Cultural Rights in Care and Support

Ensuring Equitable Outcomes for People from Non English Speaking Backgrounds to the Proposed National Disability Insurance Scheme

Multicultural Disability Advocacy Association of NSW

National Ethnic Disability Alliance

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Four Key Rights Principles for Inclusion of People from NESB with Disability

Principle 1

Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity (Article 3 (d) UN CRPD)

Principle 2

All persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law (Article 5 (1) UN CRPD).

Principle 3

Prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds (Article 5 (2) UN CRPD).

Principle 4

Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture (Article 30 (4) UN CRPD).

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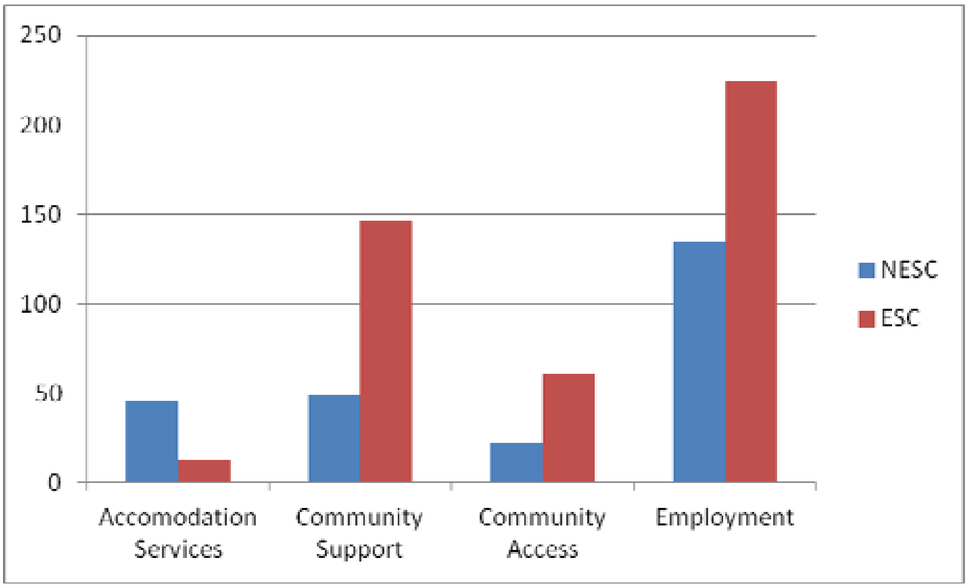
1. Introduction

The Productivity Commission have proposed a substantial change to the funding and delivery of support services to people with disability in Australia through a National Disability Insurance Scheme (NDIS). While many details of the scheme remain unresolved, there is evidence of strong support for the scheme from people with disability and service providers.

A national insurance scheme has the potential to provide entitlements to groups that currently face difficulty accessing services. ABS data suggests that 23.7% or 1 in 4 people with disability are from a Non English Speaking Background (NESB). People from NESB with disability make an active contribution to all aspects of Australian life. However there is evidence that people from NESB with disability do not utilise or are unable to access support services available to other people with disability, and as a result face barriers to full social and economic participation (see Chart 1).[1]

Chart 1: Participation in Disability Services by Country of Birth per 1000 Potential Population.



Source: 2010 *Productivity Commission Report on Government Services*

The proposed NDIS should aim to respond positively to the needs of NESB consumers. However the Productivity Commission draft report makes no substantive recommendations that aim at improving participation and outcomes for these consumers.

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[1] The 2010 *Productivity Commission Report on Government Services* identifies that people born in a non English Speaking Country are significantly less likely to receive Accommodation, community support, respite, community access and employment services than those born in English speaking Countries (see Chart 1). The labour force participation rate for people born in a non English Speaking Country with a profound or severe core activity restriction is 11.5%, roughly half that for people born in an English Speaking Country (ROGS 2010).

In the draft report the Commission acknowledged that the current system particularly disadvantages people from a non-English speaking background (p 50). However, the Commission has only suggested weak strategies to improve outcomes for people from NESB with disability, limited to information and referral:

> The provision of information and referral services should take account of cultural and lingual diversity, for example by working with existing community liaisons, particularly in non-English speaking and Indigenous communities. The importance of these contacts would be paramount during the implementation of the NDIS, as well as any other time of service and scheme reform. (Productivity Commissioner, 2011, p. 3.9)

MDAA and NEDA have argued in numerous forums that accessible information is a prerequisite for consumer power and choice. Without a strategy to enhance service access for people from NESB, the inequity between English-speaking backgrounds (ESB) and NESB will remain unchallenged or increase under an NDIS.

This submission makes five proposals aimed at ensuring that the proposed long term care and support scheme is responsive to the needs of people from NESB with disability.

Proposal 1: A Right to An Interpreter

The long term care and support scheme is based on well-informed consumers exercising their individual choices . A long term care and support scheme must make provision to fund interpreting services, either as a cost to be worn by providers, or through the use of an interpreting scheme. Interpreting costs should not be carried by low English proficiency consumers. This submission contains a proposal for the **extension of free TIS National services to NDIS participants, at a cost of $51 million per annum**. Availability of funded interpreting services is consistent with the obligations imposed by Article 21 of the Convention on The Rights of Persons with Disability.

Proposal 2: Rights for Non Residents

Some non permanent residents should be entitled to access the proposed NDIS. There are compelling reasons for allowing some non residents to access care and support services, including meeting basic rights under international human rights obligations, and the minimal expected impact of costs which could be reasonably accommodated by Australia.

This discussion paper recommends that **NDIS services be made available to non residents** including:

- All children
- Asylum seekers and persons granted refugee status
- Individuals who have applied for permanent residency
- Temporary Business Sponsored Migrants (457 holders)
- International students

It is also proposed that the Australian Government take steps to **establish reciprocal care and support agreements** to enable eligible non residents to utilise NDIS services, and guarantee coverage for Australians residents with disability overseas.

Proposal 3: A Right to Employ a Family Member as a Support Worker

International evidence suggests that the right of persons with disability to employ a family member is an important aspect of developing a culturally competent individualised care and support scheme, particularly where choice is limited for people with disability to attain a culturally and linguistically appropriate service. Relying on ‘natural supports’ such as unpaid carers disadvantages women who continue to deliver unpaid caring roles. The long term care and support scheme must not further disadvantage women from either English or non English speaking backgrounds. A recent decision by the New Zealand High Court also suggests that preventing qualified family carers from providing paid care and support to a person with disability is discriminatory both to the family member and the person with disability. Given the importance of this issue for people from culturally diverse people with disability, it is proposed that there be **a trial of the employment of family members for people from NESB with disability under self-directed funding** to assess its risks, advantages, disadvantages

Proposal 4: A Right to Culturally Competent Person Centred Support

While a more person centred disability service system is long overdue, international evidence suggests that individualised funding arrangements will not be effective for people from NESB with disability unless they are designed to respond to diverse needs. Cultural competence approaches have been effectively used in human service provision in the UK and the USA. This discussion paper proposes that the Australian Government **build a culturally competent NDIS** to improve outcomes for people from NESB with disability and other groups by:

- utilising established **cultural competence principles** to shape governance, planning, staff and training, data and quality management.
- **block funding multicultural support organisations** to offer choice to individuals in terms of brokerage and direct support organisations
- developing strong guidelines and support in relation to the availability of **accessible translated material** on the Scheme and entitlements.

Note that other proposals within this discussion paper – including the right to interpreter services and advocacy – are interconnected with a culturally competent service system.

Proposal 5: A Right to Advocacy

Given the role of individual and systemic advocacy in enabling people with disability to navigate mainstream and specialist disability services, and access rights, there is a strong case for any new scheme to also meet the advocacy needs of consumers as an integrated facet of long term care and support. Governments currently fund multicultural advocacy providers to provide specialist individual and systemic advocacy for people from NESB with disability; however existing funding for multicultural advocacy providers is inconsistent. This discussion paper contains a proposal for creating consistence in **funding for multicultural advocacy**, at a cost of $700,000 per annum

2. About NEDA and MDAA

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, Housing, Community Services and Indigenous Affairs (FAHCSIA) 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.

The Multicultural Disability Advocacy Association of NSW (MDAA) is the peak agency for people from non-English speaking backgrounds (NESB) with disability and their families/carers in NSW. MDAA aims to promote, protect and secure the rights and interests of people from NESB with disability and their families and carers in NSW. MDAA is funded by both Commonwealth and State Governments to provide a range of advocacy services and initiatives for people from NESB with disability, their families/carers and service providers in NSW.

3. Rights Obligations

Australian legislation and policy, including a long term care and support scheme, must meet international human rights obligations. In 2010 the Australian Government launched a National Human Rights framework, which contained new provisions for additional parliamentary scrutiny, and a commitment to processes to ensure compliance with human rights obligations for new parliamentary bills.

The Australian government has identified seven key multilateral treaties that it is party to:

- The International Covenant on Civil and Political Rights (ICCPR)
- Convention on the Rights of the Child (CRC)
- Convention Against Torture (CAT)
- The International Covenant on Economic, Social and Cultural Rights (ICESCR)
- Convention on the Elimination of All Forms of Racial Discrimination (CERD)
- Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)
- Convention on the Rights of Persons with Disabilities (CRPD)

Australia's obligations under the CRPD are of particular relevance to the design of a long term care and support scheme, with a number of Articles in the Convention – as detailed below, offering direction for promoting inclusion and non discrimination for people from NESB with disability.

Convention on the Rights of Persons with Disabilities (CRPD)

CRPD was ratified on the 18 July 2008, sending a powerful message for the recognition of the rights of people with disability in Australia. Ratification of CRPD created an opportunity to address areas of Australian law and policy that were inconsistent with the internationally agreed rights of people with disability, and a framework for the design of new policy / legislation affecting people with disability. CRPD also provides guidance on how to improve the responsiveness of policy and legislation to people from NESB with disability. The following articles are of particular relevance to the design of a long term care and support scheme.

- *Article 3 (d): Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity*. A long term care and support scheme must be flexible in responding to human diversity, not only in terms of impairment but also in relation to culture, language, race, and faith.
- *Article 5 (1): All persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law*. A long term care and support scheme must promote equality before the law in relation to culture, language, race and faith.
- *Article 5 (2): Prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds*. The law must actively protect people with disability from discrimination on the basis of culture, language, race, and faith. Non discriminatory access to entitlements and services is also reinforced by Article 2 of the *International Covenant on Economic, Social and Cultural Rights* ("The States Parties to the present Covenant undertake to guarantee that the rights

enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.")

- *Article 30 (4): Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture*. A long term care and support scheme must enable people with disability to maintain their cultural and linguistic identities. This is reinforced by Article 27 of the *International Covenant on Civil and Political Rights* ("In those States in which ethnic, religious or linguistic minorities exist, persons belonging to such minorities shall not be denied the right, in community with the other members of their group, to enjoy their own culture, to profess and practice their own religion, or to use their own language").

Convention on the Elimination of All Forms of Racial Discrimination (CERD)

CERD is of particular relevance to guaranteeing protections and non discrimination people from NESB with disability in the design and delivery of a long term care and support scheme. In particular:

- *Article 2 (c) Each State Party shall take effective measures to review governmental, national and local policies, and to amend, rescind or nullify any laws and regulations which have the effect of creating or perpetuating racial discrimination wherever it exists*. A long term care and support scheme must not promote racial discrimination or create racial division.
- *Article 5 (iv): ...States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of the ...right to public health, medical care, social security and social services*. CERD imposes a specific obligation to non discrimination on the basis of race or ethnicity upon the provision of social services.

Convention on the Elimination of Discrimination Against Women (CEDAW)

Australia is obligated under CEDAW to eliminate discrimination against women. This applies to women and girls with disability and female carers. In particular:

- *Article 1 the term "discrimination against women" shall mean any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field..*
- *Article 3 - States Parties shall take in all fields, in particular in the political, social, economic and cultural fields, all appropriate measures, including legislation, to en sure the full development and advancement of women , for the purpose of guaranteeing them the exercise and enjoyment of human rights and fundamental freedoms on a basis of equality with men*

Convention on the Rights of the Child (CROC)

CROC is particularly relevant to all children, regardless of residency status. Australia is obligated to place the child's best interests as a primary consideration.

- *Article 3 1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration*.

Other obligations

In so far as recently arrived refugees may be eligible for services through a long term care and support scheme, the "same treatment" obligations of the *Convention and Protocol in Relation to the Status of Refugees* appears applicable, including the relevant social security obligations in Article 24.

4. A Right to an Interpreter

Proposal: Include free telephone and on site interpreter services within the proposed long-term disability care and support scheme.

Cost: $51m per annum

Background

The proposed long-term disability care and support scheme does not appear to consider the funding arrangements to meet the interpreter needs of people with low English proficiency. This undermines the effectiveness of any scheme that relies upon informed consumers exercising their choice.

At present there is evidence of inconsistency in the provision of interpreter services to people with low English proficiency who are navigating disability services. While the Australian Government offers telephone and on site interpreter services through TIS National free services are not provided to non government organisations that receive funding for delivering their services. This means in a practical sense there is a disincentive for many organisations to offer interpreting services, particularly, as noted in a 2003 review of services to migrants, when there is "inadequate budget provision by service agencies, reluctance to pay for translating and interpreting services and/or lack of experience or training in using these services"(DIMIA, 2003).

Failure to address interpreter needs in costing for the proposed insurance scheme could mean the continuation of existing poor practices, or worse, if an individualised funding system is created, individuals may be required to meet the costs of interpreter services from their own packages (See Case Studies 1 and 2 below). There is a strong argument for prioritising access to interpreters in order to ensure quality care and support outcomes for people with use of a language other than English. International evidence, at least within the context of health provision, has "associated professional interpreter usage with increased patient satisfaction, improved patient understanding, greater patient participation in decision-making, high levels of compliance by patients with recommended treatments, improved access by patients to services, and fewer medical errors" (Garrett, 2009: 51). Provision of interpreter support is also in line with human rights obligations. The Australian Human Rights Commission, in its submission to the Productivity Commission inquiry, have clarified that funding for provision of interpreting is an obligation under Article 21 of the Convention on the Rights of Persons with Disabilities (AHRC: 2010). In addition, with the Productivity Commission's parallel inquiry into aged care arrangements, the Commission have recommended that there be "ongoing and comprehensive interpreter services (either within facilities or through telephone translators) for clients from non-English speaking backgrounds" (Recommendation 9.1 and 9.2, *Caring for Older Australians*).

There is precedent for the extension of free TIS National telephone and on site interpreting to providers of disability services through the proposed long-term disability care and support scheme. At present private medical practitioners providing Medicare-rebateable services and their reception staff can access free interpreting services through TIS National. The Australian Government has also recently extended free services to select pharmacies and real estate agents. In other words, future guaranteed provision of interpreter services for low English proficiency disability service participants would be consistent with current government policy in relation to enabling people with low English proficiency to socially and economically participate. Booked Auslan interpreting is also provided on a free of charge basis for all private medical practice consultations. In 2008 the Queensland

Interpreters – Essential for Choice and Rights

Case Study 1. Health Assessments - Interpreters

Angelo* was planning to emigrate to Australia from a non-English speaking country after visiting friends here. He had been in Australia for a while and DIAC requested he undergo a health assessment if he wished to stay here on a more permanent basis. Angelo attended a health assessment but was advised that if he wanted a professional interpreter he would have to pay for one on-site. This made it more expensive and would result in a stranger being present during the examination. As he couldn't afford an interpreter and was apprehensive of having one on site, he asked if one his friends could interpret for him.

Angelo was very uncomfortable having to discuss his medical history in the presence of his friend and could not be frank with the doctor. The doctor became frustrated as the health assessment took a lot longer than planned. The doctor was also frustrated because the friend did not have any interpreting skills and their English was limited. The doctor could not tell if the friend understood the information accurately or appropriately. The friend struggled to interpret the medical terminology and miscommunicated significant details. Angelo received a negative but incorrect health assessment. The doctor advised him that consultations are quicker and better with professional interpreters.

Case Study 2 Centrelink

Angeli* was an Australian citizen and could speak English but was more proficient in her own language, particularly with complicated scenarios or when she became nervous. She was working part-time whilst she was studying and received Youth Allowance. In her final term she quit her permanent part-time job so she could focus on studying with the long term view of using her new qualifications to gain employment. Her old job requested that she do some casual shifts, which she accepted. Following the completion of her studies, she was placed on a NewStart Allowance. When she was dealing with Centrelink they advised her that as she had voluntarily left her position she was not eligible for NewStart payments for 8 weeks. Angeli tried to explain that when she left her job she was on the Youth Allowance, not NewStart but had difficulty explaining what had occurred. After 20 minutes of trying to explain this to the Centrelink officer Angeli gave up and left. Her payments were terminated.

Angeli approached an advocate for assistance. After listening to her story the advocate suggested Angeli call Centrelink through the Telephone Interpreting Service (TIS) to explain the situation in her own language. After a 10 minute phone call the issue was quickly resolved and Angeli's payments were reinstated and she received 4 weeks back pay. She indicated to the advocate that if she had used an interpreter the first time the confusion could have been resolved, saving time for everyone involved.

** Not real names.*

government has issued a “directive to all Ministers for all Queensland Government departments to make provisions to meet the costs of accessing interpreter service by their funded organisations”(Queensland Government, 2010). Finally, The Australian Government currently funds Disability Employment Services for Auslan interpreting (anomalously, the same funding is not provided for other non English language interpreting).

Indigenous people with Disability

English is not the first language for a proportion of Indigenous people with disability. The PC Commission draft report acknowledges that language is a barrier to services for some Indigenous Australians, particularly in remote areas:

> For some Indigenous Australians, English was not the first language learnt, nor is it the main language used. In other areas, local varieties of English are spoken, which can also make communication difficult. The NATSISS (2008) suggests that around 11 per cent of Indigenous Australians aged 15 and over speak an Aboriginal or Torres Strait Islander as their main language overall, and around 40 per cent in remote areas (9.14)

Providing access to interpreting for Indigenous Australian who would prefer to use a language other than English will be a pre-requisite to building a culturally competent care and support system.

Sign Language Community

Use of sign language is a defining cultural and linguistic characteristic of the Deaf Community, with Auslan the commonly used language in Australia. The ABS Census of Population and Housing showed 7,146 sign language users in Australia, with a proportion of this community requiring long term care and support. The PC Commission report does not contain any detail on how the interpreting needs for this group might be met under a NDIS. Provision of Auslan and other sign language support will be crucial for Deaf Community members who are eligible for care and support under the proposed NDIS.

Potential Population

The potential population of interpreter service users comprises the total number of working people, 0 to 65 years of age who require interpreting to negotiate services, and have disability.

The Australian Bureau of Statistics (ABS) Survey of Disability Ageing and Carers (SDAC) could be utilised to estimate the number of people with ‘severe or profound’ disability who are likely to be eligible for support under the proposed long-term disability care and support scheme. However, because the SDAC uses only one identifier of ethnicity – country of birth – it is of limited use for estimating need for interpreter services, including for people who use Auslan.

Drawing instead from the ABS Census of Population and Housing 2006, it is possible to derive a potential population figure using the “need for assistance” indicator in that survey. The need for assistance measure is appropriate to the coverage of the proposed NDIS scheme, as the ABS shows that 372, 367 people indicated a need for assistance in the 2006 Census, roughly in line with the 360,000 people the Productivity Commission estimates will be eligible for support services under the NDIS.

The Census offers two language fields, namely an English proficiency scale, and a count of language other than English spoken at home. Language other than English spoken at home is the preferred measure (over language proficiency) because it measures the language that respondents are most comfortable using in a home setting, an indication of their preferred language for the delivery of services, including in home personal care services. Taking into account consumer language preference is important, as consumers will be negotiating services in their own home and will require services such as personal care services where ability to use a preferred language may be vital in order to allow people with disability to comfortably plan their care and support needs. The language other than English spoken at home data will also capture individuals who have low or no English proficiency.

According to the 2006 Census approximately 57,701 people aged 0-64 years speak a language other than English at home, and indicate a need for assistance. This comprises approximately 15% of all people who indicated a need for assistance in that survey. This figure would include people who use a sign language (including Auslan), as well as some 1380 Indigenous people who speak an Indigenous language at home and indicated a need for assistance in the 2006 Census.

Intensity and Type of Use

Estimates of the potential intensity of use of interpreter services are likely to vary under the proposed long-term disability care and support scheme as interpreter usage will differ given the difference between individual needs, the complexity of service types and the existing workforce mix (eg availability of bi-lingual staff).

In 2004, the Families and Community Services Report on the *Supply and Demand for Auslan Interpreters* reported a need for an Auslan interpreter for education or employment related issues on average 13.8 times over a 12 month period (FACS 2004). Given the ongoing nature of disability services, and the broad social participation scope of these services, it would appear reasonable to estimate a similar utilisation of interpreters for all individuals receiving disability services through a lifetime care and support scheme who require interpreting services. The average intensity of utilisation figure here would include individuals who require interpreters at a far higher rate, for example individuals who use accommodation services, require intensive support and might require close instruction or frequent adjustments to support delivery.

In the main human service areas, interpreting services are usually provided either on an onsite (face to face) basis or through a telephone interpreter service. Some service types – such as primary health care – prioritise face to face interpreting in their policies to minimise the possibility of miscommunication. In many circumstances, a similar approach will be required for sensitively providing effective services to people with interpreter need under a long-term disability care and support scheme, acknowledging that for some people, face to face interpreting may be the only appropriate means of communication. However there will be many circumstances where a telephone based interpreting service will be required, either in order to meet the needs of consumers in a timely way, or to enable consumers to make arrangements over the phone where a face to face meeting is not required (such arranging bookings). While there is no available data to suggest what an appropriate mix of onsite versus telephone interpreting should be for disability service users, it seems reasonable to estimate that service users will request an on site interpreter 1 in 4 times.

Costing

There is a lack of recent up to date unit cost information for interpreting services in Australia. However, the 2003 Review of Settlement Services for Migrants and Humanitarian Entrants (DIMIA 2003) provided a cost breakdown based upon 2001/2002 data for TIS National Services (see Table 1). It can be expected that these costs have changed, however a lack of data in relation to recent cost items and efficiencies in relation to TIS National make it difficult to estimate how costs have changed since.[2]

Table 1: Estimated Unit Costs Interpreting Services

Interpreting Service	Cost
Onsite	$149.88
Telephone	$34.68

Source: Review of Settlement Services for Migrants and Humanitarian Entrants 2003

These costs appear to be in line with the hourly costs for Auslan interpreting: for example the NSW Deaf Society charges within a range of $110 to $150 per hour (NSW Deaf Society, 2011).

Assuming the above costs hold true, and assuming that on average persons will request an onsite interpreter 1 in 4 times, with an average utilisation of 14 episodes in a year, it can be estimated that it will cost approximately $51 m per annum to provide interpreters for people who speak a language other than English at home.

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[2] Although this is not necessarily indicative of real unit costs, TIS National currently charges $24.42 for a 15 minute call in business hours, and $159.06 for a 90 minute business hours onsite interpreting consultation.

5. Rights for Non-Residents

Proposal: Extend NDIS eligibility to certain non permanent residents.

Background

The Productivity Commission proposes a blanket exclusion arguing that this position is in line with current policy:

> As is usual for most taxpayer-funded services in Australia, the NDIS would not provide individualised funding for people who are not permanent Australian residents (13n; see also 3.15).

A blanket exclusion of non permanent residents from NDIS care and support services would potentially exclude a number of people from receipt of services, including asylum seekers and people with accepted refugee status, individuals including children waiting for a long stay visa to be approved, and people on work or study visas (and their family members) who might be otherwise making strong social and economic contributions to Australia.

Current policy

Australian Government legislation currently prevents non permanent residents from accessing disability services funded under Section 21 of the *Disability Services Act 1986*. Eligibility criteria also disqualifies some non permanent residents from accessing income support in Australia, including the ten year eligibility period that currently applies to the Disability Support Pension. While these exclusions are features of current Government policy, they are potentially at odds with Australia's international obligations, including in relation to CRPD. It is certainly significant that that CRPD does not provide grounds for discrimination on the basis of residency, and would appear at odds with the equality and non discrimination obligations in Article 5. There are other concern areas in relation to excluding non residents from disability entitlements that are yet to be tested in Australian law. For example, NEDA's advice in relation to the ten year waiting period for the Disability Support Pension found that it interferes with CRPD obligations under Articles 28, 25 and 15, relating to standard of living and social protection, health and inhuman or degrading treatment.

Leaving aside the compatibility of current policy with respect to international obligations, it is not clear that blanket exclusion exists for non permanent residents in the receipt of taxpayer funded services in Australia (as per the Productivity Commission assertion in the draft report). Speaking broadly, taxpayer funded social infrastructure in Australia does not discriminate on the basis of residency. Many tax payer funded services and infrastructure, such as public transport services, roads and public parks, do not attract differential charging on the basis of visa status. In some state and territory based jurisdictions there is provision within policies for access to services by non residents, such as in the case of public schooling.

Medicare eligibility is perhaps the most directly applicable comparator to the proposed NDIS, not only because of the relationship between the two insurance schemes, but also because of the universal entitlement objectives of the scheme. Currently Medicare offers services to a variety of non residents including:

- some asylum seekers and people granted refugee status;
- people who have applied for a permanent resident visa (except for a parent visa) if they have a visa authorising their stay in Australia and have permission to work, or their parent, spouse or child is an Australian citizen or holds an Australian permanent resident visa;
- people who are from a country where Australia has negotiated a reciprocal arrangement that allows for access to Medicare services.

At a minimum, it would seem reasonable for a NDIS to provide a similar level of protection to the above non permanent resident groups.

Children with Disability

Persons with disability under 18 years of age who are not recognised as permanent residents are in a potentially vulnerable situation with regard to access to appropriate supports. For example excluding non permanent resident minors from eligibility to early in life early intervention services could potentially lead to less beneficial outcomes in relation to access to education and work for these individuals and could lead to higher public expenditure costs should these individuals become residents of Australia.

Excluding non resident children with disability from early intervention services is contrary to Article 3 CROC, which places the best interests of the child as a primary consideration. It would also be contrary to the obligations imposed by Article 7 (1 and 2) of CRPD, which emphasise the need for children with disability to enjoy rights on an equal basis with others, and the need for States parties to recognise the best interests of the child as their primary consideration. Similarly, excluding persons with disability under 18 years of age who are not recognised as permanent residents from support services enabling them to participate in education on an equal basis would be contrary to the CRPD obligation in Article 24.2 (c and d), which stresses the need for all children with disability to receive the supports they need in order to attain an effective education.

Asylum Seekers

Individuals with disability who have escaped their own country and apply to the Australian Government for protection as a refugee are currently not offered eligibility under the proposed NDIS.

Currently the Australian Government offers the following services to asylum seekers:

- health and welfare services, including limited financial assistance, through the Asylum Seeker Assistance Scheme)
- temporary eligibility for Medicare.

In line with recent changes, the Australian Government is also moving to provide education services to children. Provision of NDIS support services to asylum seekers with disability would be consistent with existing provided Government supports.

The Australian Government pursues a policy of mandatory detention for asylum seekers. After 2008 there was a shift of policy which focused on quicker processing for asylum seekers, a no detention policy for children, the increased use of community based detention and community based immigration housing, and use of extended facility based detention for “unlawful non-citizens who present unacceptable risks to the community” and “unlawful non-citizens who have repeatedly refused to comply with their visa conditions.” Asylum seekers with disability in detention should be entitled to care and support services, in line with the Australian Government's “Key immigration detention values” - eligibility for NDIS would be a simple way to guarantee consistency and fairness for these individuals.

Temporary Business Migrants (457)

Australia has increasingly approved temporary visas for migrants in business sponsorship programs for periods of up to 4 years (457 visas). Excluding temporary visa holders from receipt of NDIS services has the effect of:

a) excluding individuals with disability from the support services that are available to others in order to fully participate in Australian society, and preventing the full contribution of skills and experience that the individual may offer; and

b) excluding family members (including children) from entitlement, and therefore making it untenable for potential migrants with family members with disability from migrating to Australia for a short term.

Access Economics estimated in 2008/09 that every 1000 employer supported visa holders contribute between $12m to $13m in fiscal revenue to the Australian Government (Access Economics, 2008) It can be anticipated that the broader social and economic contribution of this group to Australia's prosperity is significantly higher.

The Productivity Commission estimate at the high end of the range that the NDIS will cost $12.8bn per annum to provide long term care and support to 360,000 people (equating to approximately 1.6% of the Australian population), or an average of $35,000 per person. If this rate of support need held consistent for temporary work visa holders – that is, there would be 16 people with disability who might be eligible for the NDIS per 1000 migrants – and the types of impairment and support need were also consistent, the cost of providing services for this group would be $560,000pa, a very small proportion of the $12-13m in annual fiscal revenue earned per 1000 temporary work visas.

This suggests that extension of NDIS eligibility could be reasonably accommodated by the Australian Government. Given that these short term work visa categories exist due to a skill shortage in Australia, it would be in the interest of Australia to support such a position.

Student Visas

International students make a strong social and economic contribution to Australia. The Department of Immigration and Citizenship estimates that at the end of 2010 there were approximately 291 204 international student visa holders in Australia. Excluding students from access to disability support services has the effect of reducing opportunity for international students with disability to participate on an equal basis with other students, by individualising the cost of social support for these individuals .

There appears to be a lack of Australian evidence on the economic contribution of international students to the Australian economy. However international evidence suggests that Australia would enjoy a strong fiscal and economy wide surplus as a result of the total economic contribution of students, both through fees and through general spending. A UK study by the All Party Parliamentary Group on Migration observed that “the direct value of international students alone to the UK economy (including fees and off-campus spend) was calculated by the British Council in 2007 to amount to nearly £8.5 billion per year” (APPG, March 2011). There were 325,985 international students in the UK in 2007/8 (UK Council for International Student Affairs), a total figure which is not radically dissimilar to the Australian International student co-hort.

This suggests that extension of NDIS eligibility to international students could be reasonably accommodated by the Australian Government. Aside from the strong social justice reasons for providing support to international students with disability – including meeting relevant human rights obligations – it is worth noting that ensuring care and support for student visa holders with disability would increase the attractiveness of tertiary study in Australia for prospective overseas students. Given recent poor press Australia has received in relation to racially motivated attacks against international students (and the subsequent decline in attractiveness of Australian universities for some international students), a proactive policy that attempts to attract students with disability may counteract these effects.

Reciprocal Arrangements

As stated above, Australia currently maintains reciprocal health care agreements, which allow some non permanent residents to utilise Medicare services. Similarly, Australia has negotiated reciprocal social security agreements with a number of countries, again ensuring that some individual residents are able to access benefits where they can demonstrate residency in an agreement country.

There would be a strong case for the Australian Government to negotiate reciprocal agreements with nations that have similar social insurance schemes, not only to benefit non-residents in Australia, but to guarantee coverage overseas for Australian residents. The latter would assist Australian residents with disability to better take advantage of international opportunities available to other Australians, such as study and work abroad.

Recommendations

1. That the NDIS be made available to:

- Asylum seekers and persons granted refugee status
- All children should be eligible regardless of residency status
- Individuals who have applied for permanent residency.
- Temporary Business Sponsored Migrants (457 holders)
- International students

2. That the Australia should take steps to establish reciprocal care and support agreements to enable eligible non residents to utilise NDIS services, and guarantee coverage for Australians residents with disability overseas.

6. A Right to Employ a Family Member as a Support Worker

Proposal: Commit to a NESB pilot of the employment of family members under self-directed funding to assess its risks, advantages, disadvantages and optimal design.

Background

The Productivity Commission have recommended that family members be excluded from direct payments for care and support work under the proposed NDIS (recommendation 6.4). However the commission have endorsed a trial of these payments for evaluation purposes (recommendation 6.5).

The draft report does not consider the impact such a blanket exclusion would have on women. The proposed exclusion has ramifications for culturally diverse populations and particularly disadvantages women who continue to deliver, and are the most disadvantaged by, unpaid caring roles. This simultaneously removes women from participation in the labour force and denies them the right to paid. This has long-term economic impacts on women. Women from both ESB and NESB are often viewed as 'natural carers' and can be regarded as failures if they cannot meet the domestic and caring needs of their families. This has lead to exaggeration of caring abilities by other family members and the women concerned. Research conducted by the Department of Health in the UK found:

> ... a heavy expectation in some ethnic families that its own members, usually the female members, assume the total caring role for any disabled member, can result in seriously inhibiting carers from articulating their own needs. (Harris, 2004, p. 63)

One of the consistent barriers people from NESB with disability face with accessing services in Australia is the presumption that their cultural and/or community ties safeguard them from requiring government assistance. Like mainstream Australian culture, many NESB communities are prejudicial towards people with disability. Far from having adequate support, people from NESB with disability are often hidden from their communities and services.

Paid Carers and Governance

The ability of persons from NESB to employ family members to provide care and support is potentially an important one. In certain circumstances a family member of a person with disability is the preferred / most appropriate formal carer. A person centred care and support scheme must be built to enable family carers to take on this role, by creating appropriate accountability measures, and appropriate resourcing and training. The evidence from the UK (Stuart / Social Care Institute for Excellence, 2006) suggests that this will be an important issue for people from NESB with disability, particularly where there is inadequate capacity within the open market to provide culturally competent services, and where the person with disability would prefer – for a range of reasons - not to be supported by non family members.

However there is strong need for payments to be accountable and adequately monitored, as well as a need to ensure that people with disability from NESB also have realistic choice in terms of culturally competent care and support provider. The Stuart / Social Care Institute for Excellence report (2006) suggested that there was a lack of clarity in relation to funding for family members, with the direct payment system poorly set up to enable family members to act as formal paid carers (with the assumption made that payments to family, rather than independent organisations and contractors, are less than 'best practice'), and a lack of commitment to stimulating demand to generate alternatives for individuals and families. As a result, culturally diverse people with disability are likely to be recommended direct funding of a family member as the 'ethnic specific,' albeit less than perfect, solution: "the consequence of this inconsistency amounts to the worst of both worlds – it can only result in the creation of divisions among service users" (2006: 9).

Employment of Family Members – The Recent New Zealand High Court Decision

As discussed above, the evidence from the UK research is that payment to family members is likely to be an important issue for people from NESB with disability participating in a long term care and support scheme. It is worth noting that while the capacity of schemes to enable the payment of family members to act as formal care providers is a key question in the UK scheme, it does not appear to be a feature of Australian models.

The New Zealand example provides evidence both for carefully considering the role of family members as paid carers within a proposed long term care and support scheme, and also checking for possible discrimination against both families, and people with disability. On December 17 2010 the New Zealand High Court handed down its judgement in relation to the Ministry of Health (MOH) policy of excluding family members from being contracted to provide care to persons with disability (Ministry of Health V Peter Atkinson on behalf of the estate of Susan Atkinson & Eight Others, 2010). The judgement was based on an appeal by the MOH against a decision by the Human Rights Review Tribunal that the policy of excluding family members was contrary to the *New Zealand Bill of Rights Act 1990*. The High Court dismissed the MOH appeal.

While the NZ High Court found there was some risk of dependency in payments made to family members providing care and support, it did not believe this was a reason to prevent family members from receiving payments, provided appropriate checks and balances were in place (MOH v Atkinson and Others, 2010: [257]). The High Court observed:

> rationally it could be the case that on occasions the presence of family members as caregivers could discourage disabled persons from becoming independent. However, if there is any such risk, we would expect it to be able to be mitigated by the appropriate training of family members and rigorous monitoring [257].

The High Court also acknowledged that there were challenges to financial and administrative accountability in managing a scheme were family members could be paid to provide care and support to persons with disability. However New Zealand's Accident Compensation Commission (ACC) has operated a scheme where payments to family members to provide paid care and support have been allowable, and as noted by the New Zealand High Court decision, the ACC policy and practice of contracting with family members shows that it is possible to run and monitor a contract system whereby such members care for disabled persons. It tends to show that the Ministry's objectives...[of preserving financial accountability and preventing dependence]... can be managed"[252]. Importantly the High Court observed that there wasn't strong evidence to suggest that utilisation of family members as paid care and support workers for people with disability would lead to different outcomes in terms of quality of care: “the indications were that there was no discernible difference in quality and rehabilitation outcomes between ACC and the Ministry” [244].

Above all, the New Zealand High Court decision found that a policy of excluding family members from being able to be paid to provide care and support was discriminatory, *both* to family members *and* to people with disability. In relation to family members, the High Court found that:

> We have found that those who are in comparable circumstances to the parent plaintiffs are persons who are able and willing to provide any of the four disability support services. The respondent parents fall within this group. They are persons who are able and willing to provide support services to disabled persons. But they are not treated in the same way as those other persons. When they apply to be contracted to provide home support services, they find they are not eligible to be contracted. The reason for this is a prohibited ground of discrimination. It is their family relationship with the disabled persons. More specifically, it is because they are the parents of disabled children. If they did not have this family relationship, they would be eligible. We have no doubt that they would have shown themselves to be able and willing to do the work [127].

The policy of excluding family members from receiving payments for care and support was also found to be discriminatory to people with disability by the New Zealand High Court, because it limits choice that other people with disability, in a different situation, may be able to exercise:

> The two respondent children are also discriminated against. They have a more limited range of choice of carer than others in comparable circumstances. This is because of their family status, namely their relationship with their parents. That relationship precludes them from being able to consider the full range of those able and willing to provide services to them. While other claimants who are not so related can be supported by the full range of the group of those able and willing to provide services, these respondents cannot because they have a particular family status; they are related to persons in that group. And by virtue of that relationship they cannot receive benefits from paid workers, who appear to be best able to provide that support. They are left in the position where that support, if it is made available, is unpaid [130].

This finding is particularly relevant for people from NESB with disability, in so far as inability to employ a family member will further compromise choice where there is poor availability of culturally competent services (including care and support services provided in a non English language context).

Given the potential difficulties in accurately assessing ‘willingness’, the stigmatisation of women and families, the discriminatory nature of relying on ‘natural supports’, and the infantalizing of adults with disability , any financial benefits the long-term care and support scheme would gain from assessing the capacity of unpaid carers would be cancelled by the detrimental effects outlined above.

Building Accountability and Choice

The 2010 decision by the New Zealand High Court indicates that a blanket ban on the provision of paid care and support services by the family of the person with disability is discriminatory to both the family *and* the person with disability.

While there are accountability issues to address, arguably there are strong benefits in flexibility in allowing families to provide for care responsibilities, particularly where it can be shown that family members can provide the same (or higher levels) of quality care than external providers. The NZ High Court decision offers some guidance how this might operate within the context of a national long term care and support scheme, through a:

> a policy where family members can claim and be paid, although only on condition that they must go through an interview process, (where some family members will be rejected as unsuitable) a training regime (which some will not complete), and accept various conditions imposed on them in relation to ongoing training and monitoring (which will not be acceptable to all). They would have to accept that their contracts could be terminated if they failed to meet monitoring standards, in the same way as any other independent contractor (MOH v Atkinson and Others, 2010: [282]).

Enabling family members to be paid care workers for a person from NESB with disability only makes sense if there is a simultaneous and sustained commitment to also create choices for people from diverse cultural and linguistic backgrounds, which might include block funding multicultural service providers (see section 6 below).

NESB Trial

Based on the UK evidence, there is a strong need for evaluation of outcomes for direct payments with respect to people from NESB with disability and their families. It is proposed that there be a trial of the employment of family members for people from NESB with disability under self-directed funding to assess its risks, advantages, disadvantages.

7. A Right to Culturally Competent Person Centred Support

Proposal: Commit to a person centred care and support scheme that will respond effectively to people from NESB with disability.

Background

The Productivity Commission have not provided any specific recommendations in its draft NDIS proposal to address equity issues for people from NESB with disability. This would appear to be a significant omission given the substantial evidence of poor utilisation of the existing service system by this group of people with disability and poor participation outcomes, including in employment. This evidence includes data from more than 15 years of reporting by the Productivity Commission in its *Report on Government Services* series.

Individualised Funding Schemes

There has been strong community support for a shift to more person centred care and support, in order to allow people with disability to exercise increased control over directing the delivery and orientation of their own care and support services. In line with these community concerns the Productivity Commission have recommended tying the proposed NDIS to an individualised funding model that would allow individuals to choose directly providers of services, choose 'disability support organisations' that would act as intermediaries in negotiating services, opt to 'cash out' the value of their entitlement to directly purchase services.

There are numerous models for more individualised funding approaches, which broadly conform to the proposed PC Commission model. Fisher et al / FaHCSIA (2010) outline three different models currently being used within Australian jurisdictions:

- *Individual Packages Held by Provider*. In this model the budget for services is held by the provider. The person with disability chooses between providers, and can exercise choice in relation to a suite of services from a provider (Fisher et al / FaHCSIA, 2009: 10-11).
- *Individual Budget Held by the Person to Spend Through Providers*. The person with disability is allocated a budget to purchase services from approved providers. A financial intermediary or broker can be used in this model to coordinate the delivery of services (Fisher et al / FaHCSIA, 2009: 11).
- *Direct Payment to the Person to Spend in an Open Market*. The person with disability or representative is directly provided funding which can be used to purchase services in an open market (Fisher et al / FaHCSIA, 2009: 11-12).

These approaches are used as possible Person and Culture Centred Care and Support models below and in Appendix 1

Person Centred Approaches and People from NESB

There has been little consideration in the Australian literature on the possible implications of an individualised funding scheme for people from NESB with disability. Given the poor take up of disability services by people from NESB in Australia (see Introduction), there is a strong case for ensuring any new framework for the delivery of disability services addresses the problems with the old in terms of equity and access: there is a strong need to 'get it right.'

Research from the United Kingdom on the impact of individualised funding models for ethnically diverse communities provides some guidance on the potential pitfalls for an Australian scheme. A 2000 review by the Social Services Inspectorate of independent living arrangements for people with disability found that most of the "inspected councils had only relatively low numbers of people from ethnic minorities in their areas and as service users"(Fruin / SSI, 2000: 13). The Wiener, Tilly and Cuellar (2003) study of direct payment schemes found barriers in the UK to accessing individualised funding, because "many minorities may not speak English as their first language, and translating Direct Payment materials into other languages can slow enrolment"(12; cf 51).

The UK research also found areas where the cultural competence of services to respond to different cultural needs was lacking. The Wiener, Tilly and Cuellar (2003) study found that there were areas where services were not able to flexibly respond to cultural needs, with barriers where "some cultures discourage hiring women to provide personal assistance" (12; cf 51). There were also significant problems for some culturally diverse populations in misunderstanding the messages within individualised funding programs, often as a result of a mismatch between Westernised ideas of autonomy and independence clashing with conceptions of self and family from non Western cultures. For example Joseph Rowntree Foundation interviews with people with disability of "Asian, African and African-Carribean origin" found that the majority of people thought independent living programs implied a move away from families to live on their own: something that was not necessarily desirable for the people with disability interviewed (2000:11).

Perhaps the most relevant research conducted in the United Kingdom - of relevance to designing a culturally effective long term care and support scheme in Australia - is the 2006 Stuart / Social Care Institute for Excellence report, *Will Community-Based Support Services make Direct Payments a Viable Option for Black and Minority Ethnic Service Users and Carers?* Stuart observes:

> For disabled people, the new direct payments legislation is a huge step towards 'independent living'. However, there is considerable evidence to suggest that this policy is not equally benefiting service users and carers from black and minority ethnic communities. In fact, black and minority ethnic communities are the least likely to be offered the direct payments option by local authorities, despite their mandatory duty to do so (2006: 1).

Stuart identifies a number of problems with access to direct payment community based support schemes by ethnic minorities, including:

- Confusion over the meaning of 'independent living' with "concerns that direct payments will impose autonomous lifestyles on service users. This is something that many members of black and minority ethnic communities would not choose" (2006:6).
- Poor assessment processes, including failing to acknowledge the specific circumstances of people with disability, particularly with cultural and linguistic communities, and within families.

- Lack of information, support on how to use information, and no clear ways in which to reach out to black and minority ethnic service users, beyond stating that local authorities should do so"(2006: 7)

- Problems in recruiting appropriate staff that are able to meet the cultural, linguistic and faith requirements of service users.

- A lack of flexibility in using direct funding models creatively to respond to needs of culturally diverse people with disability.

- A lack of appropriate advocacy and support services, a likely outcome that "black and minority ethnic users of direct payments will receive less support, training, advice and help from the support services when compared to the majority of direct payments users"(2006: 8).

- A lack of clarity in relation to funding for family members. As a result, NESB people with disability are likely to be recommended direct funding of a family member as the 'ethnic specific,' albeit less than perfect, solution: "the consequence of this inconsistency amounts to the worst of both worlds – it can only result in the creation of divisions among service users"(2006: 9).

Culturally Competence- Assessment

The Commission's acknowledgement that existing assessment tools are limited and the commitment to moving towards a tool box that will deliver more consistent results (Productivity Commissioner, 2011, p. 5.14) is a positive step. However, one of the limitations of the existing tools is that they do not work cross-culturally and as a result people from NESB with disability are undiagnosed or misdiagnosed (Harris, 2004, pp. 52-55). Failure to ensure that the NDIS assessment tool is culturally competent will deliver nationally consistent but invalid results and outcomes. One way to safeguard against this is to ensure assessors receive continuing cultural competence training and that the 'assessment toolbox' is culturally responsive.

Cultural competence has been defined in many ways. To prove that a provider is cultural competent it must demonstrate that it appreciates '*differences in the beliefs and behaviours, recognizes and respects variations that occur within cultural groups, and is able to adjust his/her practice to provide effective interventions for people from various ethnic groups* (Suarez-Balcazar, et al., 2011, pp. 4-5). It is not possible for anyone to be well informed of every conceivable culture in existence. It is, however, possible to create an organisational culture that recognises and responds to cultural differences. Organisations that provide an NDIS funded services should be required to commit to being culturally responsive.

For an assessment tool to deliver equitable outcomes it must be flexible enough to recognise and respond to people's differences. These factors must be considered when the NDIS determines reasonable needs, wants, aspirations etc of people with disability. Failure to take cultural considerations into account guarantees inequitable service provision.

Cultural competence approaches have been utilised in the US, UK and in Australia to improve the effectiveness of human services for people from diverse cultural and linguistic backgrounds. Cultural competence frameworks acknowledge that organisational cultures contribute to poor responsiveness, and seek to make progressive change across all aspects of the organisation in order to enable organisations to meet the needs of people from different cultural backgrounds. The US *Developmental Disabilities Assistance and Bill of Rights Act 2000* contains a commitment to cultural competence, defined as “used with respect to services, supports, or other assistance, means services, supports, or other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviours of individuals who are receiving the services, supports, or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved” (42 USC 15002 SEC. 102).

Based on MDAA's 2009 report, *Towards Cultural Competence: A Framework for Human Service Organisations and a Guide to Engage Consumers in the Process*, the following organisational competencies should inform the standards for service delivery as a part of a long term care and support scheme:

- *Cultural competence planning*, including community needs assessment and assessment of organisational ability to meet NESB needs
- *Human resource development*, including recruitment of multilingual and culturally competent staff and consultants
- *Professional development and training*, including training staff to be aware of their own cultural perspective and how to support staff and consumers from diverse backgrounds;
- *Community partnerships and governance*, including working actively with diverse communities and NESB involvement in governance
- *Linguistic competence*, such as provision of information in appropriate formats
- *Service development*, in particular ensuring that planning for culturally competent services is up front rather than an 'afterthought'
- *Continuous quality improvement*, such as linking quality management and performance benchmarking to cultural competence improvements
- *Data management*, ensuring that data collection is capable of improving services and meeting targets
- *Policy development*, to make sure that internal procedures are consistent, and there is adequate reporting and monitoring frameworks (Harris / MDAA 2009).

Block funding to establish and maintain multicultural disability support organisations.

The proposed NDIS, in combination with an individualised funding model, will create an unprecedented application of market principles to disability services. It is possible that many people with disability will benefit from the new arrangements through increased choice and – depending on the model chosen – ‘value for money’ in being able to a maximise allocated care and support budgets.

However the experience is likely to be different for other consumers with ‘specialised’ needs, where the market is unlikely to deliver choice, and in some cases will be unable to deliver needed supports. For example, African people with disability may not be able to have a choice of provider if they want a culturally competent service (there may be only one service available), while for some language groups, there will be no available same language service. There are likely to be differences between the experiences of urban and rural / regional consumers, with, for example, Chinese speakers in Sydney able to access resources and support that might not be available in country areas.

Resourcing for individualised services through a long term care and support scheme should be oriented to address market failures for particular groups of people with disability. The Productivity Commission have endorsed a block funding model as ‘a tool to redress market failure” (PC Commission, 2011 8.48). In the case of services to people from NESB with disability, a commitment to establishing and resourcing multicultural support organisations will address this market failure, by guaranteeing a level of choice to people from diverse backgrounds.

Availability of translated, easy to understand, accessible information.

Lack of information was a clear barrier cited by ethnic communities in accessing the direct payment system in the UK (Stuart / S.C. I.E 2009: 7). While there are limits to how effective translated material can be in getting the message across – for example translated material is less useful for people with low literacy, or for those whose spoken language has no written form – offering information in translation remains a powerful tool in improving awareness by consumers of services, and their rights. A UK study in the health area finds, for example, that “translation of key material....can be used to increase patient awareness of health care provision availability...” and is “... potentially useful in order to convey health promotion information, and to empower minority communities by making them aware of complaints procedures” (Szczepura et al 2005: 34). Availability of translated material is consistent with the obligations imposed by Article 21 of CRPD. National Disability Standards currently impose obligations on service providers to ensure “policies and procedures to maximise consumer participation in decision making are made available to consumers in appropriate formats” (Standard 3.2).

Arguably a long term care and support scheme would impose stronger requirements on providers to ensure the availability of translated material to potential and existing scheme participants and their families. A new long term care and support scheme will require a planned communications strategy in order to ensure take up with people from NESB, with translated information a key priority. In particular, there will be a need to provide information to consumers on the entitlements available, the service model(s), how to deal with brokers / case managers, rights and responsibilities, and complaints procedures. There are examples within other human services areas in Australia that might provide a guide for improving performance: for example, public health translations policies and procedures might provide a more rigorous guide for what would be required under the scheme. In NSW, for example, NSW Health Policy Directive PD2005_483 provides a framework for the use of translations to improve NESB access to health service, including:

- ensuring an adequate supply of relevant multilingual publications should be prominently on
- display at all public contact points
- ensuring all translated material is available free of charge
- specifying that all general material available to English speaking patients should be available in translation in community languages

- specifying the need to use accredited services to translate new material

The costs of translating services should be within existing budgets for service providers and not at cost to the consumer. It is worth noting that while translating must be a core aspect of promotion and information provision under a long term care and support scheme, translating might form an identifiable ancillary service layer within future disability insurance arrangements, and there is scope for planning for the development of quality translation services funded through the scheme.

A Culturally Competent Care and Support Scheme

It is possible to build a culturally competent NDIS to improve outcomes for people from NESB with disability and other groups by:

- utilising established cultural competence principles to shape governance, planning, staff and training, data and quality management.
- block funding multicultural support organisations to offer choice to individuals in terms of brokerage and direct support organisations
- developing strong guidelines and support in relation to the availability of accessible translated material on the Scheme and entitlements.

Note that other proposals within this discussion paper – including the right to interpreter services and advocacy – are interconnected with a culturally competent service system.

Costing

Improved responsiveness to NESB consumers should not be considered an extra cost, but as a routine ‘cost of doing business’ (that is, as part of a requirement to providing quality services to all who are entitled to them). Proposals within the above framework that have predictable additional costs (ie providing for interpreting and providing for advocacy) have been costed separately in this discussion paper. A potential additional cost element for the proposed long term care and support scheme will be block funding to establish and maintain specialist multicultural services and brokers, where the market is unable to offer these services. It is difficult to predict how funding arrangements or the care and support arrangements will affect the demand or supply for specialist multicultural services. The capacity of the proposed scheme to resource services, brokerage and advocacy should be built into planning for market failure, where the scheme is demonstrated to inefficiently respond to individual needs in terms of choice, appropriateness and effectiveness of services.

7. A Right to Advocacy

Proposal: As a component of the proposed long-term disability care and support scheme, fund multicultural advocacy services in the Australian Capital Territory, Northern Territory, Tasmania and Queensland.

Cost: $700,000 per annum

Background

The existing proposal for the NDIS does explore funding for advocacy, including systemic advocacy. Given the role of individual and systemic advocacy in enabling people with disability to navigate mainstream and specialist disability services, and access rights, there is a strong case for any new scheme to also meet the advocacy needs of consumers as an integrated facet of long term care and support or alternatively, to guarantee funding for advocacy through other revenue and expenditure mechanisms. The Australian Human Rights Commission put forward this position in its submission to the Productivity Commission inquiry:

> Consideration could also be given to the possible role of an NDIS in providing a sustainable and adequate funding base for representative organisations to enable them to engage in systemic advocacy in support of identification and elimination of barriers in Australian society and to participate in and contribute to monitoring of progress in implementation. (AHRC, 2010).

Governments currently fund multicultural advocacy providers to provide specialist individual and systemic advocacy for people from NESB with disability. 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.

The case examples below from the work of MDAA in NSW provide an illustration of the sort of specialised role multicultural advocacy providers can play in supporting people from NESB with disability.

Existing funding for multicultural advocacy providers is inconsistent. 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 and Queensland) with no consistent funding rationale from Federal and State governments.

Advocacy to Faciliate Rights and Inclusion

Case Study 3: Ms Dzino

Ms Dzino is a fifty year old refugee from the former Yugoslavia. During the war she lost her hearing aid and communicates only by writing in her language. She lived with her very protective mother and a brother who control every aspect of her life. Ms Dzino did not have access to her money and documents, and did not know how to get a hearing aid. She was not allowed to go out as much as she wanted as her mother thought she may be abused by strangers. However, her brother had thrown her out of the house a few times when she refused to obey him so Ms Dzino had slept in the nearest park.

When someone contacted a Multicultural Disability Advocacy Association (MDAA) advocate on Ms Dzino's behalf she was hungry, cold, scared and disoriented. The only document she had was a small piece of paper with her name and a wrongly written address. Due to extremely difficult communication and the overall complex situation, it took several lengthy meetings with Ms Dzino to compile information to assist her appropriately. With Ms Dzino's permission, the advocate spoke to her family and explained what services were available for her and what her options were.

In the end, the family agreed for Ms Dzino to move to separate accommodation and offered to continue supporting her with domestic chores. After extensive communication between the MDAA advocate, Centrelink, Department of Housing, the bank and Hearing Aid services, Ms Dzino got access to her own bank account, was offered accommodation by the Department of Housing and arrangements were made to get her a new hearing aid.

Case Study 4: The Nietsche family

The Nietsche family are refugees who arrived in Sydney several years ago. Both Mr & Mrs Nietsche are frail and have post-traumatic stress disorders. They care for their ten year old grandson who has physical and intellectual disability.

The Nietsches have lived for years in a small one bedroom apartment on the first floor of a building without an elevator. Their grandson was confined to bed as there was no space for a wheelchair to move around. Due to the family's lack of English, insufficient information on their living conditions and inadequate documentation, the Department of Housing refused their application for priority housing assistance.

The MDAA advocate assisted the Nietsches through the appeal process. The family's application was approved but they had to wait for an indefinite time for accommodation appropriate for a person with a disability. The only alternative was subsidised accommodation on the private rental market which had to be approved by the Department. The MDAA advocate assisted the Nietsches to lodge an application for the special assistance subsidy and finally the family was housed in a unit accessible for a wheelchair.

Potential Population

There are no clear targets at a national level for how advocacy is targeted, or who should access advocacy.

Currently, the National Disability Advocacy Program reaches 23,000 consumers per year (Pearson, 2009: 11). Using a simple measure, based on Census data 18% (Australian Bureau of Statistics, Census of Population and Housing 2006) of these consumers should speak language other than English at home (or 4140 consumers), and approximately 23.7% (NEDA, 2010) of these consumers should be born in a non English speaking country and / or have one or both their parents born in a non English speaking country (or 5451 consumers). Responsibility for meeting the needs of these consumers rests with all funded advocacy providers, however multicultural advocacy services can play an important role in responding to specialist needs, and supporting sector wide improvement.

Advocacy should ideally be prioritised for consumers who face significant barriers to social and economic participation. Arguably because of the historic poor access of people from NESB to disability services, and poor opportunities in employment and education, there is a case for advocacy providers in general to provide advocacy at a higher rate in order to address inequities. This would mean, for example committing to targeting advocacy services to achieve a higher than 25% participation rate for NESB consumers.

Costing

Costing advocacy services is a difficult exercise due to the variability in organisations, operating philosophies and structures. A recent report commissioned by the Department of Families Housing, Community Services and Indigenous Affairs (FAHCSIA) confirms this:

> Any attempt to provide a comparative analysis of the cost of advocacy supports across advocacy agencies or models using the quarterly report data is fraught with difficulties and limitations. Whilst the funding provided to each agency by the NDAP is known, the isolation of this funding from other funding sources is unknown. The mixed use of models within most agencies makes attribution of funding and consumer outcomes to specific advocacy models almost impossible. There is also significant uncertainty regarding the methods and accuracy of agencies' collection of data on consumer numbers. (Jenny Pearson and Associates Pty Ltd / FAHCSIA, 2009: 14).

An added variable for specialist multicultural advocacy providers (one not discussed in the Pearson / FACSIA report) are the potentially higher unit costs for these services: for example the additional case work time involved with arranging and using interpreters (something which is part and parcel of the bulk of the work of multicultural agencies); or the additional community development and outreach which is necessary to build trust with NESB individuals and families. Regardless, given that people from NESB with disability comprise 1 in 4 people with disability, a substantial funding commitment is reasonable to ensure that all advocacy providers (and not just multicultural providers) provide equitable and consistent services.[3] An adequate funding rationale and standards

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[3] The Jenny Pearson / FAHCSIA report finds that in 2007/08 2007-08, advocacy agencies spent an average of $721 of NDAP funding per advocacy consumer per quarter"" (2009: 15) or $2884 per consumer per year. Assuming that advocacy providers ensure that 1 in 4 of their clients are from NESB communities, and leaving aside other relevant costs such as interpreting, the cost of this advocacy to people from NESB with disability per annum should be $16.6m per annum.

should aim to resolve current inequities in terms of how services are delivered, and whether all population groups are getting their ‘fair share.’

Funding for multicultural advocacy needs to take into account states and territories where there are no specialist individual and systemic advocacy services (namely, Australian Capital Territory, Northern Territory, Tasmania and Queensland. In lieu of a consistent funding rationale, a modest commitment to funding advocacy services in Australian Capital Territory, Northern Territory, Tasmania and Queensland at the average funding rate for the National Disability Advocacy Program - $175,827per annum (Jenny Pearson / FaHCSIA, 2007-08) – would cost approximately $700.000 per annum.

6. Conclusion

The proposed NDIS creates a rare opportunity to create fundamental reform to the delivery of supports to people with disability in order to build inclusion and participation. For people from NESB with disability, the proposed Scheme has the potential to address decades of poor interaction with the formal service system, and poor social inclusion outcomes. NEDA and MDAA strongly believe that a more inclusive system can be built by stronger rights recognition, including rights to an interpreter; rights for non-residents; rights for family members to be formal support workers, rights to culturally responsive services and rights to advocacy.

References

Australian Bureau of Statistics (2006) *Census of Population and Housing*. Australian Government.

Australian Human Rights Commission (2010) “Submission to the Productivity Commission Inquiry into Long Term Disability Care and Support.” At: http://www.hreoc.gov.au/disability_rights/inquiries/NDIS.html

Department of Families and Community Services, (2004) *Supply and Demand for Auslan Interpreters*. Australian Government.

Department of Immigration Multiculturalism and Indigenous Affairs (DIMIA) (2003) *Review of Settlement Services for Migrants and Humanitarian Entrants*. Australian Government.

Fisher, K.R., Gleeson, R., Edwards, R., Purcal, C., Sitek, T., Dinning, B., Laragy, C., D'aegher L. and Thompson D. (2010) *Effectiveness of individual funding approaches for disability support*. Department of Families Housing Community Services and Indigenous Affairs.

Fruin, D. (2000) *New Directions for Independent Living: Inspection of Independent Living Arrangements for Younger Disabled People*. Social Services Inspectorate.

Garrett, P. (2009) “Healthcare Interpreter Policy: Policy determinants and current issues in the Australian context.” *Interpreting & Translation* Vol 1, No 2 (2009)

Harris, P. / Multicultural Disability Advocacy Association (2009) *Towards Cultural Competence: A Framework for Human Service Organisations and a Guide to Engage Consumers in the Process*. Multicultural Disability Advocacy Association

Jenny Pearson and Associates Pty Ltd / Department of Families Housing Community Services and Indigenous Affairs (2009*) Research of the Models of Advocacy Funded under the National Disability Advocacy Program.* Australian Government.

National Ethnic Disability Alliance (2010) *What does the Data Say? People from Non English Speaking Background with Disability in Australia.* National Ethnic Disability Alliance.

NSW Health. (2005) *Non-English Speaking Background - Standard Procedures - Improved Access Area/Public Health Services.* Policy Directive PD2005_483. New South Wales Government.

Productivity Commission (2006*) Disability Care and Support: Issues Paper*. Australian Government.

Productivity Commission (2010a) *Disability Care and Support Public Hearing Transcripts*. 13.7.10. Australian Government.

Productivity Commission (2010) *Report on Government Services*. Australian Government.

Queensland Government (2010) “Translating and Interpreting Services.” Department of Communities. At http://www.multicultural.qld.gov.au/services-resources/translating-interpreting-services/

Szczepura, A., Johnson, M., Gumber, A., Jones, K. Clay, D,, Shaw, A. (2005) *An overview of the research evidence on ethnicity and communication in healthcare.* Clinical Sciences Research Institute, Warwick Medical School / Centre for Evidence in Ethnicity, Health and Diversity (CEEHD) University of Warwick

Wiener, J.M. Tilly J. and Cuellar, A.E. (2003) “Consumer Directed Home Care in the Netherlands, England and Germany.” AARP Public Policy Institute.

Appendix A: Individual Funding / Cultural Competence Model Matrix

Person Centred Model	**Details of Model**	**Commentary**	**Cultural Competence Model**
Individual Packages Held by Provider	Government funds a single provider to deliver a suite of services to person with disability. Consumer exercises choice in relation to provider chosen, and the package of services offered (for example consumer	This model is least favourable in terms of flexibility to meet NESB needs. A single provider is unlikely to be able to meet all needs of person from NESB, particularly in relation to provision of culturally appropriate support across a range of need areas. Market failures may lead to lack of supply in culturally competent providers for people from NESB, with potentially acute problems for some language groups in some geographic areas.	• Funding support to establish and maintain specialized multicultural providers. • Flexibility needs to be built into standards and guidelines. • Capacity to employ / sub-contract multi-lingual staff • Capacity to buy in external specialist providers. • Capacity for provider to employ family member as formal carer. • Interpreting at no cost to consumer. • Availability of translated, easy to understand, accessible information. • Cultural competence frameworks need to inform promotion, intake and assessment procedures for all providers. • Funded Multicultural Advocacy

Individual Budget Held by the Person to Spend Through Providers.	Person with disability is allocated a budget which may be directed towards registered providers. Consumer exercises choice in arranging a package of services through registered providers, with a likely emphasis upon utilization of brokerage models.	This model has potential in offering consumers a range of providers that might meet the needs of NESB clients. There is a strong need in this model on the cultural competence of brokers, in order to effectively respond to the needs of NESB consumers. However market failures may lead to lack of supply in culturally competent providers for people from NESB, with potentially acute problems for some language groups in some geographic areas.	• Funding support to establish and maintain specialist multicultural / non English language brokerage schemes. • Funding support to establish and maintain specialized multicultural providers. • Flexibility needs to be built into standards and guidelines. • Capacity for brokers and providers to employ / sub contract multi-lingual staff • Capacity for broker to enable family member as formal carer. • Interpreting at no cost to consumer. • Cultural competence frameworks need to inform promotion, intake and assessment procedures for all providers. • Funded Multicultural Advocacy

Direct Payment to the Person to Spend in an Open Market.	Direct allocation of funding to person with disability to purchase their own services.	This model has potential in offering a range of providers that might meet the needs of NESB clients. Brokerage will be essential for many consumers, particularly those without the skills to coordinate service deliver, manage networks or work within budgets. The problems associated with market failures remain, with potential lack of supply in culturally competent providers for people from NESB, with potentially acute problems for some language groups in some geographic areas.	• Funding support to establish and maintain specialist multicultural brokerage schemes. • Funding support to establish and maintain specialized multicultural providers, with flexibility and capacity to contract multi-lingual staff. • Capacity for person with disability to employ family member as formal carer • Interpreting at no cost to consumer. • Cultural competence frameworks need to inform promotion, intake and assessment procedures for all providers. • Funded Multicultural Advocacy