EDAC
Ethnic Disability Advocacy Centre

Response to the Productivity Commission's Draft Report – NDIS and Disability Care and Support

Creating a scheme that is inclusive of people with a disability from a culturally and linguistically diverse backgrounds

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About EDAC

The Ethnic Disability Advocacy Centre (EDAC) is Western Australia's peak not-for-profit organisation which advocates for the rights and interests of people from Culturally and Linguistically Diverse (CaLD) backgrounds with a disability and their family carers.

The current system of disability services has resulted in numerous examples of systemic disadvantage for our client group which we have addressed in previous state and federal consultations. EDAC welcomes the federal government's initiative to revolutionize the disability system for the betterment of PWD's (People with Disabilities) nationally.

In particular, EDAC appreciates the opportunity to provide input to the Productivity Commission's draft NDIS report. EDAC has undertaken a number of consultations with clients and service providers. We have also provided input to consultations conducted by the National Ethnic Disability Alliance (NEDA) and the Disability Advocacy National Association (DANA) and would like to support their submissions to the Productivity Commission.

General Comments

The NDIS and NDII proposals represent an overall, improved disability system that provides stability of funding and a potential to achieve best outcomes for people with disability as well as national consistency in disability services and supports. The separation of NDIS & NDII is practical as it would meet the specific needs of people with catastrophic injury and those with other medical conditions. It would increase funding avenues and resources for the both schemes.

In our response to the Commission we will predominately focus on areas of concern for People with Disability (PWD) from Culturally and Linguistically Diverse (CALD) backgrounds and their families/carers.

Assessment and eligibility for CaLD people with disabilities

EDAC is pleased that the NDIS is for all Australians, in what seems to be a universal scheme. It claimed to provide a number of supports and services, depending on the person's disability types and circumstances. The assessment and planning process would be a layered approach and the Disability Support Pension is outside the NDIS.

The detail of this scheme is limited in some sections as it's still at planning stage. However we have particular concern with the Tier 3 assessment and how it would impact on people from CaLD background with disability, as it's supposed to target a much smaller group of people. Currently many disability service provisions criteria and payment rates are based on not just income but whether the person is in receipt of centrelink benefits or similar entitlements. It is our understanding that some migrants with disability are precluded or disadvantaged because they are not eligible for the DSP and other benefits due to the residency ruling. For example, there is a 10 year residency period before one is eligible to apply for the DSP and a two year period for other centrelink benefits for migrants. This situation has limited the eligibility for support services and is causing much hardship and grief to the person with disability and their family.

For example, people from CaLD backgrounds who are visually impaired and not in receipt of the DSP have been disadvantaged from receiving orientation & mobility support and visual aids assistance. HACC services and rates of payments are equally subjected to eligibility of Centrelink benefits.

Being a universal system, EDAC believes that the NDIS should be accessible for people with disability who are currently holding 457 visas and full fee paying international students with disabilities, in accordance to the UNCRPD principles, which Australia is a signatory to. We have seen the hardships and the fracturing of family structures due to poverty circumstances especially with migrants (previously refugees) who chose to come to Australia via New Zealand. We believe this is a basic human right and there is a moral obligation for Australia to address this problem whether through bilateral agreement with NZ or undertake some concessional measures.

EDAC is also concerned that there is little acknowledgement of the needs and barriers faced by people with disabilities from CaLD backgrounds except the fact that CaLD communities experience lower utilization rates and "catch up" will only occur if CALD specific needs are accounted for and targeted.

According to NEDA's (2010) data analysis,

- More than 1 million people with disability are from non English speaking backgrounds.
- Some form of recent migration heritage is a characteristic for over 40% of people with disability.
- There is a higher prevalence of impairment for people born in a non English speaking country aged over 45 years of age, especially for 'first wave' non English speaking migrants, up to 3 times that of the Australian born population.
- All people with disability face barriers to social participation – access to employment, technology, social activity and economic wellbeing - however people from non English speaking countries are likely to face deeper forms of marginalisation.

EDAC recommends that the complexities and vulnerabilities of PWD from CALD backgrounds be acknowledged in the implementation of NDIS & NDII to ensure that this group is not marginalized, exploited or "worse off" under the proposed scheme simply due to a lack of English understanding of how the system will work, that is, from eligibility to implementation.

We are pleased to note that there is a good representation of Aboriginal specific needs but we would like to see a similar undertaking for people from CaLD backgrounds. We strongly encourage research and ongoing monitoring of the impact for CaLD people with disability throughout the NDIS implementation process so as to avoid unnecessary grief and suffering by this cohort.

This assessment and monitoring should include feedback from PWD themselves within the trial period, to ensure that they are receiving the supports that they require for full participation within the Australian society. Directly engaging the people with disability involved in the trial period within the assessment and monitoring process will ensure that the voices and concerns of people with disability are brought to the fore, as the primary beneficiaries of the espoused system. Too often, the voices of carers and families have been prominent in Australian disability public policy debates, which in turn have overridden the realization of the rights of people with disability (Soldatic and Chapman 2010). Given the significance of the proposed scheme for people with disabilities and their participation within mainstream society (Soldatic and Pini 2011), it is critical that people with disabilities' feedback is prioritized above all other interests group, that is, families, carers, services and government, as ultimately this scheme directly impacts upon their democratic right for full participation within Australia's Liberal Democratic system.

Language needs and culturally responsive service delivery.

EDAC believes that although the Language policy is in existence for some time it has not being adopted or understood in the full extent by service providers. EDAC would like to see the language policy being clearly articulated in the NDIS, including cultural competency training for all staff (especially NDIS Assessors) and evidence of its applications across all service delivery. There should be ongoing evaluation and monitoring of service quality in this regard.

We also like to see an assurance that the cost of using professional language interpreters including Auslan, is not deducted from the individual's funding allocation, as language needs is not a disability. People who are not proficient in the English language should have access to professional interpreter services at all times, when navigating the system of NDIS.

Advocacy

We are disappointed that there was little mention of Advocacy support services in the Productivity Commission’s Draft Report. EDAC believes that professional and independent advocacy is crucial to equity and fairness in the implementation of the NDIS. Advocacy is especially critical for people from CaLD backgrounds with disability in order that they can access the system appropriately and are involved in the choices and decision making processes. Advocacy will assist them to effectively communicate their wishes and hopefully prevent unnecessary exploitation and discrimination as the lack of English language skill and understanding of the bureaucratic system may result in them not utilizing the vital services that they need. At the same time it would help assist service providers to better understand the cultural and linguistic needs of this group. Systemic advocacy can also play a key role in addressing anomalies and policy reforms to protect the rights of this vulnerable group.

Rural and remote issues

EDAC is concerned with limited reference made on the needs of people with disability living in rural and remote regions and the disadvantages they are facing in accessing disability services. The geographical landscape and the tyranny of distance are major barriers to establishing disability services in regional and remote areas such as in West Kimberley of Western Australia where EDAC has established an advocacy service, spanning over a 1000km radius. Disability access and housing shortages are crucial issues for residents.

EDAC welcomes the recommendation to provide travel funding for specialist support? However we are doubtful that *the fly in fly out* system will be acceptable by some locals. The flexibility of self directed care may assist in some regions but the cost of living and workforce issues are presenting problems. Additional remote allowance, attractive remunerations and incentives should be considered to encourage workers to remain and reside and work in those regions. There needs to be greater flexibility and innovation in the purchase of care and support in rural regions. Meaningful culturally appropriate consultation with people with disabilities, families and the communities before full scale implementation of the NDIS occurs is essential.

Individualised funding, market forces and consumer choice

EDAC supports the *real* choice for people with disabilities and their options to choose their service providers and exiting them when they are not satisfied with the assistance and support given. We are in favour of self- directed and individualised funding that would allow this to occur on the proviso that it would lead to better outcomes and satisfaction for many disability service end-users. However we have reservations on how achievable and realistic these options are within the current marketised framework of the NDIS, which as it currently stands, outlines limited engagement for end-users within the overall service governance structures of the organisation to feedback effective feedback in an ongoing manner.

User involvement draws upon two very different ideologies: a *consumerist* approach, …, with its embrace of a neoliberal agenda for more efficient and effective public services through market competition, and a *democratic/participatory* standpoint articulated by the disabled people's movement. This democratic approach stressed a 'choice agenda' that embodied citizenship and user rights to participate in public sector decision making as part of a wider project for the empowerment and social inclusion of disabled people, and to revitalise democratic governance in general.

Barnes and Mercer, 2011, p. 150-151, original emphasis.

As noted by the proceeding statement too often governments have interpreted the disability rights movement for having greater control and power over the governance of the disability service system as support for a fully "marketised" system of support and care (Roulstone and Morgan 2009).

The general tendency to interpret and conflate 'individualised direct payments' within fully marketised and privatized services by public officials (French and Swain 2008), such as displayed within the Productivity Commission's Draft Report, tends to limit people with disabilities' democratic control over the disability service system.

The "strong market economy" through a centralization approach in the Draft report may foster a culture whose primary motivation is profit making, agency competition, accreditation & regulation.

We are aware from the research emerging internationally that both quasi- market and full market models can result in diminishing 'choices' within the 'care market' as many small, non-profit services are unable to survive these competitive market models. The NDIS Draft Report also acknowledges that this may be the result of the full marketisation of disability services.

Finally, the commitment to pure market mechanisms within the disability service system does not recognise the unique level of vulnerabilities for many people with disabilities who have experienced multiple forms of abuse and exploitation in their care arrangements. This includes both informal care arrangements and formal care arrangements. The model assumes that people with disabilities will be able to 'vote with their feet' and move to another service if they are unable to have their needs met within their current service provider or, have found that service to be abusive or exploitative. This assumes a level of indepth knowledge about the 'available' choices within the care and support market. It also assumes that this information is readily available in Plain English Formats and other languages that are accessible to people with disabilities, particularly those within EDAC’s – people with disabilities from Culturally and Linguistically Diverse Backgrounds.

In order for self-directed' services to be realized, disability support services need to ensure that people with disabilities, as end-users of services, are active participants in the governance of the organisation so that issues are readily identified and addressed in accordance with their needs and requirements.

These issues are particularly pertinent given the fact that there is no funding structure applied for advocacy services which work to protect the interests of disability service users who are supposed to be the ultimate beneficiaries of these services as a right of citizenship of the Australian state.

Ageing and Disability

Notions of ageing are culturally relative and there is no exact nor consistent meaning of old age across cultures (Ranzijn,2010). Further, cultural understandings of ageing become more complex once this process becomes associated with the development of an impairment and disability (Priestley, 2003). As Priestley (2003, 143-163) notes, ageing with a pre-ageing impairment and disability has a very different lived experience to those who acquire a disability through old-age as conceptualised within white western cultures. People who have an impairment and disability prior to ‘old-age’ interpret, understand and experience their bodies as a continuum of one’s life journey, where as those who have acquired an impairment and disability through the ageing process view the disability as an inevitable but necessary disruption as moving closer to death.

In turn, disability services and ageing services have historically developed to reflect these cultural interplays of the body and therefore, the delivery of disability services to that of ageing services are distinct. Thus, drawing upon the rich body of the empirical research that maps out socio-cultural understandings of ageing and how this intersects with social interpretations of impairment and disability strongly suggests that people with disability who are entering the ‘ageing’ process should maintain access to both systems, where they are able to decide upon their individual needs through their own interpretation of their bodily and impairment changes.

Option Two, is far more consistent with this research and would empower people with disabilities to have control and choices of the types of services they wish to engage with, dependent upon their own understanding of their bodily changes.

EDAC therefore disagrees that after they reach pension age, the person with a disability would be subjected to a co-contribution arrangement set out by the Commission in its parallel inquiry into aged care based on a means test agenda.

If a person elected to continue to use the NDIS care arrangements, the assessment tools from that system would be used to determine their funding, and the person would continue to receive supports through the NDIS. This would ensure that people who acquired a disability before the pension age would have the assurance that they would not get a different level of care and support or having to make a co-contribution.

People who acquired a disability prior to retirement age would not have accumulated any sizable wealth due to the cost of the disability and perhaps working in minimum wage positions. It should be regarded as a work incentive if they have collected some superannuation and therefore should not be penalised.

EDAC prefers option 2 as the better way to support people in retirement as this would offer them more opportunity to remain and access their existing systems of support.

Funding and auditing process

EDAC has concerns with the premise of “natural supports” on page 17 and recommends that family supports be paid for caring for their family member (not just in rural & remote regions as proposed). EDAC recommends that the benchmarking criterion for the CALD community considers the complexities mentioned above in the community caring role for CALD & Indigenous groups and should consider paying the family supports just like paying for external supports, as most families may opt to care for their family member rather than use an external support system. This is especially important if the family member from a CALD background is caring for a PWD who has a “significant disability” and has very high support care needs.

EDAC recommends that the “support needs” within the CALD community be reasonable and culturally responsive in the benchmarking criteria. For example, if a service requires a longer contact time due to the use of interpreters, then the funding benchmark for the CALD PWD needs to be higher. Within the CALD community, clarification about “support needs” within the assessment process may be unclear due to the complexities of the inter-relationships and caring role of family members within the community. However, in a relationship situation, if the partner is the carer and possibly abusive there needs to be safeguards in place to protect the person with the disability.

EDAC recommends that Service Support Standards should be audited at least once a year & it should not only stem from complaints. Annual monitoring should be mandatory (at any given time of the year) with a reasonable time for notice. EDAC welcomes the national regulation of service support standards and the assessment structure be culturally relevant and meaningful.

The approach should focus on effective safeguarding and raising the actual quality of supports, rather than 'paperwork' initiatives, which would do little to ensure quality assurance but would impose compliance burdens on specialist disability service providers.

Data Collection and Research

EDAC recommends a commitment to data collection and research especially in the areas of cultural diversity and issues in rural and remote regions. There is a scarcity of accurate data relating to the both areas mentioned.

An important role of the NDIS would also be to minimise the impacts of disability. By drawing on its data and research capabilities in engaging with various communities into the effectiveness of disability support may result in reducing the prevalence of disability.

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