RHeaNA
Refugee Health Network of Australia

Refugee Health Network of Australia (RHeaNA) feedback to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS): Independent Assessments

RHeaNA is a national multidisciplinary network comprised of health, mental health, policy and community professionals with expertise in refugee health. RHeaNA was formed in 2009 and provides linkage for state and territory refugee health networks as an avenue for sharing of knowledge, development of best practice guidelines in refugee health, and for policy development. This submission is based on RHeaNA's collective experience of the challenges faced by people from refugee backgrounds in accessing the NDIS and navigating disability services.

This feedback has been structured around the Inquiry's Terms of Reference (ToR) and based on review of the following documents:

- Independent Assessment Framework August 2020
- NDIA Culturally and Linguistic Diversity Strategy 2018
- Queensland Transcultural Mental Health Centre, Amparo Advocacy Inc and the Refugee Health Network Qld feedback on the Consultation paper: Access and eligibility policy with independent assessments (IA).

RHeaNA recognises the NDIA Culturally and Linguistic Diversity Strategy 2018 and the ongoing work of the NDIA in responding to the challenges of diverse community members with disability in accessing and navigating the NDIS.

A. The development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS

In the current format we see considerable inequity in access to the NDIS - the scheme relies on an individuals'/carers' ability to access and navigate paths for assessment and therapy. Diagnostic assessment (and monitoring/therapy) may occur through either/both of the public or private sectors. Further, assessments may be concurrent, or sequential and multiple assessments of different domains may be required.

Refugee background communities and individuals face challenges navigating the health and disability service systems, which contributes to inequity in NDIS access. These challenges include financial instability/barriers, language barriers, variable health literacy, different cultural understandings of disability, and limited knowledge of the NDIS. These challenges are typically amplified for new arrivals, who experience multiple competing demands after arrival as they settle in Australia.

While the NDIS focus is on function, entry into NDIS is based on diagnosis, and new refugee arrivals with disability may not have a formal diagnosis. People from refugee background who are settled under Australia's Humanitarian Programme are subject to a health waiver and hence some arrive with complex health and disability issues. People over 7 years of age are unable to access NDIS until they have a formal diagnosis, which creates substantial delays for Humanitarian arrivals with disability. It is especially important that the NDIA identifies and supports this small but significant

cohort, working closely with Department of Home Affairs, refugee health services, settlement services and other key providers to enable timely access to the NDIS.[1]

Independent assessments could be a valuable mechanism to ensure the scheme is equitable and accessible for individuals who need NDIS, however it is essential to ensure that the independent assessment process does not perpetuate inequity.

B. The impact of similar policies in other jurisdictions and in the provision of other government services

The NDIS supports people in their daily lives, and helps them participate in their community and reach their goals - if IA are to promote equitable access, we suggest the following:

Effective use of (independent) collateral information to enrich the independent functional assessment. If people have diagnostic or functional assessments through government funded services (hospitals, community health, community mental health, public health, or torture trauma services), or if they have a clear diagnostic assessment from overseas - these should be considered as part of the IA.

Clarity on inclusion and funding of language services - the early stages of NDIS rollout did not provide clarity on interpreter funding, which led to differential access and effectively reduced packages for participants of language other than English (LOTE) background who needed interpreting assistance (LOTE-I). There have also been examples of previous contracts for the Humanitarian Settlement Program (HSP) that did not (initially) include funding for interpreters. If language services are not included from the earliest planning stages, the NDIS will effectively exclude and discriminate against the 3-4% of people in Australia who need interpreter assistance.

Access to accredited interpreters who have knowledge of the concepts and terminology of the NDIS is critical to the delivery of an IA. The National Accreditation Authority for Translators and Interpreters (NAATI) provides accreditation and specialist medical interpreting training. Equitable, culturally safe and inclusive IA will not be achieved for people with low English proficiency if assessors don't have access to an interpreter workforce with the appropriate skills.

Independent assessors need to be able to integrate language services into their practice. Allied health professionals (AHP) within Australia have not had free access to Translating and Interpreting Services (TIS) National so most will be unfamiliar with the process of interpreter engagement and working with interpreters. Where interpreters are not available or not utilised for LOTE-I patients, this should be documented.

[1] There are often long waits for diagnostic assessments, particularly for adults. Children born in Australia usually experience a stepwise evolution of diagnosis - i.e. they present with developmental delays and then go on to receive a formal diagnosis, which is then available on transition from Early Childhood Early Intervention (ECEI) into NDIS for those 7 - 65 years. Alternatively, if an adult develops an acquired injury or disability this is usually assessed within the health care system, which then enables their access into the NDIS. Refugee arrivals may have complex disability, but they will not have a formal diagnosis within the Australian system, which complicates and delays their access to NDIS.

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<u>We recommend:</u>

1. Inclusion of other independent health/disability reports in the IA processes (i.e. overseas diagnostic reports, or functional assessments provided through government funded services e.g. hospitals, community health, community mental health, public health, or torture trauma services).
2. NDIA provision of training for independent assessors on appropriate interpreter engagement and how to access TIS National.
3. Ensure NAATI medically accredited interpreters are available for IA for LOTE-I participants. Where accredited interpreters are not available or not utilised, this should be documented.
4. That NDIA work with NAATI and TIS National to enable training for the interpreter workforce ensuring adequate knowledge of the concepts and terminology of the NDIS.

C. The human and financial resources needed to effectively implement independent assessments

RHeaNA supports the NDIA in addressing financial and other barriers to accessing assessments: The Independent Assessment Framework states (p27) *'An assessment of functional capacity should be provided free of cost as part of an uncomplicated and clear access pathway in order to reduce the impact of any financial, social, cultural and functional barriers that may exist for an individual'*; and also that *'changes to the assessment process should seek to level the playing field so that financial, cultural, social factors do not contribute to delays or barriers to accessing the scheme'* (p8).

> There are already substantial barriers for refugee background participants to accessing NDIS and independent assessments should not become an additional barrier.

People from refugee backgrounds may not have the language, confidence or self-advocacy to describe their disability or function. There may be further complexity for people of refugee background related to cultural concepts or stigma around disability, and for those who have experienced torture or trauma which may affect their experience of i) disability and function, and ii) the assessment process.

Independent assessments should provide a culturally appropriate assessment and develop culturally appropriate formulations, requiring independent assessors to have training in cultural competency, working with interpreters, cross cultural assessment, and developing culturally appropriate formulations, with clear articulation of these principles within the IA framework and contractual agreements.

The process of formal assessment may be culturally foreign for refugee-background participants, and provisions for a trusted person to attend the IA process are essential. A trusted person can assist with collateral information for the IA, as well as information on cultural requirements.

Increased time will be required to complete IA with an interpreter - the Framework provides a timeframe of 3 hours - when working with an interpreter, everything is said twice - effectively meaning <u>LOTE-I participants are allocated half the time of other participants</u>.

<u>In order for an equitable IA process to be operationalised we suggest the following:</u>

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5. Training and monitoring to ensure assessors are able to perform trauma-informed cross-cultural assessments and develop culturally appropriate formulations, with ongoing evaluation of independent assessments and their practical implications for refugee-background participants.
6. Provisions to allow a trusted person to attend the IA process.
7. Unfettered access to interpreter services where needed, which will require funding (as per 22), training for AHP (as per 2) and training for interpreters (as per 4) and consideration of dialect and gender where relevant.
8. Increased time (longer than 3 hours) to complete assessments for participants who require an interpreter or where there is significant cultural and/or other complexity.

D. The independence, qualifications, training, expertise and quality assurance of assessors

The NDIS Consultation paper: Access and Eligibility Policy with Independent Assessments (November 2020) outlines that independent assessments will be undertaken by '*qualified health care professionals*'.

Clarification of the level of qualification and seniority for IA-AHP is important - although there are likely to be benefits in having an AHP rather than (non-health trained) planners advising on NDIS entry. There are potential issues with discipline matching and expertise in relation to age cohorts (e.g. a speech therapist will not have the same expertise as a physiotherapist in assessing physical disability, and an adult occupational therapist may be unfamiliar working with young children). We strongly recommend inclusion of other independent AHP reports and experienced providers' perspectives where available (as per 1).

Qualifications, training and expertise of assessors should include skills in working with interpreters and cultural competency. A large proportion of AHP (in private practice) have not previously had (free) access to interpreters through TIS, it can be assumed that they may have limited familiarity with working with interpreters and will require training (as per 2 and 5).

We recommend:

9. Further detail on the qualifications, discipline and seniority of the AHP within the Framework, tender documents and contractual agreements.
10. Attention to governance, quality control mechanisms, and probity - we note recent media reporting on subsidiary companies and the potential for conflict(s) of interest. This will also require adequate data collection on migration related indicators (as per 21)

E. The appropriateness of the assessment tools selected for use in independent assessments to determine plan funding

Assessment tools identified by the NDIA should be high quality, reliable, applicable and validated across different cultural and language groups. The suite of assessment tools should also incorporate guidelines on cultural considerations in relation to engagement, completing assessments and interpretation of results. As noted in the Independent Assessment Framework (NDIA, August 2020) '*the same instrument, used in a different setting or with different subjects can demonstrate wide variation in reliability' (Cook et al, 2006, p13). Hence tools which have not been used across different cultural and linguistic groups may not have enough reliability or validity*'.

The WHO Disability Assessment Schedule (WHO-DAS) shows good validation, and the domains/questions are a good match for NDIS domains, we suggest considering use of the child module when it is finalised. The WHO translations are directed to same language clinicians within same language populations, if self-report (in language) is used then translation will be required; if interview (with interpreter) is used then extra time will be needed (as per 8).

The cross-cultural validation of the other instruments is less clear and not discussed in the framework. Use of tests across languages (and with interpreters) and consequent validity issues are also not considered in the framework. It will be important that the NDIA tracks the validity of these tests with time, updates guidelines to consider participants without English language proficiency, and allows extra time to complete testing for participants requiring interpreter assistance (as per 8).

We recommend:

11. Ongoing piloting, monitoring and review of the assessment tools in consultation with key stakeholders, including AHP providers from CALD background, CALD communities, specialist CALD and refugee services, consumers, researchers and policy makers. This should include compilation of an inventory of assessment tools and their validity and measurement attributes.
12. Flexibility in contractual agreements to amend processes and assessment tools as required.

F. The implications of independent assessments for access to and eligibility for the NDIS

The framework needs to articulate that cultural safety is a key element of an accurate IA process and that added complexities are likely to exist for people of refugee background. Cultural context will impact the IA process and access to the NDIS - due to factors including life experiences, beliefs around function/disability, trauma experience, formal education opportunities, lack of familiarity with formal assessment, and language and cultural dissonance with the assessment tools/processes.

The IA process could become a useful safety net for the most vulnerable NDIS participants. While IA are intended to provide a comprehensive functional assessment by a qualified AHP, diagnostic assessments are required for access to the NDIS. The framework notes that *'some people present with a degree of complexity that requires more in-depth deliberation than assessment findings can provide on their own. The complexity, nuances and intertwining of factors may need to be examined more closely'* (p 24). An AHP is well placed to identify gaps in diagnostic assessment and could then link participants with appropriate services and allocate NDIS funding to address these gaps.[2] This would enhance the value of the IA process as a screening tool and adjunct assessment.

We recommend:

13. That the IA framework and contractual agreements clearly articulate the need for cultural safety in assessments - alongside training and monitoring (as per 2, 4, 5 and 20).
14. Using the IA process to identify and address gaps in diagnostic information, link with services, and avoiding delaying NDIS entry.

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[2] As an example, a participant may have clear evidence of an intellectual disability and a quadriplegia, but not have had either formal cognitive or physiotherapy assessment - an IA-AHP could assess function, refer for diagnostic services, and allocate NDIS funds while the participant is awaiting cognitive assessment.

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G. The implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports

NDIS planning should proactively consider language and cultural factors in funding reasonable and necessary supports. Systemic and structural factors such as participant understanding of the NDIS and Australian health system, lack of culturally appropriate disability and AHP services, limited resources in language, engagement with interpreter services and availability of culturally appropriate service delivery also need to be considered. These barriers to NDIS access will not be rectified by an IA alone.

Culturally appropriate formulations, and cultural safety are also key components of NDIS planning and determining reasonable and necessary supports, requiring independent assessors to have training in cultural competency, working with interpreters, cross cultural assessment, and culturally appropriate formulations (as per 5), and clear articulation of these principles within the IA framework and contractual agreements (as per 13).

<u>We suggest the following additional strategies should be considered:</u>

15. Active recruitment of existing culturally capable AHP and a diverse workforce; and provision of support for CALD AHP, including those with overseas qualifications.
16. Support coordination should be offered as a fixed budget item for refugee-background participants to ensure supports are enacted and enable connection with culturally appropriate services, and support coordination services should be monitored.

H. The circumstances in which a person may not be required to complete an independent assessment

Severe disability in itself may mean the IA process is unnecessary and potentially traumatic, and consideration should be given to using existing medical and AHP reports and collateral information in this circumstance. The NDIA acknowledges the importance of 'a consistent point of contact for participants to provide the opportunity to build trust, deep understanding of their culture, needs and a longer-term strategy for investment by a participant in their goals' (p4, NDIA Culturally and Linguistic Diversity Strategy 2018) - an experienced independent provider (e.g. refugee health paediatrician, general practitioner, physician or an AHP) who knows the participant is arguably this consistent point of contact. A one-off functional assessment should not be afforded greater weight than a comprehensive assessment by a long-term, trusted, and independent health provider.

Mental health conditions may, in some circumstances, need to be considered as an exemption to an independent assessment. Mental health conditions such as severe post-traumatic stress disorder (PTSD) may affect engagement with an assessor and an inappropriately conducted assessment could cause further trauma and deterioration. Advice from current care providers needs to be considered carefully.

Exemptions should be made for participants where there is no NAATI qualified interpreter available for the IA. There are multiple emerging languages in Australia where no accredited interpreters are available, and some minority languages have a very limited interpreter workforce. Family and friends cannot substitute for an interpreter.

<u>We suggest:</u>

17. Provision for exemptions from IA within the IA Framework, and scope to consider collateral information from other independent sources (as per 1).

I. Opportunities to review or challenge the outcomes of independent assessments

The proposition that the IA are non-reviewable is not appropriate and will impact quality assurance and governance. In the current IA framework, the IA is not reviewable, which raises serious concerns. Most of the proposed assessments have not been validated across languages/cultures, and interpreters may either not be available, or not be utilised. The lack of review prevents quality assurance and oversight of the IA process, and means a one-off review carries greater weight than a comprehensive assessment by an experienced independent provider.

We recommend:

18. A transparent and accessible mechanism to seek review of the IA that is open to both participants, and their healthcare providers.

J. The appropriateness of independent assessments for particular cohorts of people with disability, including … people from culturally and linguistically diverse backgrounds

This submission broadly relates to the appropriateness of IA process and framework for people of refugee background. Additional considerations are included below.

The NDIA Culturally and Linguistic Diversity Strategy 2018 **notes that further_engagement with CALD and refugee-background communities is crucial** to understand concepts of disability, stigma, and what is considered a meaningful 'good life' in their cultural context, and suggests this should occur prior to the implementation of IA. Providing quality education and discourse can raise expectations around the rights of an individual with disability and supports available and empower them to articulate their needs during the assessment process.

The framework does not articulate how cultural factors will be addressed, and it is not evident whether the IA pilot included CALD participants or individuals requiring interpreters. The engagement of CALD communities in the design of the framework is also unclear.

19. Consultation with peak bodies and CALD communities on implementation of independent assessments - including via the National Refugee Led Advisory and Advocacy Group (NRAAG), and the Federation of Ethnic Communities Councils of Australia (FECCA).

K. The appropriateness of independent assessments for people with particular disability types, including psychosocial disability

Refugee background participants may have experienced torture and/or trauma which may be related to, or the cause of their disability (e.g. physical disability, acquired injuries resulting in cognitive impairment, or psychosocial disability). Experience of torture/trauma may also impact people's experience of interacting with government structures and/or formal assessment processes. This may be a reason to use (independent) collateral information within the IA (as per 1), allow participation of a trusted person in the assessment (as per 6) and consider exemptions to assessments (as per 17). The Cultural and Linguistic Diversity Strategy (2018) does not reference either trauma or stigma around disability, both are important in understanding disability in refugee background communities.

20. In addition to training on cross cultural assessments and working with interpreters, consider including specialised training on the impact of torture and trauma.

L. Any other related matters

More vulnerable cohorts, including those of refugee background, may be disadvantaged by the free-market tendering approach unless the commissioning process actively considers complexity, and clearly specifies KPIs for IA services. The tender process, commissioning agreements, KPIs and reporting requirements must consider cultural safety, inclusion of vulnerable cohorts, use of language services and provision of cultural training. Reporting should have adequate information to analyse CALD populations (as per 21), and contract arrangements must have accountability to address gaps and shortfalls where they are identified.

Maintaining NDIS access lists will support access for refugee-background and other diverse populations. Individuals will still require a diagnosis to enter NDIS - while substantial delays to gaining a formal cognitive, psychosocial or physical/sensory disability assessment persist, the use of diagnosis-based access lists can be helpful, especially where individuals have past diagnostic assessments, including from overseas.

Extending the early intervention (EI) period up to age 9 years will offer considerable advantages to new arrival and vulnerable children. Extending the EI period to 9 years separates the EI process from school entry, reducing load on families at a critical transition point, and also enabling a safety net of further assessments, monitoring and supports within the early school years.

NDIS information accessibility is a priority - as identified in the NDIS CALD Strategy (2018) (p16). The Strategy recommends that information should be in participants 'preferred language, media and format, including verbal, visual, multimedia, written and audio that will be accessible to a range of literacy and ability levels'. However, the current NDIS website only has 12 languages translated and information is only available in written format. The automated audio function on the website does not provide a clear interpretation of the content and there is no interpreted or translated information regarding the IA process. The FAQ on the Independent Assessment webpage is only in English, and does not provide alternative languages or accessible formats.

We recommend:

21. Adequate data collection on migration related indicators[3] and ensuring inclusion - also matching data to local population data to assess inclusion and equity. Reporting requirements should include collection of minimum CALD data (country of birth, language spoken, interpreter required, year of arrival in Australia and ethnicity/cultural background). This will enable quality assurance and measurement of diversity within the NDIS and IA processes.
22. Funding for interpreters should be outside tender requirements to avoid inadequate budgeting for interpreter provision and interpreting service occasions should be included as a KPI in tendering processes and in reporting on IA delivery.
23. The NDIA should develop, evaluate and monitor tenders carefully, ensuring they address complexity and cultural diversity in their structures. The NDIA should liaise with experts in the

[3] FECCA (2020) If we don't count it - it doesn't count! Towards Consistent National Data Collection and Reporting on Cultural, Ethnic and Linguistic Diversity. https://fecca.org.au/if-we-dont-count-it-it-doesnt-count/

CALD/refugee disability space to provide in-confidence advice where there is uncertainty in the development or evaluation of tenders.

24. Extending the time period for early intervention to age 9 years.
25. Information about the NDIS and the independent assessment process (assessment, expectations of assessors and appeals and complaints process) needs to be accessible in multiple languages and culturally appropriate. Information should be available in multiple formats including written, audio and visual; taking into consideration people with low literacy and that some languages do not exist in a written format. Independent assessment reports should be translated for participants without English proficiency.

Conclusion

RHeaNA supports the delivery of the NDIS 'in a way that is sustainable and responsive to the needs of our richly diverse and multicultural nation' (NDIA Culturally and Linguistic Diversity Strategy 2018, p 3). For this to be achieved, the IA framework needs to prioritise cultural and language diversity and the needs of people from CALD and refugee backgrounds. A tendering and independent assessment process that ensures equity will ensure equal opportunity for NDIS participation and ultimately successful community engagement. This will help realise the NDIA Culturally and Linguistic Diverse Strategy 2018 vision (p6) that 'people with disability from CALD backgrounds participate socially and economically in their communities and experience wellbeing on an equal basis with others in our community'.