and issues** requiring urgent attention are:

1. Anglo-Australian Service Provision
2. Whole-of-government 'Ping Pong' - Lack of Appropriate Action
3. Lack of Accessible Information
4. Financial Vulnerability
5. Carer / Family 'Burn Out'.

1. Anglo-Australian Service Provision

In NSW, three out of four people from a NESB with disability miss out on receiving non-government disability services. In Australia, three out of four people from a NESB with disability miss out on receiving Commonwealth funded disability services. This is in addition to the current unmet need for people with disability in general (**see Appendix 2: Statistics for information about how this unmet need was estimated**).

This figure stands despite genuine efforts made by many to redress this appalling situation. This figure points towards the need to seek systemic solutions to the whole disability services system, involving all stakeholders.

Many services seem unable to accommodate linguistic and cultural diversity because:

- ▶ Ethnic communities tend to be overlooked when considering the ‘target group’
- ▶ Staff need continual accredited, quality training in cultural difference, diversity and disability, and in particular, the nature and reality of the person’s experiences
- ▶ The disability services system has not adopted even the most basic mechanisms for people from NESB such as the use of interpreters or the publication of material in languages other than English. Poor language skills prevent carers from accessing services so they have less opportunity to develop their personal, social or professional capabilities
- ▶ There are insufficient strategies and practices to ensure that people from NESB with disability and their families and carers participate in decision-making
- ▶ The myth of extended family support is still subscribed to by both service providers and funding bodies resulting in fewer services for NESB communities.

HA

Ha, a Vietnamese woman with an intellectual disability wants to receive living skills training. She has been accepted by a local service but she is not learning very much because the training is performed in English and she has limited language skills.

VERONICA

Veronica, is 30 years old and lives her family who came from Malta. She has a disability and is receiving personal care from the Home Care Service of NSW. The family has asked for a permanent Maltese female worker, because they have trouble communicating in English. Veronica is always assigned someone from a completely different ethnic background and sometimes they are male.

CURRENT SITUATION: Racist Service Provision

2. Whole-of-government 'Ping Pong': Lack of Appropriate Action

Governments in Australia have not even begun to respond to the needs of people from NESB with disability. There is very little understanding within government and its funding bodies, the community sector and the general population about disability and ethnicity.

The introduction of the Commonwealth *Disability Discrimination Act*, *Racial Discrimination Act* and *Disability Services Act* (DSA) (including the NSW Act) have provided protection for people from NESB with disability. Unfortunately, access to these protections by people from a NESB with disability is negligible.

Despite its commitments under the DSA to ensure that services are provided for in a fair and equitable manner, both Commonwealth and State governments have failed to provide resources, monitoring, policy direction, etc. to address the barriers facing people from NESB with disability.

Astoundingly, governments in Australia have neglected to establish contractual obligations with the services they fund to ensure that services are provided in an accessible and equitable manner.

A whole-of-government approach to disability on one hand, and a whole-of-government approach to ethnicity on the other, has led to government departments shuffling responsibility for people from NESB with disability amongst themselves. Ministers have had the same tendency. This approach ensures that no decisive actions are being taken by anyone to address the issues.

The whole-of-government approach provides government departments with the excuse of only doing 'core business'. It appears that core business allows only for the experience of one type of disadvantage, ie. either disability or NESB. In a policy environment dominated by a whole-of-government approach, people from NESB with disability continually fall through this gap.

This whole-of-government approach is reflected in the way services are provided by government and non-government services. In part, this approach is being perpetuated through funding arrangements and the lack of contractual obligations with service providers to ensure that services are provided in an accessible and equitable manner.

In part, this approach is maintained and perpetuated by the commonly held myth of disability service providers, that the only issue that matters is disability (and the equally strong held belief by ethnic communities service providers, that the only issue that matters is ethnicity).

3. Lack of Accessible Information

Access to information is often the first step towards people participating in the community. Access to information means, in effect, access to opportunities and therefore choices to participate in the community.

Like all people from NESB, people from NESB with disability and their families and carers experience increased difficulties in accessing services because of the lack of resources made available for interpreters and translations.

Services such as the Translation and Interpreting Service (TIS) and the Ethnic Affairs Commission language services have increasingly adopted the user pays principle, severely restricting the number of free or subsidised on-site and telephone interpreting sessions available to people and non-profit service providers.

A memorandum from the Premier (No.98/22) points out that:

" NSW Government Agencies including Government trading Enterprises are expected to ensure that contracts with private providers and funding agreements with non-government organisations identify a budget for interpreting and translation appropriate to the service provided and the needs of the clients of the service. In relation to state owned Corporations, I consider that this provision provides a sound approach when dealing with people from a non-English speaking background. Funding agencies are also expected to ensure through program monitoring that where such funding is made that language services are provided to clients who need them"

However, despite this memorandum, the costs for language services are mostly unbudgeted, resulting in:

- ▶ a reduction in community services for people with disability from NESB
- ▶ the provision of inappropriate information
- ▶ the overall increase in the use of family members and other relatives as interpreters, in violation of standards such as confidentiality, dignity, privacy, etc.

RITA

Rita is a Filipina with an intellectual disability. She migrated to Australia with her family more than 10 years ago. Even though the 10 year waiting period for migrants with disability was not yet implemented, she had not accessed the Disability Support Pension because her family, who have not had much education and have language difficulties, did not know about this entitlement.

IVAN

A Croatian refugee and her teenage son, Ivan, who has an intellectual disability, are not able to access any disability services. Ivan stays at home all day and receives no services. Due to the Settlement Officer's lack of knowledge, the family was not informed about the services that could support him.

4. Financial Vulnerability

In general, people from NESB rank lower on the socio-economic scale than their Anglo-Australian counterparts. This is often explained by:

- Levels and recognition of educational qualifications
- Levels and recognition of work skills and experience
- English Language proficiency

To make matters worse, in Australia all immigrants without disability (except for those immigrating on humanitarian grounds) have to wait two years before they can access income support.

However, immigrants with a disability, including their carers, have to wait **ten years** before being eligible for the Disability Support Pension (DSP) which is the usual entry criteria for essential disability services such as Post-School Options Program, Home and Community Care (HACC), Program of Appliances for Disabled People (PADP) etc.

There is a provision within the *Social Security Act* that allows migrants with disability to try and prove that their disability has deteriorated significantly since being in Australia. MDAA knows of many instances when convincing the Government to grant this money proved impossible, because of the Government's apparent fear of 'opening the flood gates'.

This discriminatory policy creates enormous financial and emotional strain for people with disability and their families who are left to cope with this on a day-to-day basis.

CARLO

Carlo is a young man with a physical and intellectual disability. His family migrated to Australia in 1997. Carlo used to attend a special school but as soon as he turned 16 the school would not accept him any longer. The school failed to apply for Post-School Options on his behalf and he has been out of school for one year now with no activities or access to suitable day programs.

Carlo is very keen to learn woodworking. He applied for a course at TAFE but he was rejected. Carlo has very limited English skills and there is no adequate support available for people from NESB with disability who want to attend a mainstream course.

Carlo stays at home all day and is prevented from developing his skills because of the lack of training opportunities (vocational or skills training). People with disability who have language difficulties like Carlo are considered 'too hard' to train and or gain employment for.

Carlo does not receive the Disability Support Pension and his mother does not receive the Carers' Pension because of the Commonwealth policy which forces immigrants with disability to wait 10 years before being eligible for income support.

Restricting access to this assistance also compounds the level of disability. What this means is that by the time migrants with disability are eligible for the DSP, their support

needs are significantly higher. This results in additional costs for government by placing extra demands on already limited resources.

In addition, those eligible for support pensions and other support payments or services are frequently not aware of their entitlements. This is because successive Government information strategies have failed to communicate new initiatives and programs to people with low English proficiency.

5. Carer / Family ‘Burn Out’

Excessive responsibilities are carried by families and carers from NESB with multiple layers of disadvantage – disability, poverty, disruption to the family as a result of migration, diminished support networks and lack of sufficient and appropriate services.

Carers from NESB, even more so than their Anglo counterparts, have a ‘grin and bear it’ attitude. Asking for support is seen as failing, not only in one’s caring role, but also failing the family, the community and, most importantly, the person they are caring for.

In general, carers from NESB only seek help when they are at crisis point and not before. As there are often no services involved in the carers lives, the earlier warning signs of ‘burn out’ remain undetected and many GPs are not well informed about programs and support available for carers. Thus doctors cannot act as a go-between for services and carers.

MDAA is aware of several instances where the lack of support and services has led to carers suffering extreme burn out and being admitted to hospital, whilst the person they care for, ended up in residential care or in a nursing home.

Carers from NESB usually end up incurring a disability themselves – commonly physical and mental health problems – as a result of the pressures involved with caring for a person with disability whilst juggling a range of other responsibilities.

CORNELIA

The Coroneous family is from a Greek background. They have one daughter, Cornelia, who has multiple disabilities. Cornelia cannot walk and she is using a communication device which makes communicating with her a very slow process. She used to attend a boarding school, but it only caters for children up to a certain age so Cornelia had to go home. Due to her high support needs, caring for Cornelia is a full-time job. Her family is expected to take care of her on a full-time basis even though they only receive weekend respite once a month.

Cornelia’s mother and father now suffer from depression and her father has displayed suicidal tendencies. He said during an interview with a social worker that one day he might kill his daughter, his wife and then himself to end their suffering.

FRANCESCO

The Infante family comes from Italy. They have 4 children, 2 of whom have an intellectual disability. Francesco, the eldest, has multiple disabilities – he cannot walk, communicate or see. He has high support needs and stays at home most of the time and receives limited respite. His mother cares for him on a full-time basis and his father works full-time. Although both children receive attendant care, their mother still has to provide additional support for them all the time because the hours allocated by the service provider are not adequate.

The 2 younger siblings have difficulty coping with their school work. They are resentful of the attention their elder brothers with disability receive from their mother. They have become rebellious and their mother finds it extremely difficult to cope with their behaviour.

The years of caring have also taken their toll on the mother's health and she now suffers from severe back problems. She now has difficulty providing support to her children's needs because of her recurring illness.

CHAPTER 5. LESS TALK, MORE ACTION: Model & Strategies



THE MODEL: Service Provision **for** **All**

Despite a host of legislation and Government policies aimed at providing an inclusive and supportive environment for all members of the community, the realities experienced by people from NESB with disability is a far cry from these aims.

What is desperately needed NOW is for the gaps between policy and reality to be closed. What is required NOW is a move from “Less Talk” to “More Action”.

We have demonstrated (**see section titled Anglo-Australian Service Provision**) that the current way of delivering services (all services, not only disability services) excludes people from NESB with disability because of their ethnicity.

In response to this, MDAA is proposing a service model which if implemented, will go a long way towards reducing this gap and addressing the needs mentioned above.

Culturally Diverse Service Provision

The model below, developed to meet the needs of the culturally diverse community, is made up of two components:

1. Ethno- specific services
2. Culturally diverse services.

Ethno-specific Services

This is the exceptional mode of service provision. An ethno-specific service needs to justify why it needs to be ethno-specific.

The current so called “mainstream” services are in fact ethno-(Anglo) specific. Thus, under this proposed model, these Anglo-specific services would have to justify why they are run as ethno-specific.

There are reasons why a service might be an ethno specific service. For instance, an ethno-specific service:

- provides services to a particular cultural or linguistic group only, because of their specific cultural or linguistic needs and requirements

- ▶ uses a particular service model, more appropriate to working with people of a particular cultural group only.

The ethno-specific service acts as a cultural consultant to culturally diverse services to ensure that the expertise accumulated is used.

Culturally Diverse Services

In the proposed model culturally diverse services will be the norm of service delivery providing for all people in the community. Given the cultural diversity of the community, every service must become culturally diverse.

These services:

- ▶ have a high level of cultural competency
- ▶ are run according to a culturally diverse service delivery model (see below).

These services work with all members of the community and purchase culturally specific expertise from ethno-specific services when needed.

In order for culturally diverse services to cater to all members of its target community, all services need to be run in accordance with this culturally diverse service delivery model.

The following key concepts need to be present throughout all levels of an organisation's objectives, policies and practices:

1. All staff, policy and program development must undergo cultural diversity Access & Equity audits
2. All aspects of the organisation must be designed so as to enhance diversity and accessibility
3. There can be no marginalisation of any group
4. All barriers to cultural diversity and accessibility must be removed.

The commitment to providing a culturally diverse service needs to be expressed as an integral part of every aspect of service operations, such as:

- ▶ Service location
- ▶ Service networks
- ▶ Needs assessment
- ▶ Information provision
- ▶ Communications
- ▶ Program Design and delivery
- ▶ Staff and work practices and skills
- ▶ NESB Consumer Participation.

THE FUTURE: Culturally Competent Service Provision

STRATEGIES: Actions to close the Gap - NOW

In order for current 'ethno (Anglo)-centric', that is 'mainstream' services, to become culturally diverse services, a range of strategies to address the following areas of Equity of Access need to be put into place NOW. These strategies apply equally to governments, non-government, ethno-specific / multicultural and mainstream disability agencies. We strongly suggest that the planning and implementation of these strategies involve people from NESB with disability.

1. Equity of Access to Information

Although information provision has been considered for a long time as an important issue by government departments and disability service providers, by and large information about disability, entitlements, rights and service provision has been inaccessible. The lack of information to the NESB sector has a two-fold consequence:

- ▶ People with disability know little about disability, rights and opportunities
- ▶ Families and NESB communities have no knowledge about disability, resulting in stigmatisation and isolation of people with disability and their families.

Furthermore, service providers (and governments) know little about people from NESB with disability and have little understanding about how to facilitate communication and the flow of information between people from NESB with disability and disability services.

Sample Strategies:

- ▶ Community education and information campaign to NESB communities to increase awareness about disability issues and the disability service sector.
- ▶ Facilitation of formal and informal links between ethnic communities, disability service sector and Government departments.
- ▶ Government departments to effectively monitor contractual arrangements with disability service providers which ensure that service providers comply with Access & Equity principles, produce information in community languages and utilise interpreters as required.
- ▶ Additional and adequate funding for interpreters and translators.
- ▶ Peer community education and information for people from NESB with disabilities and their families about disability, rights, services and entitlements.
- ▶ Development of Access & Equity plan in relation to communication.
- ▶ Development of concrete and relevant multilingual information and resources about disability, rights, services and entitlements.
- ▶ Funding, developing and attending training in how to provide culturally competent information.
- ▶ The establishment of a credit line with the interpreter and translator service

of the Ethnic Affairs Commission to be available to all ADD funded disability services.

- ▶ Disability awareness training to interpreters and translators.

2. Equity of Access to Disability Services

Equity in accessing and retaining the necessary services has traditionally been identified as the primary area of concern of Access & Equity policies.

The main consequence of inequitable access to disability services has been that 3 out of 4 people from NESB with disability are missing out on services.

Sample Strategies:

- ▶ Undertake accredited Access and Equity audit and develop Access and Equity plan.
- ▶ Staff to access accredited Cultural Competency Training relevant to their area of service provision.
- ▶ Development of culturally specific service information and disability information in community languages.
- ▶ Government departments to effectively monitor contractual arrangements with service providers in relation to people from NESB with disability.
- ▶ Disability service providers have access to a diverse range of ethno-specific workers who act as cultural consultants and who are trained, supported and accredited.
- ▶ Monitor, evaluate and further research the impact of Access & Equity plans in terms of increasing participation rates of people from NESB.
- ▶ Continued improvement and development of culturally competent disability service provision.

3. Equity of Access to Service Development

This area involves a range of provisions within a service, from developing policies and plans that aim to increase cultural competency in service provision, to departmental monitoring of services, to policy making and planning which is culturally competent. Traditionally, this area has not been considered in discussions about Access & Equity.

The main consequence of this lack of consistent planning, service development and monitoring has been that people from NESB with disability are falling through the gaps.

Sample Strategies:

- ▶ Government departments and service providers to consult culturally competent and to achieve quality outcomes for organisations and participants.
- ▶ Transform identified needs into policy advice and strategies on a state-wide and local level.
- ▶ Government departments to implement and monitor effective contractual arrangements with service providers which ensure that they meet the diverse needs of their target group and are culturally competent.
- ▶ Document and promote of best practice models.
- ▶ Government departments and disability service providers to implement consultation outcomes and policy advice.
- ▶ Conduct further research to identify barriers to people from NESB with disability using services equitably.

Achieving Outcomes

Given the stated commitment of the Government to the principles of cultural diversity and social justice (Ethnic Affairs Commission Act 1996, NSW Social Justice Directions Statement, NSW Disability Services Act 1993), the Government must translate these commitments into tangible strategies / mechanisms. This will ensure that government provided and funded services can cater to the needs of all members of the community.

The overarching result of the implementation of the above mentioned strategies and the development of culturally diverse services will be a service system which is able to effectively, efficiently and equitably cater to all members of its target community.

These outcomes can be measured against the following benchmarks:

- ▶ People from NESB have awareness and understanding of disability issues and the disability services sector similar to that of the English speaking community.
- ▶ Service providers and governments are culturally competent in providing information about disability issues and the disability services sector to people from NESB.
- ▶ Participation rates of people from NESB with disability in disability services match their distribution in the general population of a local area.
- ▶ State-funded disability services are culturally competent and meet the diverse needs of their target group.
- ▶ Departmental disability planning, disability services monitoring, and disability policy making is culturally competent.
- ▶ Planning and policy making in state funded disability services is culturally competent.
- ▶ Participation rates services continue to match the prevalence of ethnicity and disability in the general population of the serviced geographic area.

CLOSING

People from NESB with disability and their families do not want “special treatment”.

We do not demand “special rights”.

People from NESB with disability may be of different skin colours, speak different languages, have different beliefs and customs.

Yet, people from NESB with disability and their families are also part of the wider community – the community of human beings.

*Why is it people
Either think I'm just like them
Or else
Like nothing on this earth
And no part of their lives?*

*Here are my tears, I say
Salty and wet like yours
Here are my hopes
Which need tending
Like anything you want to grow
And what hurts worse
Than my pain
Is the denial.*

*If I can live with this dilemma
It doesn't seem too much
To ask others
To recognise
How I'm different
But very ordinary
Ordinary and very different.*

(From “The Horns of My Dilemma” by Maria Jastrzevska, in “Mustn't Grumble, 1994)

We demand to be acknowledged and valued in our diversity. We believe diversity makes for a richer, better community. People from NESB with disability can and want to contribute and participate in the community. The challenge for all of us is to provide an environment in which such contributions are possible and welcomed. People with disability and their families are ready for that challenge.