



**NEDA submission to the Productivity Commission Inquiry into
long term disability care and support**

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1. Executive Summary

NEDA estimates that one in every four people with disability is a person of either first or second generation Non English Speaking Background (NESB); that is around 1 million people.

These people make a positive contribution to Australian social and economic life, as integral part of communities, families, organisations and businesses.

However people from NESB with disability face a number of barriers to rights recognition, participation, support and wellbeing.

This submission aims to highlight key directions to improve the care and support for people from NESB with disability. Any transformation of the current disability system that does not explicitly acknowledge the different realities of people from English speaking and non English speaking backgrounds with disability and develop concrete strategies to address these, will be judged as a major failure by those affected, their families and supporters.

RECOMMENDATION 1

That the disability care and support scheme applies the definition of disability in line with the UNCRPD definition.

That this definition explicitly includes psycho-social illness as disability.

RECOMMENDATION 2

That the disability care and support scheme makes information available to people from NESB with disability in their mother tongue and in a way that suits them most, be it visually through DVD productions in various languages, orally via interpreters, or in written translated material made available in Braille, audio and other formats as requested.

RECOMMENDATION 3

That the disability care and support scheme includes dedicated funding for community education on disability in linguistically and culturally diverse communities; across all states and territories, regional, rural and remote areas.

RECOMMENDATION 4

That the disability care and support scheme guarantees that all people with disability have an income above the Henderson poverty line without compromising access to required support services.

RECOMMENDATION 5

That the disability care and support scheme guarantees that income support payments are flexible to not discourage employment participation.

Limits to income support should be dismantled as long as people qualify for income support on the basis of their disability, especially to account for episodic disability.

Concessions must be available to people with disability to counter the higher cost of living regardless of income or assets.

RECOMMENDATION 6

That the disability care and support scheme works across Government departments to establish dedicated systems of entry into the workforce for people with disability. These should include targets for those from NESB, at a minimum to be 25% as per population groups; included needs to be targets for gender equity.

That the Scheme explore mechanisms such as tax incentives and fines to establish such entries. That opportunities for work experience be considered with a conscious avoidance of exploitation.

RECOMMENDATION 7

That the disability care and support scheme provides for access to NESB specific disability employment services for people from NESB with disability and requires mainstream disability employment services to set targets for people from NESB with disability.

RECOMMENDATION 8

That the disability care and support scheme works across Government departments to ensure that the current 510 hours provided for people from NESB to learn English is increased for people with disability. That the hours are doubled at a minimum and extended further if assessed as beneficial.

RECOMMENDATION 9

That the disability care and support scheme follows principles of *Substantive Equality* in order to address real equality gaps for population groups including people from NESB with disability.

That the disability care and support scheme works across Government to ensure that the Disability Discrimination Act 1992 (Cth) is applied to all Federal Acts, including the Migration Act 1958 (Cth) and the Social Security Act 1991 (Cth).

RECOMMENDATION 10

That the UN Convention (UNCRPD) is the framework for the design and implementation of a new system requiring a significant cultural paradigm shift based on a social model of disability.

RECOMMENDATION 11

That the disability care and support scheme is designed to allow people with disability to live a self determined, fully accessible life that guarantees full human rights.

This is regardless if care and support is required frequently, infrequently, episodically or on an ongoing basis.

RECOMMENDATION 12

That the disability care and support scheme guarantees equity and sustainability in service delivery and outcomes as part of its design, implementation and monitoring.

RECOMMENDATION 13

That the disability care and support scheme is allocated authority and situated in Government in such a way that empowers it to resolve current existing disabling systems with a view to allow all people with disability full participation and self-direction in daily life.

That the PC Inquiry research into the additional cost of disability caused by disabling systems including racism.

RECOMMENDATION 14

That the disability care and support scheme is governed by an independent body with a majority of people with disability and DPOs (organisations of persons with disability), including representation from people from NESB with disability. Governance at all levels is made up in this way.

It is recommended that this body be established as soon as possible to be effective and give direction as part of the planning and development process of a new scheme.

RECOMMENDATION 15

That the disability care and support scheme is:

- a) Based on entitlement for all who are eligible.
- b) Properly funded to address additional costs related to disability so that a person is able to have full enjoyment of their human rights.
- c) Based on equity for all who are eligible.
- d) Takes into account the impact of gender, indigenous background, cultural and language diversity and specific needs of children.
- e) Based on self determination.
- f) Committed to the empowerment of people with disabilities.
- g) Portable (a national scheme).
- h) Responsive to changing circumstances of an individual over their lifespan.

RECOMMENDATION 16

That all existing obligations and commitments to non-discrimination and inclusion of people with disabilities are maintained outside this scheme – i.e. – costs not to be shifted to individuals and preventative mechanisms put in place to prevent this happening.

RECOMMENDATION 17

That the disability care and support scheme will form a major initiative under the National Disability Strategy.

RECOMMENDATION 18

That the disability care and support scheme includes a strong independent advocacy support program, separately funded under the scheme to support and protect the rights and interest of people with disabilities eligible for funding.

RECOMMENDATION 19

That the disability care and support scheme guarantees transparency in funding arrangements and appropriate consumer rights protection mechanisms.

RECOMMENDATION 20

That the disability care and support scheme be funded as a social health insurance model via a levy on taxpayers.

This needs to allow for scope for growth and change as necessary, and protection from financial downturns to ensure stability of support.

RECOMMENDATION 21

That the disability care and support scheme be eligible to all people with disability regardless of:

- type or severity of disability
- age
- income or assets
- citizenship or residency status, including those awaiting decisions
- institutional settings including correctional service system or boarding/rooming house

No other restrictions or waiting periods shall apply.

RECOMMENDATION 22

That the disability care and support scheme develops a nationally consistent assessment process on the basis of:

- self determination of need
- empowerment
- recognition of gender, cultural or faith based needs including the pro-active offer of professional interpreters
- assessment to be conducted at a location where the individual is most comfortable
- reassessment can be initiated by person with disability
- assessors must be qualified in cultural competence
- safeguards must ensure against abuse or violation of rights

RECOMMENDATION 23

That the disability care and support scheme embraces individual or self-directed and managed funding as part of an empowerment strategy for people with disability.

However, this funding must be voluntary with opportunity to opt-in and opt-out as required.

That the disability care and support scheme fully fund advisors, independent from the service system for people with disability to guarantee informed decision making with unlimited access.

That safeguards are developed to ensure against abuse or violation of rights.

The level of funding entitlements must be designed to support full participation in all areas of life, political, social, cultural, religious and economic, as set out in the UNCRPD.

Whenever, individualised funding is not chosen or the person with disability is not able to make a choice the disability care and support scheme must be guaranteed access to a fully equipped and accessible service system.

RECOMMENDATION 24

That the disability care and support scheme be responsive to whole-of person needs including the need to develop social relationships.

That funding is allocated for regular, ongoing social activities, including transport and supported assistance.

RECOMMENDATION 25

That the disability care and support scheme develop a national plan with targets for improving access and utilisation for people from NESB to government funded disability services.

RECOMMENDATION 26

That the disability care and support scheme build obligations into service level contracts to improve representation of people from NESB communities using disability services.

RECOMMENDATION 27

That the disability care and support scheme applies a cultural competence approach as part of its design, implementation and monitoring processes.

RECOMMENDATION 28

That the disability care and support scheme works across Government departments to:

- ensure the development of a solid and qualified workforce;

- guarantee funding for up-skilling and retraining of staff on an ongoing basis;
- support and fund pay equity in the non-Government community and disability sector in line with the Government sector;
- support a migration strategy to attract support workers from NESB.

RECOMMENDATION 29

That the disability care and support scheme ensures that all services are able to provide information in relevant community languages, are able to provide language assistance and access to translators, and engage in community education to diverse communities.

Funding for language services must be kept separate from individual funding under all circumstances and should be made available from different sources outside a disability care and support scheme. Access to information and communication in a preferred language is a human right and thus non-negotiable.

RECOMMENDATION 30

That the disability care and support scheme build adequate service coordination and flexibility to tailor service deliver to meet the needs of individuals.

RECOMMENDATION 31

That the disability care and support scheme improve available data and research on utilisation of services and service needs of people from NESB with disability.

That the disability care and support scheme is allocated authority and situated in Government in such a way that empowers it to:

- Review current data collection by service providers with a view to improving availability of data relating people from NESB, including second generation NESB.
- Amend the reporting requirements under the National Disability Agreement (NDA) to include people from NESB with disability as a priority research area.
- Work with agencies such as the Australian Bureau of Statistics and Australian Institute of Health and Welfare to refine the sophistication of data relating to people from NESB with disability and to make them consistent, nationally.
- Collect, analyse and report on disaggregated data in regards to gender, language, culture and location. To include benchmarks and measurement of progress over time.

RECOMMENDATION 32

That the disability care and support scheme as part of the strong independent advocacy support program mentioned before, guarantee the resourcing of specific advocacy to meet needs of people from NESB with disability in all states and territories, including regional, rural and remote areas.

2. About NEDA

The National Ethnic Disability Alliance (NEDA) is the national peak organisation representing the rights and interests of people from non-English speaking background (NESB) with disability, their families and carers throughout Australia. NEDA is funded by the Commonwealth Department of Families, Community Services and Indigenous Affairs (FACSlA) to provide policy advice to the Australian Government and other agencies on national issues affecting people from NESB with disability, their families and carers.

NEDA actively promotes the equal participation of people from NESB with disability in all aspects of Australian society. It manages a range of projects relating to NESB and disability communities and works closely with its state and territory members to ensure that its policy advice reflects the lived experiences of people from NESB with disability. In states and territories where no NESB-disability advocacy agency exists NEDA undertakes development work to establish a structure that can support people from NESB with disability, their families and carers.

NEDA estimates that one in every four people with disability is a person of either first or second generation NESB, representing approximately 1 million people across Australia.

Defining NESB and Disability

NEDA uses the term *Non-English Speaking Background* in preference to *Culturally and Linguistically Diverse Background* as those from an English speaking background are encompassed by the latter term and they are not part of NEDA's constituency. NEDA contends that coming from a linguistic and cultural background other than Anglo-Australian can be a great social barrier and a source of discrimination in Australia. The intention of using NESB is not to define people by what they are not but to highlight the inequity people experience due to linguistic and cultural differences. NEDA also uses the term *people from NESB with disability* rather than *people with disability from NESB* as we consider cultural background (not disability) an appropriate means of developing social identity.

NEDA maintains that disability is a social construct and arises when a society's infrastructure is not developed to ensure all individuals, regardless of capacity or impairment, can fully participate in society. Thus NEDA refers to *people with disability* rather than *people with disabilities* to underline that disability is not a characteristic of an individual but a consequence of a society designed (whether consciously or inadvertently) to exclude many of its citizens from equal participation.

People from NESB with disability in Australia

People from NESB with disability are an expanding population group within the Australian community, and continue to make a significant contribution to social and political life.

The 2003 Survey of Disability Ageing and Carers (SDAC) indicated that approximately 20% of Australians (or around 4 million people) have disability, defined as “any limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities.”¹ The same survey found that the rate of profound or severe core-activity limitation was 6.3%.²

It should be noted that there is some variation between definitions of disability as used by Australian Bureau of Statistics surveys, and as a result strongly variable data on the prevalence of disability in Australia. For example the 2006 Census of Population and Housing asks a broad “need for assistance” question which finds that people with disability make up approximately 4.4% of Australians.³ The 2006 General Social Survey, on the other hand, finds that 13.1% of Australians have a core activity restriction, and a further 5.5% have a “schooling or employment restriction.”⁴

Defining NESB

No consistent method has been developed to measure the number of people from non English Speaking Backgrounds in Australia. NESB may be defined as incorporating people:

- born overseas and whose language or culture is not English or Anglo-Celtic / Saxon
- born here in Australia and the first language or culture of at least one parent is not English or Anglo-Celtic / Saxon
- born in Australia with linguistic or cultural background other than English or Anglo-Celtic / Saxon who wish to be identified as such.

This means that people may fall into the category of ‘Non English Speaking Background’ even if their family has lived in Australia for several generations.

Country of Birth

¹ Australian Bureau of Statistics, *Survey of Disability Ageing and Carers: Summary of Findings*, 2003.

² Australian Bureau of Statistics, *Survey of Disability Ageing and Carers: Summary of Findings*, 2003.

³ Australian Bureau of Statistics, *Census of Population and Housing*, 2006. Note that the ‘non responses’ for this question exceeded the number of people who answered positively that they required assistance of some kind – indicating problems with the survey methodology in this area.

⁴ Australian Bureau of Statistics, *General Social Survey 2006*.

The Australian Bureau of Statistics General Social Survey finds that 17.1% of Australians are born in a country other than Australia or a main non English speaking country.⁵

In isolation, Country of Birth remains a poor indicator of cultural and linguistic diversity, since it does not capture key NESB groups, such born here in Australia and the first language or culture of at least one parent is not English or Anglo-Celtic / Saxon.

Language Spoken at Home

Excluding not stated responses, the 2006 Census of Population and Housing found that approximately 17% of Australians speak a language other than English at home.

Language spoken at home data is useful as it indicates the extent of active non English speaking language use within the Australian population. However it does not capture cultural practices – for example migrant groups that speak English at home but have culture and faith practices that differ markedly from Anglo-Celtic / Saxon Australians.

Ancestry

The 2006 Census of Population and Housing included questions on ancestry. The ancestry questions are useful, as in combination with country of birth and language other than English spoken at home data, the potential exists to accurately estimate the extent of cultural and linguistic diversity in Australia.

Of the responses to the ancestry questions in the 2006 Census of Population and Housing, approximately 28% of responses indicated that one or both parents were born in a Non English Speaking Country.⁶

One Million People from NESB with Disability

NEDA has previously estimated that people from NESB with disability comprise 1 in 20 Australians, or approximately 1 million people. This estimation was based on the assumption that one in every four Australians with disability is a person of either first or second generation NESB. According to the broad finding from SDAC, there are approximately 4 million people with disability in Australia. The Ancestry data quoted above suggests that an estimate of 1 in 4 people with disability from NESB is reasonably accurate.

⁵ Australian Bureau of Statistics, *General Social Survey 2006*.

⁶ Australian Bureau of Statistics, *Census of Population and Housing*, 2006. Excluding Scottish, English, Irish, New Zealand and no stated responses, 6,702, 326 responses indicated that either one parent or both parents were born in an overseas country.

Country of birth data (which excludes born in Australia and the first language or culture of at least one parent is not English or Anglo-Celtic / Saxon) provides a strong representation of people from Non English Speaking Countries amongst people with disability. The 2006 General Social Survey, for example, reports that 18.5% of people with a core activity restriction are born in a non English Speaking Country, while the 2003 Survey of Disability Ageing and Carers found that people born in Non English Speaking Countries accounted for 14.4% of people with disability.

The Age Characteristics of People from NESB with Disability

The prevalence of disability for people from NESB differs from that of other people with disability in relation to age. While the rate of disability gradually increases with age for the general population, there is generally a lower proportion of younger people born in Non English Speaking Countries with disability in Australia, while there is a substantially higher representation at ages above 40 years old (see Chart 1). This means that there is a sharp spike in the prevalence of disability for people from non English Speaking Backgrounds aged above 40 years (see Appendix A).

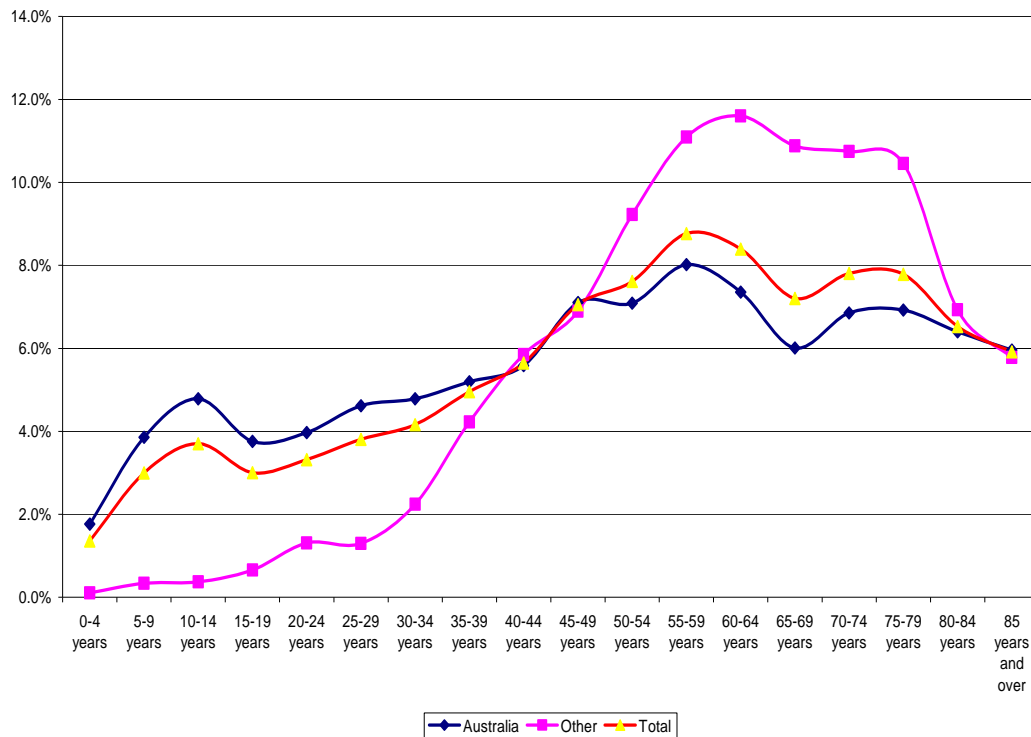
English Proficiency and Disability

There is a higher incidence of disability for people born in a non English speaking country who have low English Proficiency.

Table 1, derived from the Australian Bureau of Statistics General Social Survey 2006, indicates that 25.9% of people aged 18 years and over not proficient in spoken English and born in a non main English speaking country have a core activity restriction as an indicator of disability or long term health condition. This prevalence rate of more than 1 in 4 people with low English Speaking proficiency, is more than twice that of all persons, and more than twice that of people born in Australia.

The correlation of disability and low English proficiency has important implications for policy development.

Chart 1: Age Characteristics of People with Disability by Country of Birth



Source: Brian Cooper, Faculty of Health Sciences, University of Sydney 2008. Derived from Australian Bureau of Statistics, Survey of Disability and Carers 2003.

Table 1: Disability or long-term health condition, by country of birth and proficiency in spoken English

			Born in other country		
	Born in Australia	Born in main English-speaking countries	Proficient in spoken English	Not proficient in spoken English	All persons
PROPORTION (%)					
Has core activity restriction	13.0	13.1	11.0	25.9	13.1
Has a schooling/employment restriction only	5.6	5.3	4.7	7.9	5.5
Has no specific restriction	21.1	22.8	19.6	19.4	21.0
Has no disability or long-term health condition	60.3	58.8	64.8	46.7	60.4

Source: Australian Bureau of Statistics General Social Survey 2006.

3. About this submission

NEDA appreciates the recognition as expressed by the Disability Investment Group (DIG)⁷

‘that current policy settings of all governments are leaving multiple barriers for too many people with disability and their families...These barriers are less to do with particular impairments and more to do with the lack of guaranteed access to customised plans of timely support and development.’

NEDA congratulates the Government for having the vision to pose the question of a transformation of the current failing system into something that will improve the quality of life of people with disability, their families and carers.

NEDA urges the Government however, to use this as an opportunity to develop the best possible care and support scheme and not one limited from the start.

While the Productivity Commission (PC) is charged with the investigation it is disappointing that so little time and resources have been given to the disability sector to provide input into the development of a new system of disability care and support.

This is despite the timeframe for submissions which was extended from June 30 to August 16 and the \$520,000 which was made available for community engagement; both changes were positively received by the sector including NEDA.

While the sector is working hard to develop a coordinated response and produce quality research, the limitations of these are real.

Further, the Terms of Reference (TOR) given to the PC Inquiry are considered limiting also. It is disappointing that the Inquiry is to focus on people considered with severe or profound disability and excludes those with disability acquired as part of the natural process of ageing.

As will be argued in this submission, definitions of disability are first of all highly inconsistent in Australia’s research and policy context and therefore unreliable.

It is also unclear what would happen to those people with disability who are not captured by the restriction of the TOR, is it acceptable that they will continue to have to live with a dysfunctional disability system?

In addition, this submission endorses the view that a transformation of the disability system must be in line with the most advanced thinking about disability.

⁷ DIG, 2009, The Way Forward, http://www.fahcsia.gov.au/sa/disability/pubs/policy/way_forward

This is expressed through the social model of disability and inclusive definitions of disability as articulated in the UN Convention of the Rights of Persons with Disabilities;

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.⁸

RECOMMENDATION 1

That the disability care and support scheme applies the definition of disability in line with the UNCRPD definition.

That this definition explicitly includes psycho-social illness as disability.

Finally, NEDA fears that the prime motivation for the Inquiry is in fact not the problems of the current disability system as it relates to unmet and under-met demand, quality of service delivery and workforce issues but an pre-occupation with cost savings for the future;

‘...there is a very strong argument that the NDIS would prove net-cost beneficial over a reasonably short time horizon (perhaps 10 years after introduction)’

‘On costing, the resulting Scheme (of new incidences of disability and pre-existing disability) on a fully-funded basis was seen to be both beyond an affordable level of acceptability at the present time (as discussed with the DIG), and also probably not necessary to achieve the objectives of the Scheme.’⁹

This appears to be at odds with the objective of a NDIS, National Disability Insurance Scheme which is articulated as:

‘As discussed in more detail later in this report, the objective of the proposed scheme is to provide a range of care and support services to those who need assistance always or frequently as a result of their disability, as determined by a set of consistent eligibility criteria to be developed. The scheme plans to be focused on individual planning and realisation of potential, with a focus on aggregate and individual outcomes.’ p51

Despite and given the concerns and limitations as outlined, NEDA is committed to contribute to the PC Inquiry. The recommendations in this submission are not exhaustive and considered a work in progress.

Listed in this submission are recommendations that would go a long way towards ensuring that any new system of disability care and support will not fail people from NESB with disability.

⁸ UNCRPD, <http://www.un.org/disabilities/default.asp?id=261>

⁹ PriceWaterhouseCoopers, October 2009, DIG National Disability Insurance Scheme: Final Report, p.7

NEDA has been able to and will continue to:

- Draw on previous experiences, research and reports.
- Participate in collaborative discussion with other organisations of persons with disability (DPOs) on coordinated input into the PC Inquiry.
- Jointly organise and facilitate consumer consultation forums together with NEDA member organisations and others.
- Financially support people from NESB with disability to attend and present at the PC public hearings.
- Arrange for consumer consultations after the release of the first PC report.

NEDA recognises that the collaboration with people from NESB with disability; member and other stakeholder organisations and DPOs has been essential in the development of this submission and we are grateful for this collaboration. A list of collaborating organisations is listed in Appendix B.

This submission will articulate some principles which are considered as non-negotiable among DPOs; little or no discussion will be facilitated to substantiate these as they will be repeated in other submissions to the PC. Focus of the submission will be on areas of critical importance to people from NESB with disability.

4. Exclusion of an ethnic based analysis

The PC Inquiry has been set up on the basis of numerous reports issued by the Government assessing the current disability system as it exists in Australia paving the way for change. The two most prominent of these reports are the PricewaterhouseCoopers: National Disability Insurance Scheme - Final Report (2008) and the Disability Investment Group: The Way Forward report (September 2009).

Both of these reports share a complete omission of any ethnic based analysis. Such omission is at odds with the intent to meet the needs of people with disability, unless it is assumed that people from NESB with disability have no other needs than those from English speaking background (ESB).

Any such assumption is wrong when the differing realities for people from NESB with disability are considered.

Disability Data

There has been an inability and/or unwillingness by successive Governments and their respective Departments to improve the data collection, consistency and analysis on disability as it pertains to people from NESB.

This has occurred despite active advocacy for such changes by NEDA and other organisations.

NEDA's dedicated report on data 'What does the data say'¹⁰ highlights the key issues and summarises improvement recommendations.

- Consistency is needed across the identified data collections in regards to defining disability.
The 'need for assistance' approach by the Census is considered not useful in a culturally and linguistically diverse context due to an implied Anglo-centric set of values and assumptions underlying the meaning and concept of 'need for assistance'.
The broad characteristics of the SDAC appear to be the more useful approach in capturing differences in need.
- Consistency is needed across the identified data collections in regards to defining ethnicity.
The combination of the country of birth and ancestry approach of the Census is considered as most useful as it also captures people born in Australia but being raised in a NESB family context.
- The sampling size of the SDAC is inadequate and will not be improved by simple quantitative increase, even doubling.
A proportional, stratified sampling within cultural and language groups would be substantially more effective for informed data analysis.

In the absence of solid data, the realities of people from NESB and ESB are not captured in a way that is reflective of their circumstances. The snowballing effect of such lack of recognition of people from NESB with disability means that this large section of people with disability is effectively excluded from the discourse.

Unfortunately, this is the starting point of the PC Inquiry and the above mentioned reports informing the Inquiry.

To be more crude, the analysis and debate on long term disability care and support so far has been ethnocentric in nature, based on culturally insensitive assumptions, values and beliefs.

Despite the poor data available, it is still possible to extract significant disadvantage for people from NESB, including those with disability.

This chapter outlines some of the barriers that are faced by people from NESB with disability. The issues outlined here reflect the specific issues faced by people who both encounter barriers to participation because of both disability and cultural, linguistic and / or faith background.

Recommendations for improvements are articulated.

¹⁰ NEDA, 2010, What does the data say, <http://www.neda.org.au/page/publications.html>

NEDA notes that people from NESB with disability face many of the other barriers that people with disability also face, including poor access to services, difficulties with mobility and transport, poor access to education and employment, poverty and discrimination. However, people from NESB also face barriers in the context cultural, linguistic and faith differences that overlays and complicates the picture.

In November 2008, NEDA worked with Action on Disability in Ethnic Communities (ADEC) and Diversity and Disability to convene two consumer workshops on the National Disability Strategy.

From May to July 2010, NEDA facilitated a range of consumer consultations in collaboration with member and stakeholder organisations specifically around the questions of the PC Inquiry. These workshops were made possible due to the community engagement funding NEDA received for the PC Inquiry.

The feedback from these workshops has shaped the material in this chapter; where appropriate, quotations from the workshops have also been included.

General Barriers Faced by People from NESB with Disability

People from NESB with disability in Australia on a daily basis encounter entrenched disability and racial discrimination within the disability and mainstream communities, and disability discrimination within their own cultural groups. People from NESB with disability encounter the following barriers:

- lack of accessible information informing about rights, entitlements, essential services and supports structures available;
- lack of culturally competent service provision in mainstream and specialist services;
- lack of interpreters and resources to meet needs;
- prevalence of myth, misconceptions and negative stereotypes about disability and ethnicity;
- lack of effective legislative and policy direction and government intervention.

The impacts on people from NESB with disability, their families and carers include:

- extreme isolation and marginalisation;
- financial vulnerability and fewer opportunities;
- reduced capacity to participate in social, economical, political and cultural life;
- carer burn-out due to lack of appropriate support;
- disregard of linguistic and cultural needs.

It is also important to note that many new arrivals in Australia, particularly refugees, enter the country having little or no education and people with disability have had minimal supports/services, if any. Such people are very often not even aware that services/supports for people with disability, or carers, are available in Australia, and thus are not likely to seek help until they are provided with the information.

In addition, the lack of support for people with disability and their carers in their previous country of residence can mean that they have little or no skills in numeracy and literacy and have low confidence. This often results in situations where people from NESB with disability are unable to exercise independence, being overly protected by their family, who perceive them to be highly vulnerable in public. This sometimes obstructs the person with disability in their intellectual development.

At times, there is a notion of cultural shame that can be observed in association with disability.

One participant noted that the word 'support' is stigmatised and associated with a form of failure.

Another participant stated that in the Karen language it is rude to say 'NO'. It thus may happen that a wrong or misleading answer is provided to avoid such rudeness.

It is thus imperative that people from NESB with disability have access to information that is available to people with disability in general, in their mother tongue and in a way that suits them most, be it visually through DVD productions in various languages, orally via interpreters, or in written translated material made available in Braille, audio and other formats as requested. If implemented correctly, a new disability care and support scheme can go a long way to diminish these barriers.

RECOMMENDATION 2

That the disability care and support scheme makes information available to people from NESB with disability in their mother tongue and in a way that suits them most, be it visually through DVD productions in various languages, orally via interpreters, or in written translated material made available in Braille, audio and other formats as requested.

RECOMMENDATION 3

That the disability care and support scheme includes dedicated funding for community education on disability in linguistically and culturally diverse communities; across all states and territories, regional, rural and remote areas.

Migrants and Poverty

Migrants and refugees are often over represented within low income groups in Australia, with some migration groups experiencing long term financial disadvantage. For example 36.5% of humanitarian entrants have a household income that falls in the lowest quintile of all earners¹¹.

Migration outcomes tend to be better for people from English Speaking Countries. People born in non English speaking Countries are likely to have lower incomes than people born in English Speaking Countries / Australia: for example around 48% of people born in non English Speaking Countries have a weekly income less than \$400; where approximately 31% of people born in Australia are in the same group.

English proficiency also has a bearing on poverty outcomes for migrants. Around 60% of people born in a Non English Speaking Country with low English proficiency have an income level less than \$400 per week¹².

A number of participants in the workshops indicated that limited income remained an ongoing area of concern.

One participant observed that they had to forego other items of expenditure, including food, in order to pay for support services.

Another noted that 'good nutritional food is important for overall health but unaffordable on the DSP' and that they felt 'very tired' dealing with the challenge of living on the pension.

Further, migrant who do find work, largely work in low-paid, casualised contingent labour markets which are more likely to lead to issues of impairment and disability. Therefore the risk on their bodies is more likely to end in a disability; so therefore in a risk-assessment situation they would be extensively disadvantaged in such a system.

It is for these reasons that NEDA does not support a funding system based on risk assessment.

Consultation participants repeatedly noted the problems associated with the DSP. It was suggested that the aim of a disability system should be to avoid people with disability living in poverty and to encourage employment participation. It was observed that the positive step towards employment was important in the long term but that access to the DSP was also important for episodic disability.

¹¹ Australian Bureau of Statistics General Social Survey 2006

¹² ABS Migrants, 2006 Census of Population and Housing

A participant explained how they were working for 20 hours at a fast food outlet despite mental health issues. That this work contributed to their independence and confidence. However, they were informed by Centrelink that the DSP may be cut off due to a new limit of 15 hours work per week. This has increased stress levels and anxiety for the person.

Other participants noted that they were worse off financially working full-time as they lost access to the DSP, health care card and concessions. That they were told informally to work part-time to improve their financial situation.

This is clearly a counter-productive situation not only in the immediate sense but also in the long term as people with disability are prevented from building up a superannuation for retirement.

RECOMMENDATION 4

That the disability care and support scheme guarantees that all people with disability have an income above the Henderson poverty line without compromising access to required support services.

RECOMMENDATION 5

That the disability care and support scheme guarantees that income support payments are flexible to not discourage employment participation. Limits to income support should be dismantled as long as people qualify for income support on the basis of their disability, especially to account for episodic disability.

Concessions must be available to people with disability to counter the higher cost of living regardless of income or assets.

Employment Outcomes for Migrants

In general, some migrants face barriers to accessing employment. Although unemployment rates are generally comparable to the general population for Skilled and Family Visa holders, Humanitarian entrants face additional barriers to getting work (see Table 2)

Table 2: Labour Force Status by Visa Category

	Skilled	Family	Humanitarian
Employed Full-time	66.4	42.7	34.7
Employed Part-time	14.5	20.5	22.7
Unemployed	4.2	4.0	11.7

Source: Australian Bureau of Statistics, General Social Survey 2006.

The barriers faced by some migrants to accessing employment will also broadly affect people from NESB with disability.

Labour Force Participation for People from NESB with Disability

Labour force participation indicates the proportion of people who are actively looking for work or who have a job.

It is acknowledged that labour force participation rates for people with disability in general are poor – nationally at 18.4%, compared to 76.4% for people without a profound / severe core activity restriction.¹³

However the labour force participation rates for people born in a non English Speaking Countries are substantially worse than for those born in English speaking Countries (see Table 3). Labour force participation for people born in a Non English Speaking Country with disability is approximately half that of people born in an English Speaking Country with disability (11.5% and 20.1% respectively).

Table 3: Labour force participation for people with a profound or severe core activity limitation 2006 (per cent)

	<i>NSW</i>	<i>Vic</i>	<i>Qld</i>	<i>WA</i>	<i>SA</i>	<i>Tas</i>	<i>ACT</i>	<i>NT</i>	<i>Aust</i>
ESC	19.5	19.9	19.0	24.0	21.2	15.8	33.8	23.3	20.1
NESC	12.0	9.4	12.9	15.6	10.6	13.7	20.4	17.8	11.5

Source: Productivity Commission *Report on Government Services*, Table 14.41.

Employment Rate for People from NESB with Disability

The employment rate provides an indication of the number of people of working age (15-64) who have a job of some kind (at least 1 hour or more per week).

Once again, it is acknowledged that the employment rate for people with disability in general is lower than that for the population as a whole. The Productivity Commission observes that: “nationally, the estimated employment rate of people aged 15–64 years with a profound or severe core activity limitation in 2006 (86.6 per cent) was below the rate for people without a profound or severe core activity limitation (94.7 per cent).”¹⁴

As indicated in Table 4, the employment rate for people born in a non English Speaking Country (82.3%) is significantly below that of people born in an English Speaking Country (87.1%).

¹³ Productivity Commission *Report on Government Services*, Table 14.38

¹⁴ Productivity Commission *Report on Government Services*, 14.61

Table 4: Employment Rate for people with a profound or severe core activity limitation, 2006 (per cent)

	<i>NSW</i>	<i>Vic</i>	<i>Qld</i>	<i>WA</i>	<i>SA</i>	<i>Tas</i>	<i>ACT</i>	<i>NT</i>	<i>Aust</i>
ESC	86.1	86.6	85.9	90.4	89.0	87.6	91.4	91.4	87.1
NESC	79.3	82.7	84.0	90.2	84.6	78.3	83.5	85.7	82.3

Source: Productivity Commission *Report on Government Services*, Table 14.41.

The above data indicates that the unemployment rate for people from NESB with disability is above 17.5%, or more than three times higher than the general population. .

RECOMMENDATION 6

That the disability care and support scheme works across Government departments to establish dedicated systems of entry into the workforce for people with disability. These should include targets for those from NESB, at a minimum to be 25% as per population groups; included needs to be targets for gender equity.

That the Scheme explore mechanisms such as tax incentives and fines to establish such entries.

That opportunities for work experience be considered with a conscious avoidance of exploitation.

Experiences of Poor Cultural, Linguistic and Social Inclusion

The experience of social, cultural, linguistic and religious inclusion for people from non English Speaking backgrounds, will impact upon employment outcomes for all people from NESB, particularly incidences of racism and discrimination, anti immigration sentiments and Islamophobia.

All migrants face these obstacles - for example, a longitudinal study of skilled migrants found that “more than 40 per cent arrivals thought that there was either a lot of racism or at least some racism in Australian society.”¹⁵ Further people from NESB tend to not score as well on typical measures of social cohesion, for example feelings of safety and trust; and ability to call on friends and neighbours for support.¹⁶

A key issue that arose in the workshops, was the need to substantially improve the availability of interpreters in order to facilitate cultural inclusion, and allow NESB communities to access key services.

¹⁵ Commonwealth of Australia, “New Migrant Outcomes” August 2007

¹⁶ Australian Bureau of Statistics, *General Social Survey* 2006.

NESB Access to Disability Employment Support Services

Employment services either provide supported employment opportunities for people with disability or offer support to access employment in the open labour market.

People from NESB with disability have traditionally experienced poor access and utilisation of Government funded employment services (see Table 5). The Productivity Commission noted in 2008 that: “the proportion of people born in a non-English speaking country who used CSTDA funded employment services in 2005-06 (1.9 service users per 1000 people aged 15–64 years) was lower than the proportion of people born in an English speaking country who used these services (5.6 service users per 1000 people aged 15–64 years).

In the consumer workshops, a number of participants observed the need to provide language support to migrants, particularly in relation to education and training, and use of information technology. Participants also observed that many support services do not focus on building employment skills.

Table 5: Users of CSTDA employment services, per 1000 people, by country of birth 2005-06

	<i>NSW</i>	<i>Vic</i>	<i>Qld</i>	<i>WA</i>	<i>SA</i>	<i>Tas</i>	<i>ACT</i>	<i>NT</i>	<i>Aust</i>
NESC	1.3	2.8	2.3	1.8	1.6	2.4	1.2	1.7	1.9
ESC	5.4	6.0	5.5	5.4	6.3	6.3	3.9	2.7	5.6

Source: Productivity Commission *Report on Government Services*, Table 14.31.

RECOMMENDATION 7

That the disability care and support scheme provides for access to NESB specific disability employment services for people from NESB with disability and requires mainstream disability employment services to set targets for people from NESB with disability.

RECOMMENDATION 8

That the disability care and support scheme works across Government departments to ensure that the current 510 hours provided for people from NESB to learn English is increased for people with disability. That the hours are doubled at a minimum and extended further if assessed as beneficial.

NESB Access to Accommodation Support Services

People from NESB with disability do not have equal access to funded supported accommodation in Australia.

While approximately 1 in 5 people in Australia are born in a Non English Speaking Country, less than 1 in 20 people from a Non English Speaking Country receive CSTDA funded supported accommodation services.¹⁷ This means of the 33,787 people participating in supported accommodation programs nationwide, a mere 1,787 of these people were born in a Non English Speaking Country (see Chart 2).¹⁸

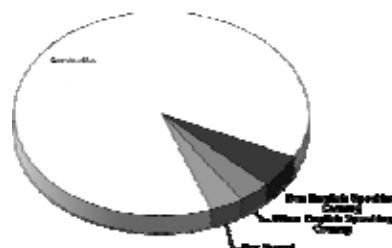
The effect of this is a lower proportion of people from NESB with disability in the community who access supported accommodation services: in effect, a person born in Non English Speaking Country with disability is more than 3 times less likely to be receiving supported accommodation than a person born in an English speaking country.¹⁹

Equal participation for people from NESB with disability has not substantially improved over time. People from NESB with disability face historical exclusion from supported accommodation in Australia, with no substantial improvements over this period to increase the number of people from NESB with disability accessing supported accommodation services.

In the consumer workshops, many participants noted the need to improve support services for people from NESB with disability. The need to target information more effectively was also highlighted. One participant observed that they were not made aware of the availability of disability services for close to two decades: “We didn’t know about the services the government provided.”

NEDA urges the Australian Government to take seriously the poor access to supported accommodation services for people from NESB with disability. This means working with states to improve cultural competence of services across information, assessment, service delivery models, and quality assessment, and where present, addressing discriminatory policies.

Chart 2: Users of CSTDA Supported Accommodation by Country of Birth



Source: Australian Institute of Health and Welfare, Users of CSTDA-Funded Services 2005

¹⁷ Derived from Australian Institute of Health and Welfare, Users of CSTDA-Funded Services, 2004-05.

¹⁸ Australian Institute of Health and Welfare, Users of CSTDA-Funded Services, 2004-05

¹⁹ Derived from Productivity Commission, Report on Government Services, 2007.

Migration Rights

Potential migrants and refugees to Australia are subject to a health assessment in order to determine their eligibility. In most cases (including for humanitarian entrants), the assumed future costs associated with a health condition or disability are taken into account as part of the assessment procedure.

This means that migrants and refugees with disability are routinely refused entry to Australia as a result of an assessment of the potential health costs associated with their illness or disability. It also means that many families supporting people with disability make a difficult decision to leave behind a family member in order to build a life in Australia. In cases involving humanitarian entrants, these family members with disability will remain in extremely vulnerable situations, having also been displaced by war, persecution, or civil unrest, but unable to join their families in Australia.

In early 2008 NEDA sought legal advice on the consistency between the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and key issues affecting refugees and migrants with disability. The advice found that the current Australian migration health test is at odds with the equal protection obligation under Article 5 of UN CRPD, leading to unjustifiable indirect discrimination for some refugees and migrants with disability.

More recently in June 2010, the Joint Standing Committee on Migration (JSCM) released a report 'Enabling Australia'²⁰. In the report the JSCM argued for substantial administrative changes. While these changes are positive they fail to call for a full application of the Disability Discrimination Act 1992 to the Migration Act 1958. Exempting legislation designed to protect the rights of a given group effectively leaves any such groups of people without rights.

In the workshops, one participant noted that the "immigration issue has been around for more than 50 years." NEDA strongly believes that the time has come to shift Australia's policy in relation to migration rights for people with disability.

Income support for migrants

Migrants with disability granted visa status (except for those immigrating on humanitarian grounds) must wait ten years before being eligible for the Disability Support Pension (DSP). Eligibility for DSP affects eligibility for other programs, such as essential disability services and equipment. As a result, migrants with disability are unable to access appropriate financial support, or a range of services and support that are available to other Australian residents with disability.

²⁰ JSCM, 2009, Enabling Australia,
<http://www.aph.gov.au/house/committee/mig/disability/report/Final%20report.pdf>

Legal advice released by NEDA in July 2008 suggests that the ten year qualifying period for the Disability Support Pension is at odds with the obligations of the ratified United Nations Convention on the Rights of Persons with Disabilities. In NEDA's view, the ten year qualifying period for the DSP is both unfair and discriminatory.

NEDA's submission to the PC is an alarming call for people from NESB with disability to be recognised and specifically considered for any future transformation of the disability care and support scheme.

This means a commitment to targeting planned strategies to achieve results for people from NESB with disability, using specific strategies where appropriate, and measuring achievement of results.

Application of a Substantive Equality framework would ensure consistency in existing laws and agreements pertaining to disability, such as the Disability Discrimination Act (DDA), the National Disability Agreement and Strategy as well as those that are not disability specific, including the Equal Opportunity and Race Discrimination law.

RECOMMENDATION 9

That the disability care and support scheme follows principles of *Substantive Equality* in order to address real equality gaps for population groups including people from NESB with disability.

That the disability care and support scheme works across Government to ensure that the Disability Discrimination Act 1992 (Cth) is applied to all Federal Acts, including the Migration Act 1958 (Cth) and the Social Security Act 1991 (Cth).

5. A rights based approach

The discourse and analysis of a long term care and support scheme for people with disability needs to move towards a rights based approach.

People with disability have the same rights to a self determined, fully accessible life that guarantees full human rights than any other person.

It is the role of Government and its bureaucracy to ensure that people with disability are able to achieve this through elimination of existing barriers.

These rights are expressed most clearly through the UNCRPD which Australia ratified in 2008.

The recommendations in this submission are guided by the UNCRPD with a view of addressing barriers that demand to be dismantled.

RECOMMENDATION 10

That the UN Convention (UNCRPD) is the framework for the design and implementation of a new system requiring a significant cultural paradigm shift based on a social model of disability.

RECOMMENDATION 11

That the disability care and support scheme is designed to allow people with disability to live a self determined, fully accessible life that guarantees full human rights. This is regardless if care and support is required frequently, infrequently, episodically or on an ongoing basis.

6. Systemic Issues

Market language

The discussion in the DIG and PricewaterhouseCoopers report heavily rely on the concept that the market will be the most appropriate approach to deliver services based on the notion of demand and supply.

NEDA takes issue with this approach and is not convinced that the market can adequately deliver services for the following groups of people amongst others:

- people with disability living in regional, rural and remote areas
- people from NESB with disability
- Aboriginal and Torres Strait Islander people

The example of the Northern Territory notes the lack of service provider presence and the need to offer options to people in rural and remote areas as the reason to introduce Individual Support Packages²¹.

NEDA suggests that any disability care and support scheme needs to provide certain guarantees of equity and sustainability in service delivery for all people with disability regardless of personal characteristics or geographic location.

RECOMMENDATION 12

That the disability care and support scheme guarantees equity and sustainability in service delivery and outcomes as part of its design, implementation and monitoring.

²¹ Department of Families, Housing, Community Services and Indigenous Affairs, 2009, *Occasional Paper 29: Effectiveness of Individual Funding Approaches for Disability Support*, viewed online at: <http://www.fahcsia.gov.au/about/publicationsarticles/research/occasional/Documents/op29/default.htm>

Disabling Systems

While it is recognised that a new scheme is not in a position to address all issues, there needs to be commitment and processes in place in order to address matters including disabling environments, structures, legislation and regulations. Such approach is in line with the UNCRPD and thus part of the obligations of signatories.

Here it is suggested that racism, systemic and individual, is inherent in departments, organisations and the community. The social and personal costs of racism in combination with disability, remains unexplored.

In the workshops, experiences of racism were repeatedly raised as an issue. It was articulated that racism negatively affects people from NESB with disability emotionally and in a practical sense; denying them access to services.

One participant stated that People said that ‘service providers need to be more patient with people and not rush them through their services’.

Further, it needs to be pointed out that the current exemption of the Disability Discrimination Act from the Social Security Act and the Migration Act are considered inconsistent with the intend and direction as articulated in the UNCRPD.

RECOMMENDATION 13

That the disability care and support scheme is allocated authority and situated in Government in such a way that empowers it to resolve current existing disabling systems with a view to allow all people with disability full participation and self-direction in daily life.

That the PC Inquiry research into the additional cost of disability caused by disabling systems including racism.

7. Generic issues

As indicated earlier NEDA is supportive of generic aspects and principles of a disability care and support scheme that apply to all people with disability. For the purpose of focus of this submission these principles are not discussed in detail as they will be repeated by others.

RECOMMENDATION 14

That the disability care and support scheme is governed by an independent body with a majority of people with disability and DPOs (organisations of persons with disability), including representation from people from NESB with disability. Governance at all levels is made up in this way.

It is recommended that this body be established as soon as possible to be effective and give direction as part of the planning and development process of a new scheme.

RECOMMENDATION 15

That the disability care and support scheme is:

- a) Based on entitlement for all who are eligible.
- b) Properly funded to address additional costs related to disability so that a person is able to have full enjoyment of their human rights.
- c) Based on equity for all who are eligible.
- d) Takes into account the impact of gender, indigenous background, cultural and language diversity and specific needs of children.
- e) Based on self determination.
- f) Committed to the empowerment of people with disabilities.
- g) Portable (a national scheme).
- h) Responsive to changing circumstances of an individual over their lifespan.

RECOMMENDATION 16

That all existing obligations and commitments to non-discrimination and inclusion of people with disabilities are maintained outside this scheme – i.e. – costs not to be shifted to individuals and preventative mechanisms put in place to prevent this happening.

RECOMMENDATION 17

That the disability care and support scheme will form a major initiative under the National Disability Strategy.

RECOMMENDATION 18

That the disability care and support scheme includes a strong independent advocacy support program, separately funded under the scheme to support and protect the rights and interest of people with disabilities eligible for funding.

RECOMMENDATION 19

That the disability care and support scheme guarantees transparency in funding arrangements and appropriate consumer rights protection mechanisms.

RECOMMENDATION 20

That the disability care and support scheme be funded as a social health insurance model via a levy on taxpayers.
This needs to allow for scope for growth and change as necessary, and protection from financial downturns to ensure stability of support.

8. Critical issues

Eligibility

Discussion

Currently people from NESB with disability are highly disadvantaged when it comes to access care and support as it applies to their disability. The ten year waiting period for access to the Disability Support Pension (DSP) prevents this group of people an opportunity to offset higher costs of living due to disability. Further however, access to the DSP is often an eligibility requirement in order to qualify for access to other disability support services. This access is denied to the people who are affected by the ten year waiting period.

This is a major inequity and must not be continued in a new scheme.

People from NESB contribute to Australian life significantly, through culture and economics. They do so regardless of their visa status for instance through the relatively new 457 visa category. However, despite their contributions access to disability services is denied to these people and their families. This is a major equity and human rights issue.

Access to disability care and support is a human right and compliant with the UNCRPD; it thus needs to stay clear from any restrictions that can potentially compromise this right.

RECOMMENDATION 21

That the disability care and support scheme be eligible to all people with disability regardless of:

- **type or severity of disability**
- **age**
- **income or assets**
- **citizenship or residency status, including those awaiting decisions**
- **institutional settings including correctional service system or boarding/rooming house**

No other restrictions or waiting periods shall apply.

Assessment

Discussion

Currently people with disability are assessed under a medical model of disability. If the new disability care and support system aims to be transformational in character it must embrace the social model of disability.

A critical test of such application will be in the assessment stage.

In addition, there are issues around cultural ignorance with current assessment tools. Assessment tools are largely ethnocentric, unable to take into account different experiences about impairments and disability for people from NESB, from a different cultural background.

One example provided in the workshops was the difficulty of proving and obtaining medical records required in some assessment processes.

Participants also repeatedly articulated the stress and anxiety but also the expenses they endured due to repetitive assessment processes.

NEDA endorses the view that the starting point of assessment should be self-assessment, accepting that people with disability have the best knowledge of their whole-of-life circumstances and what it takes for them to live a fulfilling life.

Self-assessment will avoid mistakes in the assessment process which often is more costly to redress if undetected for a lengthy period of time.

Self assessment allows for inclusiveness when it comes to gender, culture, language and faith based needs. Interpreters and translations must be offered in a pro-active manner rather than waiting for a person with disability or their family to ask for such.

Here it is important also that the assessment is conducted in an environment and at a location of choice by the person with disability. Scope for requests reassessment needs to be available to people with disability.

For people who are unable to or wish to involve family and friends as part of the assessment need to be given the opportunity to do so.

Assessors must be independent from the service delivery sector and must be qualified, culturally competent. Where possible and desired assessors should be of the same ethnic background as the person with disability; as long as no conflict of interest exists.

RECOMMENDATION 22

That the disability care and support scheme develops a nationally consistent assessment process on the basis of:

- **self determination of need**
- **empowerment**
- **recognition of gender, cultural or faith based needs including the pro-active offer of professional interpreters**
- **assessment to be conducted at a location where the individual is most comfortable**
- **reassessment can be initiated by person with disability**
- **assessors must be qualified in cultural competence**
- **safeguards must ensure against abuse or violation of rights**

Individual funding

Discussion

NEDA supports the concept of individualised funding which was requested in the consultation workshops. However, this needs to be on a voluntary basis with options to opt-in and out when required.

People with disability requested access to information from a one-stop shop. The advice needs to be separate from the service provision to avoid conflict of interest.

A model like the Western Australian Local Area Coordination appears to be useful to this effect; calling it a Disability Resource centre might be more appropriate.

Emphasis is put here in the independence of the information and advice to allow people with disability to make informed decisions. As noted earlier, all staff need to be culturally competent and if possible bi-lingual especially in areas with high concentration of particular language groups.

Individual funding must be flexible and responsive to the whole-of person circumstances. That is needs based on gender, culture or faith must be included.

One participant noted the need to visit the cemetery regularly for cultural and faith based reasons; however that she was unable to do so unassisted. That individualised funding should allow her to determine such needs.

RECOMMENDATION 23

That the disability care and support scheme embraces individual or self-directed and managed funding as part of an empowerment strategy for people with disability.

However, this funding must be voluntary with opportunity to opt-in and opt-out as required.

That the disability care and support scheme fully fund advisors, independent from the service system for people with disability to guarantee informed decision making with unlimited access.

That safeguards are developed to ensure against abuse or violation of rights.

The level of funding entitlements must be designed to support full participation in all areas of life, political, social, cultural, religious and economic, as set out in the UNCRPD.

Whenever, individualised funding is not chosen or the person with disability is not able to make a choice the disability care and support scheme must be guaranteed access to a fully equipped and accessible service system.

Social relationships

Discussion

Participants highlights repeatedly that they felt isolated and were yearning for opportunities to build up social relationships and networks.

It was state that they 'need a place where people can come once or twice a week for learning , doing activities, opportunities for people to come together'.

At the same time it was stated that limited resources for transport and support workers hinders people with disability to participate in activities.

It is beyond question that social relationships and peer support will have a positive effect on self confidence and increase social skills

RECOMMENDATION 24

That the disability care and support scheme be responsive to whole-of person needs including the need to develop social relationships.

That funding is allocated for regular, ongoing social activities, including transport and supported assistance.

NESB Disability Targets

Discussion

A new disability and care scheme offers an opportunity to deliver a spectrum of targeted strategies that improve delivery of services to people from NESB with disability.

While some people from NESB with disability will take up individual funding as it is rolled out, others will not. It is critical that for the latter a fully equitable and accessible, government funded service system exists with real access to people from NESB.

RECOMMENDATION 25

That the disability care and support scheme develop a national plan with targets for improving access and utilisation for people from NESB to government funded disability services.

Service Obligations

Discussion

As documented earlier, the data on utilization rates for people born in a non English speaking country suggest that disability services in Australia have not been adequately monitored to ensure they meet the needs of the whole community.

Service obligations would bind services who receive public funds to improve the representativeness of the delivery of services to people from NESB, with a long term goal to ensure that all people from NESB with disability are able to access the services they are eligible for.

RECOMMENDATION 26

That the disability care and support scheme build obligations into service level contracts to improve representation of people from NESB communities using disability services.

Cultural Competence

Discussion

Internationally, human service agencies and providers have used a *cultural competence* framework in order to improve their effectiveness in meeting the needs of people from culturally and linguistically diverse backgrounds.

Essentially, cultural competence is about acceptance and respect for cultural diversity at the individual, organisational and systemic levels. Its aim is to develop the capacity of services to respond meaningfully to diversity in the communities they serve. Key strategies using this approach include:

- Affecting cultural change in the organization through continual education and training.
- Involvement of NESB consumers in planning and governance of organisation.
- Use of tools to evaluate the cultural competence of service information, community education and referral, assessment processes, service delivery, complaint and feedback measurement, service planning and policy and quality assessment.
- Service by service examination of need to provide specialist cultural and language appropriate services through employment of bilingual workers and recruitment of people from NESB in order to best service target group.

One participant noted that culturally appropriate food is important 'my body craves for it'.

Participants highlighted the need to be formally addressed for some cultures. That service providers and staff ask a person from NESB with disability how they wish to be addressed rather than assuming the common ethnocentric form of address. As such, participants stated that calling someone by their first name, 'darling' or 'little boy' was degrading and disrespectful for them.

RECOMMENDATION 27

That the disability care and support scheme applies a cultural competence approach as part of its design, implementation and monitoring processes.

Workforce Issues

Discussion

Participants repeatedly noted issues with the quality of services they received. While this was partly attributed to a lack of cultural understanding there were also general comments with respect to qualifications of disability workers.

NEDA is concerned about issues of staff qualifications, recruitment, retention and pay equity issues in the disability sector.

It is doubtful that a major transformation of the disability care and support system can occur in isolation without ensuring a guarantee of qualified staff.

Participants noted the problems of the shortage of support workers in general and in particular accessing support workers who are culturally aware and respectful or from NESB, let alone from specific language or cultural groups.

It was noted that with age many people from NESB with disability will regress to their first language. In these discussions the suggestion of access to support workers from overseas was made.

A participant noted that 'support workers are paid peanuts. That is disrespectful'.

RECOMMENDATION 28

That the disability care and support scheme works across Government departments to:

- **ensure the development of a solid and qualified workforce;**
- **guarantee funding for up-skilling and retraining of staff on an ongoing basis;**
- **support and fund pay equity in the non-Government community and disability sector in line with the Government sector;**
- **support a migration strategy to attract support workers from NESB.**

Language assistance

Discussion

One of the key barriers to access for people from NESB with disability is a lack of awareness of the availability of support and services, and a lack of language and culture appropriate assistance to people with disability, families and carers to navigate the service system and secure services. Improved access to translated material and language assistance can assist people to access and utilize the services they are entitled to, particularly where English language proficiency is the main barrier to service access.

Cultural barriers that prevent people accessing services – eg stigma and lack of awareness of support system – can be also addressed by outreach to diverse communities and community education strategies.

At a basic level:

- All service providers should be resourced to provide translated material in relevant community languages about their service
- All service providers should be able to provide language assistance when offering information, at assessment, during service delivery, and in feedback and quality assurance.
- Within existing resources, Service Providers, information providers and advocacy providers have a responsibility to work with culturally diverse communities to provide education on disability and the support system in Australia.

RECOMMENDATION 29

That the disability care and support scheme ensures that all services are able to provide information in relevant community languages, are able to provide language assistance and access to translators, and engage in community education to diverse communities.

Funding for language services must be kept separate from individual funding under all circumstances and should be made available from different sources outside a disability care and support scheme. Access to information and communication in a preferred language is a human right and thus non-negotiable.

Flexibility and Service Coordination

Discussion

Many people from NESB with disability do not participate in government funded disability services because they are inflexible, difficult to coordinate, and ultimately are unable to take into account cultural needs.

For example, some people from NESB are reluctant to accept a 'place' in supported accommodation programs because they are unable to stay in touch with their family and cultural and linguistic community, have limited control over food and surrounding environment, or may not be able to easily observe religious and spiritual practices.

NEDA supports design of a service system around meeting the need of individuals first. This means being able to working to design and coordinate the delivery of supports that also take into account the cultural and linguistic needs of the individual. In many cases a more individualized approach to funding and delivering services would assist people from NESB with disability to better design services to meet needs.

RECOMMENDATION 30

That the disability care and support scheme build adequate service coordination and flexibility to tailor service deliver to meet the needs of individuals.

Data and Research

Discussion

As illustrated earlier, data on the use of services by people from NESB with disability is poor. Accommodation support and employment services report on country of origin of clients, but no data is available relating other incidents of service across government funded disability services relating to country of birth, and no data is available relating people from NESB who are born in Australia but raised in a non English speaking context (ie second generation NESB).

There is a strong need for a research agenda that will address how to improve services to people from NESB with disability within the Australian context. This sort of research can develop tools for use within Australia, and look to trialling new models for linguistically and culturally diverse communities.

RECOMMENDATION 31

That the disability care and support scheme improve available data and research on utilisation of services and service needs of people from NESB with disability.

That the disability care and support scheme is allocated authority and situated in Government in such a way that empowers it to:

- **Review current data collection by service providers with a view to improving availability of data relating people from NESB, including second generation NESB.**

- **Amend the reporting requirements under the National Disability Agreement (NDA) to include people from NESB with disability as a priority research area.**
- **Work with agencies such as the Australian Bureau of Statistics and Australian Institute of Health and Welfare to refine the sophistication of data relating to people from NESB with disability and to make them consistent, nationally.**
- **Collect, analyse and report on disaggregated data in regards to gender, language, culture and location. To include benchmarks and measurement of progress over time.**

Multicultural Advocacy

Discussion

Specialist multicultural advocacy providers exist in different state and territory jurisdictions, although funding for these providers is often limited, with some states and territories lacking access to this support (e.g. Australian Capital Territory, Northern Territory, Tasmania).

Multicultural advocacy providers play an important role in:

- Providing culturally appropriate advocacy to people from non-English speaking backgrounds with disability.
- Assisting mainstream advocacy providers to become culturally competent.
- Working with governments and services providers to improve their responsiveness to people from NESB with disability.

NEDA also supports an enhancement to the program in order to address gaps in resourcing for multicultural advocacy in some states and territories.

RECOMMENDATION 32

That the disability care and support scheme as part of the strong independent advocacy support program mentioned before, guarantee the resourcing of specific advocacy to meet needs of people from NESB with disability in all states and territories, including regional, rural and remote areas.

9. Conclusion

People from NESB with disability continue to make a profound contribution to Australian life. However there are significant barriers for people from NESB participating in social and economic life and accessing rights, which is a result of both *disability* and *ethnicity*.

These barriers were discussed in this submission.

The recommendations outlined provide common sense directions towards improving outcomes for people from NESB with disability.

NEDA believes that disability is a lived experience by the Australian populace similarly to the experience of health. It is therefore entirely possible to achieve understanding among the wider population for the need of a disability care and support system that is rights based following a social model of disability.

NEDA looks forward to working with the Australian Government and the Productivity Commission to achieve the articulated and much needed change in the disability system.

Appendix A : People with Disability by Country of Birth and Age.

	Australia		Main English-speaking countries		Other countries		
Age of person	Count	%	Count	%	Count	%	Total
0-4 years	52,475	98.12%	1,007	1.88%	-	0.00%	53,482
5-9 years	114,986	97.24%	2,510	2.12%	751	0.64%	118,247
10-14 years	142,578	97.57%	2,587	1.77%	966	0.66%	146,131
15-19 years	112,054	94.63%	2,276	1.92%	4,084	3.45%	118,414
20-24 years	118,273	90.36%	4,326	3.31%	8,285	6.33%	130,884
25-29 years	137,584	91.64%	4,778	3.18%	7,779	5.18%	150,141
30-34 years	142,534	86.81%	12,060	7.35%	9,598	5.85%	164,192
35-39 years	154,761	79.14%	14,674	7.50%	26,128	13.36%	195,563
40-44 years	166,452	74.66%	27,962	12.54%	28,534	12.80%	222,948
45-49 years	211,794	76.09%	28,539	10.25%	38,025	13.66%	278,358
50-54 years	211,332	70.35%	35,221	11.72%	53,864	17.93%	300,417
55-59 years	238,907	69.05%	37,013	10.70%	70,068	20.25%	345,988
60-64 years	219,254	66.19%	43,552	13.15%	68,432	20.66%	331,238
65-69 years	179,151	63.04%	43,572	15.33%	61,473	21.63%	284,196
70-74 years	204,313	66.32%	34,815	11.30%	68,939	22.38%	308,067
75-79 years	206,241	67.14%	37,656	12.26%	63,291	20.60%	307,188
80-84 years	190,643	74.03%	29,723	11.54%	37,169	14.43%	257,535
85 years and over	177,607	76.09%	35,490	15.21%	20,311	8.70%	233,408
	2,980,939		397,761		567,697		3,946,397

Source: Brian Cooper, Faculty of Health Sciences, University of Sydney, 2008. Derived from Australian Bureau of Statistics, Survey of Disability and Carers 2003.

Appendix B

List of collaborating organisations

The National Ethnic Disability Alliance (NEDA) acknowledges the following member and stakeholder organisations as well as their consumers who provided valuable input into the community engagement consultations.

- Action on Disability Within Ethnic Communities (ADEC) (VIC)
- Amparo Advocacy Brisbane (QLD)
- Ethnic Disability Advocacy Centre (EDAC) (WA)
- MALSSA Incorporated (SA)
- Multicultural Council of Tasmania (MCoT) (TAS)
- Multicultural Disability Advocacy Association (MDAA) (NSW).

NEDA greatly appreciates the consultative advice provided to the community engagement project by the following stakeholders;

- Canberra Multicultural Community Forum- CMCF;
- Children with Disability (CDA);
- Ethnic Child Care Family and Community Services Co-operative Limited (ECCFCS);
- Multicultural Aged Care SA (SA);
- Multicultural Community Services of Central Australia (MCSCA) (NT);
- Multicultural Mental Health Australia (MMHA);
- Network of Refugee and Immigrant Women Australia (NIRWA);
- Refugee Council of Australia (RCOA);
- Spectrum Migrant Resource Centre (VIC)
- Women With Disability Australia (WWDA);