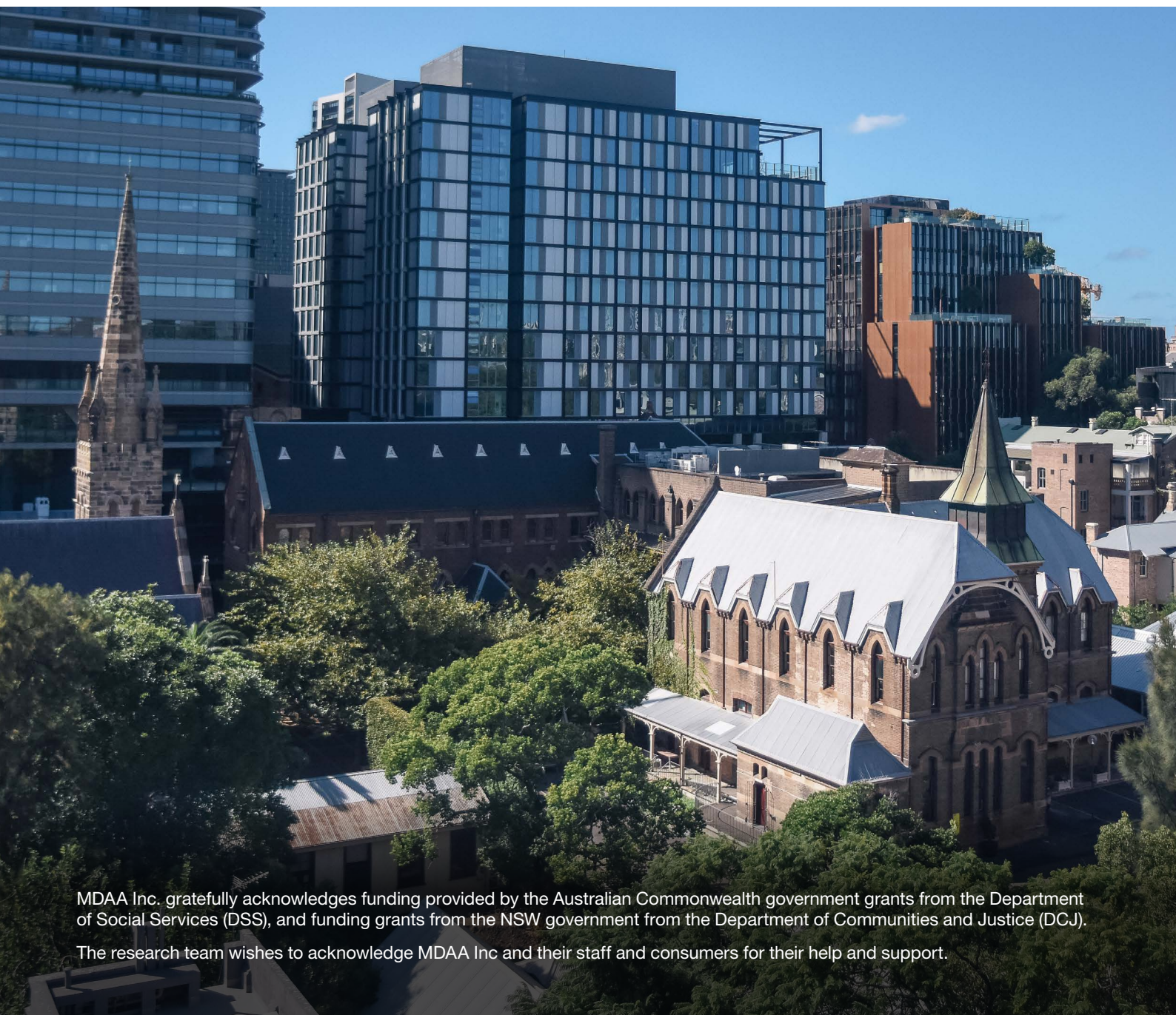


An Evaluation of NDIS Appeals and Review: Experiences of Culturally and Linguistically Diverse People with Disability, their Families and Carers

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Acronyms

AAT	Administrative Appeals Tribunal
ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
CALD	Culturally and Linguistically Diverse
CEO	Chief Executive Officer
DSP	Disability Support Pension
DSS	Department of Social Services
GP	General Practitioner
ILC	Information, Linkages and Capacity Building
LAC	Local Area Coordinators
MDAA	Multicultural Disability Advocacy Association
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NEDA	National Ethnic Disability Alliance
NES	Non-English Speaking
NSW	New South Wales
OT	Occupational Therapist
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNDA	The University of Notre Dame Australia

1. Executive summary

In 2013, through the National Disability Insurance Scheme Act (Cth) changes were made to how disability support is provided to people with permanent and significant disability in Australia. The National Disability Insurance Scheme provides individualised funding packages for eligible people with significant and permanent disability to meet their care and support needs.

While the National Disability Insurance Scheme rolled out across Australia in 2018, the number of people from Culturally and Linguistically Diverse backgrounds with disability accessing the National Disability Insurance Scheme is below predicted figures and the number of people from Culturally and Linguistically Diverse backgrounds with disability in Australia.

Furthermore, the Multicultural Disability Advocacy Association, which is based in New South Wales, anticipates that based on their experience, people from Culturally and Linguistically Diverse backgrounds with disability would have difficulty seeking a review of a decision or appealing a decision made by the National Disability Insurance Agency. The National Disability Insurance Agency determines National Disability Insurance Scheme eligibility and the funding and supports granted to a person with an individualised plan.

This report presents the findings of an evaluation of the National Disability Insurance Scheme review and National Disability Insurance Scheme appeals process as experienced by people from Culturally and Linguistically Diverse backgrounds with disability, their families and/or carers and staff at the Multicultural Disability Advocacy Association working in this space.

Following in-depth interviews with consumers and staff from the Multicultural Disability Advocacy Association, this research found that a significant proportion of people from Culturally and Linguistically Diverse backgrounds with disability, their families and/or carers have difficulty with not only applying for the National Disability Insurance Scheme, but also with the National Disability Insurance Scheme review and National Disability Insurance Scheme appeals process. Difficulties with applying for the National Disability Insurance Scheme, seeking further funding and supports, and with the review and appeals process translated into a lack of support, reliance on other people and services, and exacerbation of existing conditions. This was caused by:

- unclear evidence requirements;
- the cost and type of evidence required;
- a lack of consideration of languages other than English in information, correspondence, and materials;
- a failure to consider cultural interpretations and understandings of disability;
- a complicated, lengthy and time consuming process;
- unclear communication;
- power inequalities between the system and the applicant with disability, their families and/or carer.

Based on these findings, several key recommendations are made around accessing the National Disability Insurance Scheme, appealing a decision and the review and appeals process. Recommendations are also made about independent assessments proposed by the Australian government and the National Disability Insurance Agency.

Independent assessments were being debated, but are currently on hold, proposed as an alternative means to determine eligibility for the National Disability Insurance Scheme and assess what supports and funding are required by applicants in National Disability Insurance Scheme participant plans. Independent assessments are proposed as a 'solution' to some of the problems identified with accessing and receiving supports via the National Disability Insurance Scheme. However, independent assessments have been extensively criticised as inadequate by many disability advocacy organisations. The findings and recommendations in this report add further evidence and commentary on why they are problematic.

Generally, the recommendations made in this report include:

- making communication generally clearer and more accessible;
- providing clearer information about the type of evidence required for applications, reviews and appeals and where this can be sought from;
- taking into consideration cultural and linguistic differences;
- ensuring that those engaging with people from Culturally and Linguistically Diverse backgrounds with disability, their families and/or carers have training, knowledge and experience working with people from Culturally and Linguistically Diverse backgrounds with disability, their families and/or carers;
- suggesting methods to address the unequal power relations between the system and the person with disability, their families and/or carer;
- ensuring that organisations like the Multicultural Disability Advocacy Association are funded on a continuing and ongoing basis.
- ensuring that the National Disability Insurance Scheme is in line with the United Nations Convention on the Rights of Persons with Disabilities, to which Australia is a signatory;
- revising rejection letters so that they:
 - are easier to understand for people with disability and people from Culturally and Linguistically Diverse backgrounds with disability, their families and/or carers;
 - recommend support services to assist with reviews and appeals;
 - recommend alternative supports while a person is ineligible or waiting on further funding and supports;
 - include the details of advocacy organisations and mental health support services.

2. Introduction

The National Disability Insurance Scheme (NDIS) was legislated in 2013 and commenced in full Australia-wide in 2018 following trial sites across Australia testing various aspects of the Scheme (Walsh & Johnson, 2013). The NDIS has three tiers consistent with the recommendations of the Productivity Commission report, which investigated the feasibility of a long-term care and support scheme for people with disability in Australia in 2011 (Productivity Commission, 2011). These tiers include:

a. Tier 3: individualised funding packages for people with significant and permanent disability who meet the disability, age and residency requirements (National Disability Insurance Agency (NDIA), 2019; Productivity Commission, 2011);

b. Tier 2: an information, linkages and capacity building program designed for people with disability eligible and not eligible for individualised funding packages, known as the Information, Linkages and Capacity Building (ILC) program;

c. Tier 1: a tier intended to provide protection and insurance to all Australians “in the event that they or a family member, acquire a significant disability” (Productivity Commission, 2011, p. 10). This tier also sought to reduce the impact of disability on people with disability through “promoting opportunities for people with disability” and “creating awareness ... of the issues that affect people with disability and the advantages of inclusion” (Productivity Commission, 2011, p. 12). Additionally, it intended for the data and research acquired by the NDIA, the body in charge of administering, delivering and managing the NDIS (Buckmaster & Tomaras, 2013), to be used “to engage with other agencies to improve public health and safety” (Productivity Commission, 2011, p. 12).

This report is concerned with examining Tier 3 (individualised funding packages) and any reference to the NDIS throughout this report is a reference to this tier.

In Tier 3, packages fund services to meet the care and support needs of people with disability and assist them with social and economic participation. The Scheme was said to be underpinned by the principles of choice and control. Unlike previous disability care and support systems, the Scheme was designed to give people with disability more choice and control over the supports they need and who provides them. The supports they require as well as their goals and aspirations are documented in a NDIS plan. However, the extent to which the NDIS enables choice and control for people with disability has been critiqued in the media, by advocates, scholars, and people with disability (see Australian Capital Territory Council of Social Services, 2017; Cukalevski, 2019; Office of the Public Advocate, 2018; Warr et al., 2017).

This report is particularly concerned with evaluating the NDIS review and NDIS appeals process as experienced by staff at the Multicultural Disability Advocacy Association (MDAA) of New South Wales (NSW) and their consumers. The NDIS review process and NDIS appeals process allows those applying for an individualised funding package or who have an individualised funding package to seek a review of a reviewable decision made by the NDIA. MDAA

“is the peak body for all people in NSW with disability and their families and carers, with a particular focus on those from a Culturally and Linguistically Diverse (CALD)/non English Speaking (NES) background with disability” (MDAA, 2019). In their experience as an advocacy organisation that works closely with people from CALD backgrounds with disability, their families and/or carers who are applying for the NDIS or appealing decisions made by the NDIA, MDAA identified the NDIS review and NDIS appeals process as a potential problem for their consumers. As such, they wanted to evaluate the experiences of their consumers with the NDIS review and NDIS appeals process; understand why their consumers are seeking a review of and appealing decisions; and determine what barriers people from CALD backgrounds with disability, their families and/or carers experience. This report therefore documents the findings of an investigation into the NDIS review and NDIS appeals process for people from CALD backgrounds with disability, their families and/or carers; and identifies systemic problems and opportunities for improvement.

According to the Australian Bureau of Statistics (ABS) for the year ending 30 June 2020, 29.8 per cent of Australia’s population were born overseas (ABS, 2021). According to the 2016 Census, 49 per cent of Australians were either born overseas or had one or both parents born overseas and “more than one-fifth (21 per cent) of Australians spoke a language other than English at home” (ABS, 2017). This could translate into a significant cohort who are eligible for NDIS services but may not understand the application, review and appeals processes due to language, cultural and comprehension barriers. This issue needs to be considered in practical terms otherwise people may miss out on supports they require.

The NDIA, which implements the NDIS, have developed a Cultural and Linguistic Diversity Strategy (NDIA, 2018). The Cultural and Linguistic Diversity Strategy “is the NDIA’s public statement of commitment to working alongside people with disability from CALD backgrounds to achieve access to, and outcomes from, their NDIS Plan on an equal basis with the broader population” (NDIA, 2018). However, despite the Strategy, research shows that people from CALD and Non-English Speaking (NES) backgrounds with disability are experiencing difficulties accessing the NDIS (Mortimer & McMahon, 2018). Data indicates the number of people from NES and CALD backgrounds with disability accessing the NDIS is well below rates of disability documented (National Ethnic Disability Alliance (NEDA), 2019). Furthermore, NEDA has described the strategy as “ineffective” because “it has no implementation plan or real concrete measures” (NEDA, 2019).

Scholars have found that there are certain groups who would have trouble accessing the NDIS for various reasons (see Bigby, 2014a, 2014b; Townsend et al., 2017). However, there is very little academic discussion of the appeals process specifically despite an increase in the number of people appealing NDIS decisions to the Administrative Appeals Tribunal (AAT) in recent years (Young, 2020a). According to Young (2020a), “The Administrative Appeals Tribunal – which reviews federal government decisions – received 1780 appeals related to the NDIS in 2019-20, an

increase of some 727 per cent when compared with the 215 NDIS-related appeals in 2016-17”. Furthermore, “[in] 2019-20, the decision under review was changed in 65 per cent of all finalised applications, up from 59 and 42 per cent in 2018-19 and 2017-18 respectively” (Young, 2020a). While this could be explained by an increased number of people attempting to apply for or accessing the NDIS, then Minister for the National Disability Insurance Scheme, the Honourable Stuart Robert MP suggested in a statement that the increase could also be explained by “inconsistent decisions” (Young, 2020a) and the complexity of the process. He also acknowledged that access to evidence to support an application is costly and unequal with not all Australians with disability able to afford and access quality assessments which document their functional capacity as required for a NDIS application. This has led to the introduction of independent assessments (to be discussed shortly).

This evaluation of the NDIS review and NDIS appeals process found that there are many barriers to accessing the NDIS for people from CALD backgrounds with disability, their families and/or carers, including culture, evidence requirements and a lack of information. It found that generally consumers appealed NDIS decisions for two reasons. Firstly, because their application for the NDIS was denied and, secondly, because the supports and funding provided via their plan was insufficient to meet their needs. Many, however, experienced significant barriers to the review and appeals process and found the process “difficult”. Some conceded that without the help of MDAA they would have been unlikely to get a successful outcome from their appeal and others conceded that they would not consider appealing again. These findings inform the various recommendations that are included throughout the findings section and which are summarised in the recommendations and conclusion section. This research is important because there is little detailed research on the NDIS review and NDIS appeals process and the experience of it, particularly for people from CALD backgrounds with disability, their families and/or carers. Additionally, the research is important because there is a significant change proposed to the NDIS that is currently on hold, but which would affect NDIS applicants and consumers. This change would benefit by being informed by the results of this research. Such change will be detailed in the policy and legislative context section.



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This report is divided in sections.

1. It begins with establishing the policy and legislative context for the NDIS, the review and appeals process and the proposed change to the NDIS. While the proposed change was announced following data collection and analysis, the research can speak to this change hence it is worth detailing.
2. Next the report briefly examines existing scholarly and non-scholarly literature including:
 - a) What existing literature establishes about the experiences of people from CALD backgrounds with disability and the NDIS.
 - b) Existing literature on the NDIS more broadly and the experiences of people with disability.
 - c) The experiences of people from CALD backgrounds with disability with disability services.
3. The next section of the report explains the research design.
4. This is followed by the findings.
5. Then the recommendations and conclusion section.

3. Policy and legislative context

This section will establish the policy and legislative context for the NDIS and NDIS review and NDIS appeals process. It will also outline a key change that has been proposed to the NDIS, and which is likely to have implications for the findings. This is the introduction of independent assessors.

3.1. The NDIS

The NDIS provides a person-centred, self-directed approach to reasonable and necessary care and support for people with permanent and significant disabilities in Australia. It uses an individualised funding model (Buckmaster & Tomaras, 2013) and is a significant shift in the provision and funding of disability services in Australia (National Disability and Carer Alliance, 2018). It is underpinned by the principles of choice and control for participants who can choose the provider of their care and support needs. The need for a new approach to disability care and support was well documented, based on problems with the previous disability care and support system, including its fragmentation and complexity (Buckmaster & Tomaras, 2013). Previously, the disability care and support system in Australia provided different levels of care and support depending on how disability was acquired and in what State or Territory the person lived (NDIS, 2012). The previous system also struggled to address the needs of many persons with disabilities, their families, and carers (NDIS, 2012). In addition, the increasingly ageing population provided further impetus for a new approach. It was thought that an ageing population could, for example, place increased demand on an already under-resourced and underfunded system and could contribute to a decrease in the number of unpaid carers, including family members, available to support and care for persons with disabilities (NDIS, 2012). This was problematic because the previous disability support system was propped up by the extensive unpaid and informal work of family members as carers.

The NDIS emerged as a ‘Big Idea’ of the Rudd Labor Government’s 2020 Summit in 2008 (Bonyhady, 2009; Soldatic & Pini, 2012). The 2020 Summit was an Australian Government forum that gathered “1,000 of the “best and brightest brains”” (Davis, 2008) from outside the government to discuss Australia’s long-term future in an array of policy areas. The acceptance of the NDIS as a ‘Big Idea’ of the Summit followed a proposal outlining the need for a care and support scheme for persons with disabilities by Bruce Bonyhady and Helen Sykes (Bonyhady & Sykes, 2008).

In 2009, the Rudd Government committed to investigating a care and support scheme for persons with disabilities “in response to the campaign for national disability insurance” (Buckmaster & Tomaras, 2013, p. 6) by disability and carer organisations, in conjunction with developing a National Disability Strategy (Australian Government, 2009). The government specifically requested that the Productivity Commission investigate the feasibility of a long-term care and support scheme for people with disability (Buckmaster & Tomaras, 2013). Additionally, in 2009, the report by the National People with Disabilities and Carer Council, Shut Out, was released. This report was to inform the development of a National Disability Strategy (National People with Disabilities and Carer Council, 2009).

In July 2011, the Productivity Commission recommended a new disability care and support scheme problematising the adequacy of the previous care and support system (NDIS, 2012a). The Productivity Commission report outlined a three-tiered care and support Scheme (as outlined in the Introduction). Tier 2, now known as the ILC program is for all persons with disabilities and provides “information and referral services (as distinct from [the] funded support [provided in Tier 3])” (Productivity Commission, 2011, p. 12). It also includes community capacity building where local area coordinators (LAC) (NDIS case managers) will connect persons with disabilities to existing community organisations and provide small grants to these organisations assisting them to involve persons with disabilities. This “strengthen[s] the voluntary links between the community and people with disabilities ... stimulat[ing] social capital” (Productivity Commission, 2011, p. 13). Tier 3 provides funded support “for people with significant care and support needs” (Productivity Commission, 2011, p. 13) who meet the age, disability or early intervention and residency requirements (Productivity Commission, 2011).

The ‘Every Australian Counts’ campaign emerged to urge the government to implement the recommendations of the Productivity Commission report and consequently, the NDIS. The ‘Every Australian Counts’ campaign included persons with a lived experience of disability, carers, families, service providers and advocates (Della Bosca, 2011). Its plan was to “build a movement”, “spread the word” (Della Bosca, 2011) about the need and importance of a NDIS, and encourage campaigners to speak to their local MPs to get their support for the NDIS.

A month after the Productivity Commission report, the Federal Gillard Labor Government committed to the NDIS and announced funding for it in the 2012-13 Federal Budget (Buckmaster & Tomaras, 2013). In November 2012, the NDIS legislation was introduced into Parliament, passing in March 2013. The NDIS operates through “complex bilateral agreements between the relevant States and Territories and the Commonwealth” (Bigby, 2014a, p. 313).

The NDIS is not means tested. However, to be eligible for an individualised funding package people have to meet age, disability or early intervention and residency requirements (Buckmaster & Tomaras, 2013). Specifically, the age requirements exclude persons aged 65 and over from becoming participants in the Scheme unless supported through the Scheme prior to turning 65 (Buckmaster & Tomaras, 2013). “A person meets the disability requirements if: (a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition” (NDIS Act 2013, p. 28). The impairment must be permanent and impact one’s psycho-social functioning or functional capacity to communicate, socially interact, learn, be mobile, self-care and self-manage (NDIS Act 2013). It also must impede an individual’s economic and

social participation and require lifetime care and support under the NDIS (NDIS Act 2013). The early intervention requirements require that the person has a disability defined as above that is likely to be permanent or “is a child who has a developmental delay” (NDIS Act 2013, p. 29). Additionally, the Chief Executive Officer (CEO) of the NDIA must be satisfied that the early intervention supports provided are likely to decrease the supports required in the future and will benefit the recipient (NDIS Act 2013). In relation to residency requirements, persons accessing the NDIS must be “an Australian citizen, permanent visa holder or holder of a protected special category visa” (Buckmaster & Tomaras, 2013, p. 30).

The NDIS commenced in full across Australia from 2018 (Buckmaster & Tomaras, 2013) though individualised funding packages rolled out to trial sites (previously ‘launch sites’) prior to the nationwide roll out. These trial sites tested different aspects of Tier 3 and the best ways to transition persons from the existing disability care and support system to the NDIS. For example, the South Australian trial site targeted children aged 0-14 years and considered mainly early intervention supports. The Tasmanian trial targeted young persons aged 15-24 years, focusing on the school to work or higher education transition. NSW trialled the Scheme in the Hunter local government area and from July 1, 2014 the ACT trialled the whole Scheme (Buckmaster & Tomaras, 2013).

3.2. NDIS review and NDIS appeals process

The review process of a decision made by the NDIA is outlined in the NDIS Act 2013 and largely relates to Tier 3. To have a decision reviewed by the NDIA, the decision must first be deemed ‘reviewable’ pursuant to section 99 of the Act, which then allows for an internal and possible external review. A decision must first be reviewed internally by the NDIA before an appeal can be lodged with the AAT (Section 103 NDIS Act 2013).

a) Internal review

The internal review process is outlined in sections 99-102 of the NDIS Act. When a reviewable decision is made by the Agency, they must inform the person who is directly affected by the decision that they are entitled to a review of the decision. The person affected must make a request either orally or in writing for the decision to be reviewed within three months of receiving the notice. A failure of the Agency to provide notice of a reviewable decision will not affect the validity of the reviewable decision or the right of the person to have the decision reviewed. Once the request is made to the Agency the decision is reviewed by a ‘reviewer,’ a person who was not involved in making the original decision. The reviewer is entitled to confirm the decision, vary the decision, or set aside the decision and substitute a new decision but must do so in a ‘reasonably practicable’ time. No definition is provided for what is considered reasonably practicable. However, data from the NDIS 2020 in review report suggests review times have improved over the past year. Specifically, “98 per cent of reviews of reviewable decisions are completed within the 90-day timeframe, compared to 60 per cent a year ago” (NDIA, 2020a, p. 4). Upon the decision made by the reviewer the person affected is entitled to make an application to the AAT for a review of the decision made by the reviewer.

b) External review

The AAT is an independent Tribunal used to assess the merits of administrative decisions made by the Federal government. A separate division of the AAT called the NDIS division is dedicated to dealing with merits reviews of decisions made by the NDIA (AAT, n.d.). The AAT is a no costs jurisdiction that has no application fees and reviews decisions regarding the eligibility of applicants to access the scheme, reasonable and necessary supports provided, and who can act on behalf of participants (Byrt, 2013). The AAT will only review decisions that have been internally reviewed by the Agency and the applicant must lodge a request with the AAT within 28 days of receiving the decision of the internal review. The NDIS division of the AAT provides applicants with the ability to have the decisions fast-tracked in an effort to accommodate those who may be suffering due to a decision by the Agency (Byrt, 2013). The AAT process is case-managed by an officer of the AAT and intended to be a conciliatory process in which the parties are given the opportunity to reconcile the dispute through alternative dispute resolution measures such as case conferences before the matter is heard at the Tribunal (Brookes & Ballantyne, 2019). The nature of tribunals means that applicants do not need to obtain legal representation and in fact may find it difficult due to the no cost jurisdiction of the AAT.

In the instance the AAT is unable to review a decision, the applicant may write to the AAT stating the reason(s) why they believe their decision is reviewable. The AAT may reject such an argument or hold a hearing to determine whether the decision is reviewable by the AAT. The process of review by the AAT of NDIA decisions is currently under review (AAT, n.d.).

Due to the nature and principles of Australian Administrative law applicants who are dissatisfied with the outcome of the tribunal decision are entitled to appeal further to the Federal Court of Australia (Part IVA AAT 1975). However, doing so is extremely costly and time consuming as the applicant will require legal representation.

3.3. Independent assessments

To apply for the NDIS, applicants are required to collect evidence from their treating medical professionals and other medical practitioners which demonstrate the impact of their disability on their functional capacity. Independent assessments are set to change this requirement. Instead, the independent assessments are free assessments completed by independent qualified health care professionals who assess the participant’s capability using recognised and standardised tools (NDIA, 2020b). Through research and consultation with health care providers the NDIS has created six toolkits for adults and children to assess how the individual functions in their daily lives (NDIA, 2021). The assessments are intended to take three hours and the applicant can choose the organisation the assessors come from with a list of eight organisations provided by the NDIA (NDIA, 2020c). The independent assessments will be used to determine eligibility to access the scheme and will be part of the existing plan review process (NDIA, 2020c). In the instance that the individual is unsatisfied with the result of the independent assessment they will have to apply for an internal review.

The introduction of the independent assessments is the most substantial reform to the Scheme since its introduction in 2013 (Department of Social Services (DSS), 2020). The new independent assessments are a response to the Tune Review (Tune, 2019), which reviewed the NDIS Act 2013. It urged the NDIS application process be simplified to make the Scheme more accessible and fairer to groups who were disadvantaged by the previous format. The Government claims the reforms are intended to assist in ensuring the core objectives of the NDIS to “provide people with a permanent and significant disability true choice and control over a flexible support package to achieve their goals” is fulfilled (DSS, 2020). However, critics and disability activists believe that the introduction of independent assessments is intended to decrease costs by reducing the number of participants eligible for the Scheme (Michael, 2020). This was confirmed in secret government documents which showed that independent assessments “would save the federal budget \$700m and lead to smaller funding packages “on average” (Henriques-Gomes, 2021). Furthermore, on April 6, 2021, the independence of the Tune Review was called into question through the public release of emails and draft copies of the report under freedom of information laws. The emails and draft copies of the report show intervention by public servants in the reports’ findings and recommendations (Harris, 2021).

Nonetheless, former Minister for the National Disability Insurance Scheme the Honourable Stuart Robert MP stated that independent assessments will be a “simpler, faster and fairer” mechanism to determine eligibility for the Scheme and the appropriate supports (DSS, 2020).

The intention of the program, to solve the burden of medical evidence and increase access to the Scheme is sound. However, advocacy organisations have raised concerns about the independent assessments. The notion came under scrutiny due to a decision made by the AAT in October 2020, where “[t]he tribunal said it did not have confidence that the independent assessors’ opinion “were based on an accurate understanding of Ms Ray’s background, past achievements and her current state of mental health” (Young, 2020b). Ms Ray was denied access to the NDIS because it was claimed she did not meet the disability eligibility criteria. At the Tribunal Ms Ray presented evidence from multiple medical professionals obtained over several years, while “the NDIA presented evidence from a single assessor, an Occupational Therapist (OT) who had seen Ms Ray once for a period of three hours” (Young, 2020b). The Tribunal found that the evidence provided by the NDIA was insufficient by comparison to that provided by Ms Ray. People with Disability Australia have voiced their concerns about the assessments as the notion of attending assessments with unfamiliar health professionals in a time limited schedule is extremely distressing for some (People with Disability Australia, n.d.). There is also concern regarding the three-hour time frame, which does not seem to be sufficient to determine one’s individual function in their daily lives (Michael, 2020) and assessments conducted by professionals whose qualifications may not be appropriate. NEDA has also expressed serious concern regarding the new assessment especially regarding CALD communities as it is not clear whether assessors will have the required cultural training or language skills to work with people

from CALD communities (NEDA, 2020). A joint statement has been signed by 25 disability groups requesting a halt to the implementation of the new reforms and a proposal to rebuild the reforms in an ‘end-to-end co-design’ with disability advocacy groups (Young, 2021).

Overall, most disability activists support the simplification of the accessibility process. However many have been disappointed with independent assessments and the lack of consultation with disability groups and existing participants. The introduction of independent assessments is currently being reviewed by the Joint Standing Committee on the NDIS, which was accepting submissions until March 31, 2021 (Parliament of Australia, n.d.). There is no date noted on the Parliament of Australia website by which the Committee is due to report the findings of their inquiry. More recently, the current Minister for the National Disability Insurance Scheme, Senator the Honourable Linda Reynolds ‘paused’ the introduction of independent assessments in response to community hostility.

4. Existing literature

This section reviews existing literature on the NDIS and people from CALD backgrounds with disability, the barriers experienced to accessing support services for CALD communities, and the NDIS review and NDIS appeals processes. As there is very limited research on the experience of the review and appeals processes by people from CALD backgrounds with disability, this review begins to provide insights into some of the findings that may emerge from the data.

4.1. The NDIS and people from CALD backgrounds with disability

A national evaluation of the NDIS and the transition process from a state-based system to a national uniformed system found that certain groups, specifically people from CALD backgrounds have been significantly disadvantaged and excluded through the practical application of the NDIS (Mavromaras et al., 2018). Upon implementation it was predicted that 20 per cent of participants would be people from



MDAA supporter and consumer

CALD backgrounds. However, in 2019 only 8.7 per cent of participants were from CALD backgrounds (Tune, 2019). The complex process of applying for the NDIS has significantly disadvantaged people from CALD backgrounds with disability and excluded them from accessing services (Heneker, Zizzo, Awata & Goodwin-Smith, 2017; Mavromaras et al., 2018; Senaratna, Wehbe & Smedley, 2018). Eligible participants may lack the skills and resources to be able to engage with the NDIS model and the complex eligibility criteria as well as have the means to acquire the required medical evidence to be eligible for the scheme (Howard et al., 2015). In addition, people from CALD backgrounds are considered to be one of the more vulnerable groups to receive negative outcomes from their NDIS application (Mavromaras et al., 2018). Literature suggests this is due to the current model, which places the onus on applicants and effectively favours those who can freely advocate for themselves (Mavromaras et al., 2018; Senaratna et al., 2018).

Existing literature suggests that, in theory, the NDIS model is built upon the fundamental principles of choice and control, which gives individuals, their families and/or carers the freedom to select the necessary service providers to provide them with disability support. However, in practice, it only advantages those who can advocate for themselves whilst disadvantaging those who cannot (Heneker et al., 2017; Mavromaras et al., 2018; Senaratna et al., 2018). The ‘choice and control’ model supports those who have the ability to freely and coherently exercise their own agency (Howard et al., 2015). Those who do not have these skills or access to resources experience difficulties engaging with the NDIS structure and are wholly or partially excluded from the NDIS (Bigby, 2014b; Cortese et al., 2020; Heneker et al., 2017; Howard et al., 2015; Mavromaras et al., 2018; Senaratna et al., 2018). People from CALD backgrounds were also identified as being at risk of receiving less funding for supports compared to other applicants with similar circumstances (Mavromaras et al., 2018; Senaratna et al., 2018). This could be explained by the challenges

which people from CALD backgrounds with disability experience to “articulating their needs at their planning meetings as well as the difficulties they experienced understanding how their individual plans were supposed to function” (Senaratna et al., 2018, p. 8). Heneker et al suggest that additional funding is required to assist CALD communities with accessing support services as people from CALD backgrounds may experience “cultural and systemic barriers to self-advocacy” (2017, p. 6) and “to understanding and negotiating the planning process and process of NDIS services” (2017, p. 6).

Alongside the problems with the design of the scheme for people from CALD backgrounds with disability, other barriers have been documented. Scholarship has identified barriers such as a lack of cultural training for NDIS staff, issues related to sufficient interpreter services and a failure to incorporate translation services into NDIS plans to support access to services for people from CALD backgrounds with disability (Heneker et al., 2017; Mavromaras et al., 2018; Senaratna et al., 2018). Additionally, barriers experienced to accessing services prior to the NDIS by people from CALD backgrounds with disability and the historical marginalisation of people from CALD backgrounds from previous disability supports has been suggested to impact on their access to the NDIS. Cultural barriers and differences in understandings of disability have also been documented to shape outcomes and NDIS engagement (Heneker et al., 2017; Senaratna et al., 2018; Soldatic, van Toorn, Dowse & Muir, 2014). The collectivist understanding of disability care and support which underpins some cultures has been found to impact engagement with the NDIS which has an individualist focus and emphasises independence (Heneker et al., 2017). Additionally, Heneker et al found that “cultural views of disability based on home country experience; stigma; a lack of familiarity with Western healthcare systems; and familial and community responsibility for the care of people with disabilities” (2017, p. 4) can also shape the experience of people from CALD backgrounds with disability and their interaction with the NDIS. Furthermore, some people from CALD backgrounds with disability are unfamiliar with how to access the NDIS and NDIS supports and there are issues related to information literacy and sociocultural literacy for some (Heneker et al., 2017). Resources and workshop sessions available to inform people from CALD backgrounds with disability, their families and/or carers about the NDIS were also found to be inadequate (Senaratna et al., 2018).

The NDIA has acknowledged that the current scheme significantly disadvantages people from CALD backgrounds with disability, their families and/or carers and has committed to working with CALD communities to achieve equal access and better outcomes. One of the key findings from the 2019 review of the NDIS was the need for a more concerted effort to engage with eligible participants from CALD backgrounds (NDIA, 2018; Tune, 2019).

Programs have also been run by organisations to assist CALD communities with the barriers they experience to apply for the NDIS and as NDIS participants. For example, Fang and Fisher (2019) present an evaluation of the NSW St Vincent De Paul Society’s Community Access Network. The Community Access Network was one initiative by the LAC of the St Vincent De Paul Society and sought to provide “culturally responsive support to CALD communities” (Fang & Fisher, 2019, p. 1). Fang and Fisher’s evaluation, which focused on Australian Chinese communities, found that the Community Access Network achieved the objectives of the Community Access Network Strategy which were to “[e]quip participants from CALD backgrounds with the skills and knowledge to utilise the NDIS”, “[d]evelop a network of relationships with key stakeholders and participants from CALD backgrounds” and “[e]nhance ... LACs knowledge about cultural responsiveness” (2019, p. 1). The Community Access Network did this through running information sessions about the NDIS, creating opportunities for networking and facilitating one on one consultation sessions. The success of these initiatives support the findings of Senaratna et al (2018) which found that people from CALD backgrounds with disability, their families and/or carers preferred peer to peer support and individual one on one sessions on the NDIS, rather than general workshops and information sessions. The St Vincent De Paul Society also adopted a “co-production approach to the operation of [the Community Access Network]” (Fang & Fisher, 2019, p. 11), learning from participants, encouraging opportunities for networking, and building rapport. Building rapport with CALD communities and between CALD communities and service providers was also found to be an important way to address the barriers experienced to accessing support services and the NDIS (Heneker et al., 2017). So too was “work[ing] in collaboration with CALD community leaders to build capacity and enhance knowledge of disability and available services” (Heneker et al., 2017). Despite this though, the number of people from CALD backgrounds with disability who are accessing the NDIS is still below the predicted figures perhaps suggesting that the barriers identified still remain.

4.2. Support services, CALD communities and barriers

When examining CALD access to support services more generally data suggests that the majority of individuals from CALD backgrounds who access services are older residents, specifically first-wave migrants as they are more likely to acquire early onset disability due to the nature of employment typically available to new immigrants and the residential eligibility legislative requirements for accessing services (Soldatic et al., 2019). The length of residency requirements such as the 10-year permanent residency requirement needed to access income support through the Australian Disability Support Pension (DSP) in effect excludes new migrants from accessing this income support payment (Soldatic et al., 2019). Therefore, it is not to say that younger or new migrants do not require access to disability services or income support, rather they are excluded from accessing the services and income support due to legislative eligibility criteria. Furthermore, new

migrants with disabilities may be eligible to access income support through the benefit paid to the unemployed, JobSeeker Payment for income support because it does not require a length of residency. However, substantive medical evidence is required to be categorised as someone with a disability on JobSeeker Payment with a reduced capacity to work. The process can be complicated and expensive and can therefore exclude migrants with low-socioeconomic status from accessing income support (Soldatic et al., 2019).

Other literature suggests that people from CALD backgrounds tend to rely on informal supports. This may be because they are excluded from accessing services, there are different definitions or understandings of disability or due to cultural norms and expectations (Boughtwood et al., 2011; Soldatic et al., 2019; Zhou, 2016). Each culture understands and therefore interacts with disability and the services provided differently. The role and expectation of family members can impact upon the types of services accessed by people from CALD backgrounds and their willingness to request assistance (Boughtwood et al., 2011; Zhou, 2016). For some cultures the understanding of ‘carer’ is different to a Western definition and therefore impedes their access to assisted caring. In a study assessing individuals from CALD backgrounds understanding of dementia, participants from four different language groups identified an expectation for families and communities to care for elderly members (Boughtwood et al., 2011). Therefore, accessing assistance in caring for the elderly members of the family was shameful and considered a failure on the part of the family to perform their cultural expectation (Boughtwood et al., 2011). This sense of shame produced a fear of judgment from the community, which ultimately prohibited individuals from CALD backgrounds accessing support services (Boughtwood et al., 2011). The cultural understanding of who should be ‘caring’ for family members and labeling those who provide support ‘carers’ has resulted in a reluctance of people from CALD backgrounds to access support services.

4.3. NDIS appeals and the gap in literature

The NDIS review and NDIS appeals process is considered inoperable and fundamentally undermines the core principles of the NDIS scheme due to its lack of transparency and accountability (Brookes et al., 2019). The ‘no cost’ jurisdiction of the AAT is intended to make the proceedings conciliatory, however, it in effect further disadvantages the appellate as it can preclude them from obtaining legal representation (Brookes et al., 2019). The appeals process significantly disadvantages people with disability if they do not have access to financial and legal resources. Nonetheless, there is a significant gap in the literature regarding CALD peoples experience with the NDIS review and NDIS appeals processes. This will be addressed through the following evaluation.

5. Research design

5.1. Method

There were two phases to the research design with the data being collected in the latter half of 2020.

Phase 1 included semi-structured, voice-recorded interviews with MDAA consumers who were identified by the NDIS appeals officers at MDAA as either having gone through the NDIS review or NDIS appeals process or who were currently going through the NDIS review or NDIS appeals process. Participants were initially contacted by MDAA staff and researchers from The University of Notre Dame Australia (UNDA), and they agreed to be interviewed initially and then subsequently. Interview participants were frequently interviewed on two occasions. First, by MDAA advocates, with follow-up interviews conducted by the UNDA research team. The follow-up interviews sought to clarify any details from the first interview and ask any of the questions missed or misunderstood in the first interview. Interviewers asked consumers about the supports they required from the NDIS, their experience of applying for the NDIS, their experience of the NDIS review and NDIS appeals process, why they were seeking a review of a decision and any recommendations that they had to improve the process. Calculating the duration of both interviews, the interviews lasted between half an hour and an hour. Interviews were conducted via phone or in person, taking into consideration COVID-19 restrictions and measures at the time and the method most convenient to participants. Participants received a \$50 Coles or Woolworths voucher acknowledging their contribution to the research.

There was a total of 11 participants in this phase. Participants had sought a review or appealed a NDIA decision on their own behalf or had sought a review or appealed on behalf of their child or family member (see Chart 1 on p. 13). While some participants were born in Australia, they came from a range of cultural backgrounds (see Chart 2 on p. 13). There was also a variety of ages, genders (see Chart 3 on p. 13) and disability types. Children whose parents had sought a review or appealed a decision on their behalf either had autism (2 children) or an intellectual disability (2 children). Participants who sought a review or appealed a NDIA decision on their own behalf had a range of physical and/or psychological disabilities such as arthritis, depression, anxiety, back pain, and spinal degeneration. Participants in Phase 1 of the research are referred to as ‘Participant’ in the findings section.

Phase 2 of the research included semi-structured voice recorded interviews with staff from MDAA and one small focus group of two advocates. Participants in this phase were selected by the CEO of MDAA for their direct involvement and work on NDIS matters and then approached by UNDA researchers to be interviewed. Staff were from different MDAA offices, including Granville, Bega and Sydney city. Staff were either NDIS Appeals Officers or advocates. A total of five people participated in this phase. Staff were asked about their role at MDAA, their experience with the NDIS review and NDIS appeals processes, their perception of the experience of MDAA consumers with the review and appeals processes, whether there are any barriers to seeking a review or appealing for MDAA consumers and any recommendations for improving the review and appeals processes. Interviews and the focus group were conducted via Zoom, each lasting for approximately one hour. Staff interviewees are referred to as ‘Interviewees’ in the findings section below.

a) Data analysis

Interviews from both phases were transcribed by Pacific Transcription, coded into NVivo and analysed using a thematic analysis technique. A thematic analysis involves the identification of themes within the data. Themes can be predetermined or emerge (Walter, 2019). All codes and themes were checked and confirmed by all members of the UNDA research team.

b) Ethics and funding

Ethics approval for the research was granted in July 2020 by the Human Research Ethics Committee at UNDA (Ethics approval number: 2020-088S). The research was funded by MDAA.

Chart 1:
Interview participants

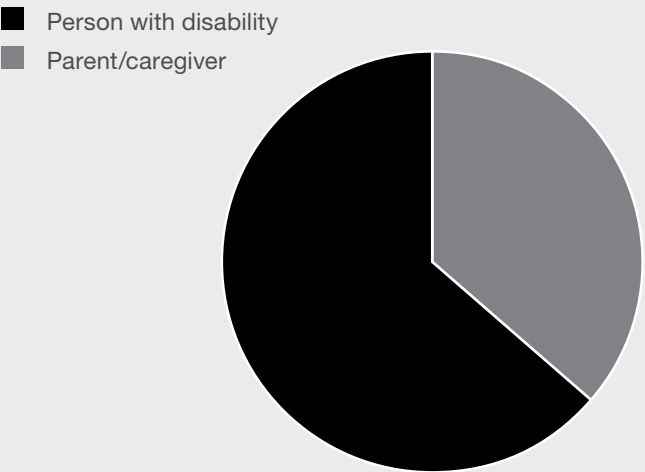


Chart 2:
Cultural background of interview participants

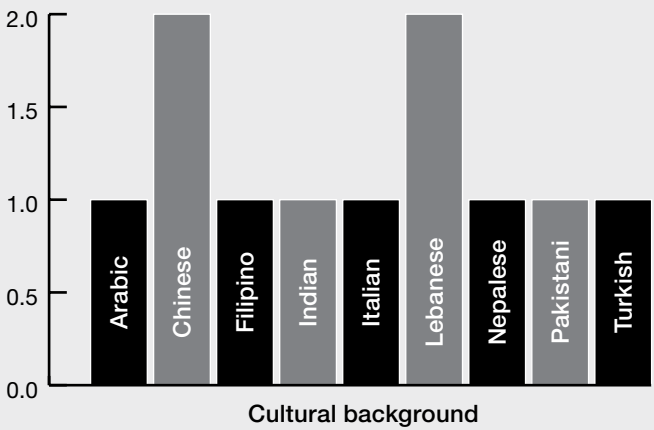
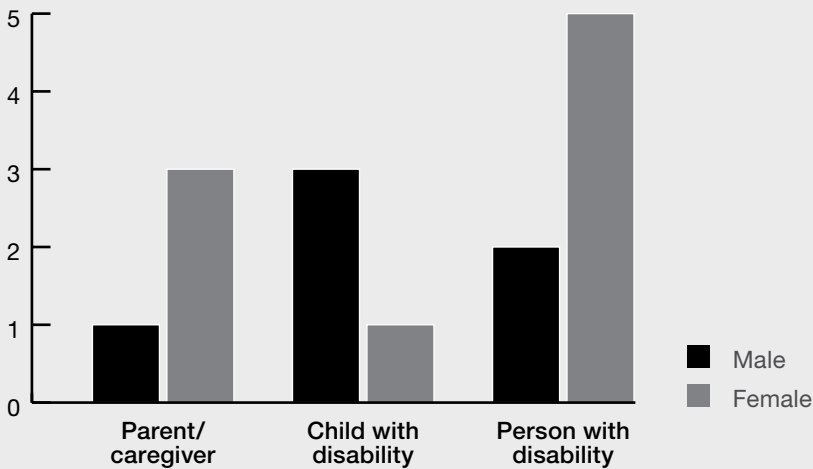


Chart 3:
Gender of interview participants and their children (where relevant)



6. Findings

This section begins by outlining the supports people are seeking or receiving via the NDIS. Next it explores consumers’ experiences of applying for the NDIS, the barriers to applying, why people appeal decisions and the impact of getting an unfavourable decision. Following this, it examines the NDIS review and NDIS appeals processes including how long a review or appeal can take, barriers to seeking a review or appealing a decision, and whether people would appeal again. Finally, it discusses consumers’ experiences with MDAA throughout this process. For ease, the findings are divided into findings relevant to the NDIS generally, under the subheading ‘The NDIS’. This is followed by findings pertaining to the NDIS review and NDIS appeals processes specifically, under the subheading ‘NDIS review and NDIS appeals processes’.

The NDIS

This section of the findings examines the supports consumers are seeking or receiving from the NDIS, the experience of applying for the NDIS, the barriers in applying for the NDIS, the reasons people seek a review or appeal a decision and the impact of being rejected for the NDIS or additional funding and supports.

6.1. Types of supports sought or received

Generally, consumers were applying for or receiving support for daily living tasks (Participant 1 and 3) such as showering, cleaning, and shopping and/or various therapies (Participants 4, 5, 7, 10). (see Table 1 below for further details).

Table 1: Types of supports sought or received by participant

Participant ID	Participant type	Impairment type	Support provided/sought and benefits	Outcomes
7	Parent of child with disability	Mild intellectual disability	Occupational therapy to assist with building confidence	Not applicable
10	Parent of child with disability	Autism	Support to build functional capacity. Funding to attend occupational therapy, speech pathology and behaviour management.	Noticed improvement due to speech pathology, occupational therapy, behavioural therapy, and activities such as, swimming and drawing.
5	Person with disability	Psoriatic arthritis, low blood pressure and migraines	Support for osteopaths and exercise physiology to assist with movement, walking and daily activities.	Not applicable

6.2. Applying for the NDIS

Consumers described applying for the NDIS as difficult (Participants 9 and 11). They also describe the application process as “very hard” (Participant 5) and time consuming (Participants 4 and 7). One consumer explained how it took her a long time to apply for her son and then when she finally applied, the application was rejected. She explains “it’s not an easy process. It’s a painful, painful process” (Participant 7). Participant 4 also described applying for the NDIS as “difficult”, explaining that “they are not helpful, they don’t understand” and that they “just say no” because it is “an easier answer for them”. Participant 11 explains that applying for the NDIS “has been extremely difficult. I have been ... struggling with the NDIS for two years or more ... I do have a permanent disability, but they are very difficult with people who have disabilities like mine”. Participant 5 also found it extremely hard because she “was getting knocked back a lot”.

Another reason MDAA consumers found applying for the NDIS difficult was because their treating medical practitioner/s did not support their application. One consumer explained that his General Practitioner (GP) was not supportive of the NDIS application for his daughter (Participant 4). He asked his GP to write him a letter to support the application and the GP wrote one line. When he prompted the GP to write more to fit with the type of language and evidence required by the NDIA they refused. The consumer felt the GP’s contribution to the application would not meet the evidence requirements under the NDIS.

Participant 1 also found that her doctor was not supportive of her NDIS application and would not help her with the paperwork. She suggested that this was because the paperwork was too complicated. She explained that the requirement to have medical evidence for the application is a barrier, particularly when the doctor does not want to complete the paperwork because it is too time consuming and complex. As such, she tried to find another doctor to help her complete the paperwork but because this doctor did not know her medical history, the doctor could not help her. Furthermore, the doctor assumed that the consumer would be unlikely to be eligible and would take the place of someone who they considered to be “more eligible”.

While the independent assessments could mitigate some of the concerns raised by Participant 1, the introduction of independent assessments and their proposed structure must be met with caution. Participant 1 explains that a new doctor felt reluctant to provide evidence because they were unfamiliar with her medical history and circumstances. Thus, independent assessments of three hours are insufficient for an assessor to ascertain a person’s medical history and lived experience. This point needs to be taken into consideration with regards to the independent assessments.

6.3. Barriers to applying for the NDIS

It is clear then that medical evidence requirements and the medical profession may be a barrier for some applying for the NDIS (discussed further in 6.3.5). However, staff and consumers of MDAA indicated other barriers to applying for the NDIS.

a) Lack of information

One of the barriers identified by staff for accessing the NDIS, particularly when the NDIS emerged, was a lack of access to information. Consumers, the community, and service providers did not have enough information about what to expect, how to deal with the NDIS and where to seek help. This was suggested to be one of the main reasons why there was a significant percentage of people from CALD communities who did not know about the NDIS and therefore did not access the NDIS nor access support from organisations to help them apply. Although the government sent out LACs, LACs were said to lack connections with the CALD community. As such, it felt as if CALD communities were excluded from the initial NDIS plan. Staff concede that it is only now that some documents providing details about what the NDIS is and how to access it are produced in multiple languages that information has become more available. Therefore, it is important that LACs have connections with the CALD community and have the training, knowledge, and experience of working with people from CALD backgrounds with disability. Information should also always be made accessible for people from CALD backgrounds with disability, their families and/or carers.

b) Initial contact

Another barrier that staff identified to accessing the NDIS for MDAA consumers was making the first phone call to initiate the process of access. Some consumers need support to know what number to call to instigate the NDIS process and require an interpreter. One staff member (Interviewee 5) explained that having support whilst making the initial phone call can ease feelings of ‘fear’ for consumers. The work that organisations like MDAA do in assisting consumers to initiate contact with important supports they are entitled to indicates the significance of such organisations’ work. It is important that this work continues to be supported and funded.

c) Cultural differences

Cultural differences were also identified as a barrier for people from CALD backgrounds with disability applying for the NDIS. As one staff member commented, in some cultures, disability cannot be spoken about and people keep to themselves, caring for the person with disability in the home. There is shame associated with disability (Interviewee 3). When the NDIS was implemented many people were informed about it through their links with existing disability services. However, those who were not connected to these services and largely stayed at home received no information about the NDIS. How culture shapes understandings, experiences and definitions of disability needs to be considered and addressed in the NDIS. Consultation to develop strategies in this regard is important. This consultation process should include genuine listening to the experiences of organisations such as, NEDA and MDAA and people from CALD backgrounds with disability, their families and/or carers.

d) Age limits

The age cut-off at 65 years for NDIS eligibility was also identified as a barrier to applying for the NDIS by a MDAA advocate. It was suggested that this cut-off is bureaucratic and arbitrary and does not serve the needs of the individual. NDIS applicants do not lose their forms of disability after they turn 65 years of age. Furthermore, there may be various reasons why someone may not be able to complete a NDIS application prior to reaching 65. As the advocate explains “for people whose main spoken language is not English, a lack of awareness can contribute to a late application”.

The age-cut off is also a problem because aged care packages are often not adequately funded compared with disability supports. Applicants can be desperate to get allocated a NDIS package before their age disqualifies them. For example, for one MDAA consumer whose application for a NDIS package had been rejected he decided not to re-apply because he would be “timed out” due to turning 65. The rejection of his application had a profound impact on his mental health, and he was worried that his specific needs would not be met through the age care system.

The age limit to NDIS applications should be scrapped in line with the actual requirements of people with disability.

e) Medical evidence to support the application

Medical evidence to support the NDIS application was identified as a barrier to applying by MDAA consumers and staff. Some consumers felt that the evidence that they provided to support their NDIS application was why their application for the NDIS was rejected. Some participants felt that their treating practitioners completed the paperwork incorrectly, which impacted on a successful NDIS application (Participants 5 and 11). Participant 11 felt that his doctor’s report of his capacity was an unfair assessment and Participant 5 felt that because she was constantly made to re-do this part of her application, her rejections resulted from problems with reports by her treating doctors.

MDAA staff also identified medical evidence as a problem for consumers applying for the NDIS and Interviewee 5 argued that most people that they assist with NDIS applications at MDAA are not aware of the types of medical reports they must provide. The LACs also do not assist in making what is required clear. Thus, the main concerns of staff can be summarised as follows. Firstly, concerns were raised with a lack of understanding of what type of medical professional would be best to provide evidence. Secondly, there were concerns raised about consumers and medical professionals not knowing the type of evidence required to support a NDIS application.

Consumers were unaware of the type of evidence required for their application and trusted the referrals of medical professionals such as GPs would be sufficient. However, Interviewee 1 suggests that access to the NDIS often requires consumers to undergo a full functional assessment by an OT. This is costly (\$1000+) and while this can be obtained through the public hospital system, there is a waiting list. Interviewee 2 said that consumers with psycho-social disabilities have rarely been assessed by an OT. Yet, as established, OT assessments are almost always

a requirement for gaining NDIS access. For example, for Interviewee 2’s clients an OT report is often requested by the NDIA if not already provided. The need for an OT assessment is often not known by consumers.

Furthermore, several staff emphasised that there was a distinction between medical evidence and disability evidence, with many consumers and treating medical professionals providing the NDIA with medical evidence of impairment/s not disability evidence as required. The medical evidence supplied by a GP or specialist to be used in an access request form is frequently not written in a way that represents what the NDIS requires (Interviewee 1). People go to the doctor and get a medical description of their condition. Rather, the NDIS is looking for specific terminology and phrases that come through an OT report which assesses and then presents one’s functional capacities as a person with disability (Interviewee 3), therefore, providing “disability” evidence and medical evidence. For example, a consumer can go to the doctor with back pain. The doctor will write on their medical record that they have back pain and prescribe them medication. However, the NDIA wants to understand the impact of the back pain on the consumer’s life. For instance, how does it impact their movement, their ability to walk, their ability to get out of bed, and so on. This type of evidence changes the type of interaction between the patient and GP, the type of examination undertaken and what is written (Interviewee 3). The confusion by applicants and medical professionals about the type of evidence required (Interviewee 1) acts as a barrier to accessing the NDIS and is a problem.

To navigate this problem one staff member will sometimes attend medical appointments with her consumers (Interviewee 4) in the hope that the medical professionals will listen to her and write in the style she is suggesting. In part, this is to help the consumer with their application but it is also to save them from having to pay for multiple appointments to get the right type of evidence and going back and forth trying to get approved for the NDIS. She explains that, in her experience, when the NDIS was launched there was an active effort to inform service providers but not a similar effort to educate the medical profession, who are ultimately responsible for compiling and writing the evidence to ensure eligibility and approval when completing the forms.

Additionally, Interviewee 1 explains the inadequacy of GP appointments to fulfil report requirements because visits are short – usually fifteen minutes (OT assessments take hours). She also problematises the likelihood of a GP’s ability to really know the lived experiences of their patients both at home and within the community. Interviewee 1 states that both issues affect a GP’s ability to fill out access request forms in the way the NDIS requires. Similarly, an OT assessment is not always an accurate assessment of a person’s lived reality. Rather, they spend two to three hours with someone who may be having a good day. If an OT comes on a good day, their assessment cannot capture the full extent or impact of disability on functional capacity (Interviewee 1).

Medical evidence can also be costly, yet medical evidence such as OT reports and specialist reports are essential to an application. Staff report that for many consumers it is not possible to obtain the medical evidence required

because it is well beyond their financial means, particularly for those who receive income support payments (Interviewee 4). Sometimes consumers are supported by MDAA to outsource funding for reports. Such outsourcing is occasionally successful, but also adds to the complexity of the process because they are then navigating another system as well (Interviewee 5).

Collating and collecting evidence can also be time consuming. Interviewee 4 explains this can make consumers feel anxious and overwhelmed and is therefore one reason why some consumers choose to disengage from applying for the NDIS.

As such, there needs to be greater clarity provided to applicants as well as treating medical professionals about the type of evidence required for applications by the NDIA (Interviewee 4). There also needs to be clear guidelines about who can and cannot access the NDIS. Additionally, there needs to be some recognition of the cost of evidence on the consumer. The introduction of independent assessments could address some of the concerns raised about the type of evidence and the cost of evidence. However, as established, caution must ensue about accepting independent assessments as a solution without reform to acknowledge that it is unlikely that an assessment of three hours can lead to a complete understanding about the experience and medical history of the person. Additionally, it is crucial that assessors have adequate training, experience, and knowledge of CALD communities.

f) Barriers specific to Regional Areas – Bega and Griffith

MDAA has offices in Bega and Griffith. People with disability in Bega, Griffith and surrounding areas experience other barriers to accessing the NDIS in comparison to those in greater Sydney. One of the most significant barriers is access to support and medical services. There are limited public transport options to travel outside of Bega and Griffith; it can take 20 to 30 minutes to get to neighbouring towns. This makes appointments hard, costly and time consuming to get to. Accessing specialists and specialist appointments is also difficult due to a lack of available services. Some consumers have to travel three to four hours to get to a specialist appointment. This is compounded by limited bus services which travel to Canberra, Melbourne, or Wagga Wagga regularly which means that people often have to stay the night in Canberra, Melbourne or Wagga Wagga at an added expense. There are also few psychiatrists available for face-to-face appointments and lengthy waiting lists for access to some medical professionals mean it could take months to get evidence.

While independent assessments again could address some of these concerns, further consideration needs to be given to the particular experiences of people living in regional and rural areas and the barriers to accessing evidence.

6.4. Reasons for rejection and seeking a review or appeal

Consumers sought a review of a NDIA decision or appealed an internal decision for two reasons. Firstly, because their application for the NDIS was denied, that is, they did not qualify for NDIS support under the eligibility criteria (Participant 7). For example, two consumers were rejected for NDIS support because their conditions were not considered permanent (Participant 1 and 9).

Secondly, consumers who had access to the NDIS asked for a review of a decision or appealed a decision because the funding granted for their plan or the plan for their family member was not enough to meet their care and support needs. For example, Participant 5 is currently seeking a review of her funding package because the funding she was granted is unlikely to cover the supports she needs and how often she needs these supports over the course of a year.

Participant 4 found that there were some supports for his daughter that the NDIA refused to fund as they were not considered “reasonable and necessary”. For example, following the recommendations of an independent OT assessment funded by the NDIA, he sought funding for safety mechanisms on his balcony so that his daughter does not get hurt or fall. He suggests that such supports were not funded because the NDIA assumed that it is a parent’s responsibility to monitor their child to make sure they do not fall from the balcony. Participant 4 told the interviewer that this logic “doesn’t fit with people with special needs who got the mental problem, they might jump and then fall from there”. He also described how he requested \$80,000 for particular therapies for his daughter and was granted only \$20,000. He explains later in the interview that he also questioned the cost of the supports deemed necessary in the OT assessment but given that the sum was calculated by a professional he did not refute the cost. For providers the NDIS is a business, none of the funds granted through a plan go to the family or participant and the balance between all parties families, providers and the NDIA needs to be sought without compromising adequate, timely and appropriate support for the person with disability, their families and/or carers.

Some consumers had requested a review of the funding for supports provided by the NDIA on multiple occasions (Participant 10) with some consumers appealing the internal review decision (Participant 10). One participant for example, often found that the amount for supports granted was inadequate and that she needed more funding for her son. She concedes, however, that sometimes following an appeal “you’re not satisfied with the result ... the funding ... is still not enough ... You keep on repeating the process and then at last the appeal” is granted. This demonstrates the importance of awarding a sufficient amount of funds for the reasonable and necessary supports people require, covering how often they require them initially.

It is worth noting that insufficient funding was listed as a concern by multiple consumers. However, not all decided to seek a review of their package. For example, while Participant 9 did not indicate that she would seek a review of her package now that she was finally granted access to the NDIS, she did raise concerns about the time and

money allocated to tasks in her package, suggesting that the amounts were insufficient. For example, she felt that 10 physiotherapy sessions per year was inadequate given that she is due to have back surgery, has osteoporosis and is unable to walk for lengthy periods of time. She suggested that regular physiotherapy works effectively to relax her muscles and would be ideal once or twice a month, not less than once a month. She also explained that the amount she was allocated for transport was not enough. While she does drive, she is unable to when her condition flares up and must take public transport or taxis. She receives \$60 per fortnight for transport through her package and has had to cancel doctor’s appointments when she has been too unwell to drive but cannot afford to take public transport or a taxi.

While the reasons identified above by some consumers were why people sought an internal review of a decision by the NDIA or appealed a decision to the AAT, others did not understand why their application for NDIS support was rejected and therefore were not sure what to appeal. According to Participant 5, her application for NDIS support was rejected on three or more occasions. However, she “wasn’t understanding why each time [she] received the rejection letter. They just kept saying not enough information”. She elaborates further, “Well, I had given them medical documentation, but they kept saying it wasn’t enough. With me – because I have a lot of brain fog from taking a lot of medications and stuff like that, I just – no matter how much I read the letters I wasn’t understanding what they actually wanted”. Upon receiving a rejection, sometimes she would apply again, starting from the beginning. At other times, she would attempt to send the information that the NDIA required and when this was rejected would start the application process again.

Staff also identified the same two reasons for why consumers appeal, that is, for access to the NDIS and for reasonable or necessary funding increases.

In Interviewee 2’s experience a lot of his clients (roughly 80 per cent) have mental health and psycho-social disability and are denied access because of NDIS legislation, which is complex in relation to psycho-social disabilities. For example, consumers can be deemed to have a permanent disability, for example, post-traumatic stress disorder, anxiety and/or depression. They are required by legislation to demonstrate that this results in having ‘substantially reduced functional capacity’ in order to access the NDIS. Most of his clients are initially denied because they do not have or cannot prove functional capacity reduction. If Interviewee 2’s consumers are not trying to meet the access criteria, it will be a parent trying to increase funding for their child. This is consistent with other staff members who suggest that nowadays concerns have shifted from seeking access to acquiring more supports and funding (Interviewees 3 and 4). This could be because, as Interviewee 5 has found in her experience, funding requests based on medical evidence and support requirements are not met.

One staff member suggested that the amount of funding and supports allocated to NDIS funding packages over the years has decreased. This was identified as a concern for consumers whose disability is permanent and whose condition is unlikely to change. Hence, they annually require

the same funding, rather than a decrease in funding. In her experience, these are the cases that often go back and forth between consumers and the NDIA (Interviewee 4).

Some consumers also contest the NDIS’ determination of reasonable and necessary support and seek a review on this basis. This is because they have lived experience of their disability and thus question the power of the NDIA to determine for them the types of supports they require and how frequently. One staff member suggests that if sound definitions of reasonable and necessary were provided then consumers would not need to appeal decisions because the funding requested would be granted (Interviewee 4) or they would understand decisions. Consumers felt under the current system that rather than a decision being made on what supports are required for the person to be adequately supported, something which they are most familiar with given their lived experience, the NDIA makes a decision from a place concerned about conserving funding.

Several staff members noted that recently, some consumers have also begun to compare NDIS plans leading to recognition that planners are inconsistent in allocating the equivalent amount of money for the same issue or the same circumstance (Interviewees 3 and 5). In some cases, this has led consumers to seek a review. Therefore, the planning meeting and process is a crucial point of receiving a NDIS package that is likely to meet the reasonable and necessary needs of the applicant and this is worthy of discussion.

a) Preparing the plans and understanding the funding

Interviewee 5 communicates that the adequacy and success of a plan is largely dependent on the allocated planner. If the planner is informed and has a good understanding, consumers are more likely to receive a plan that meets their needs. If not, this can make the process inconsistent and unfair on some.

Furthermore, two staff members suggested that one of the most prominent parts of their role is helping consumers understand how to use the supports in their plans (Interviewees 3 and 5). Consumers need help navigating the process and need supports in place to understand their plans and how to use the them. This is largely due to language barriers which create difficulties in understanding. MDAA staff also take on this role because not all consumers receive support coordination once they have received their plans (Interviewee 5). Often, consumers have questions and uncertainties and little support when trying to address these. One staff member said that at this stage it is difficult to contact LACs for support. As such although they may have been granted access to support services through an NDIS package, they are not familiar with the details and require clarification from MDAA staff about what exactly they can get from the service and how they can implement this support. Additionally, some consumers are dissatisfied with the standard of the service they are accessing and seek guidance in this regard too (Interviewee 4).

6.5. Impact of rejection on consumers

There are various costs for consumers whose applications for the NDIS are rejected or who do not get enough support allocated through their plan and funding package. These costs can be emotional, physical, social, and economic and can impact the consumer and their carer/s, families and friends as well as other support services and organisations. Generally, consumers described how the rejection of their NDIS application or their request for further funding significantly affected them (Participant 4).

a) No funded supports

Consumers found it difficult to get access to necessary supports without the NDIS. Participant 9 applied for the NDIS three years ago, but her application was rejected because there was not enough evidence. She decided to wait to reapply. During that time her health deteriorated and so she decided to apply again. While she was waiting for her application to be processed, she tried to access transport and services, but the providers were asking whether she had a NDIS funding package before advising her she should try to apply for the NDIS. She conceded that it was difficult to get support without the NDIS.

Other consumers whose applications were rejected had to examine other avenues for support while they were waiting for a review of the decision (Participant 4) or stop attending appointments (Participant 5). Participant 5 explained that the cost of attending her supports on her wage without NDIS access was unsustainable and so she stopped attending her appointments. The impact of this meant that she would get severe migraines and stiffness.

Participant 4 also explained how she was unable to afford to pay for a support worker to help with daily living tasks because she is on the DSP. This barely covers the cost of her rent and other living expenses.

Another participant explained the impact on her and her son should the NDIS not fund the supports applied for. She explains that if the funding is insufficient then she would have to cut services that are essential for her son, such as speech therapy. Participant 10 similarly suggested that should she not get funding for a particular support for her son, she would have to prioritise the most important supports and perhaps stagger or change how regularly her son accesses or attends such supports.

It is clear, then, that denying access to the NDIS or increased supports has implications for the care and support people with disability receive. This should be considered when applicants are rejected and referrals or information about other services should be included in rejection letters.

b) Reliance on family

Without access to the necessary supports through the NDIS for daily living activities or to an adequate amount of support through a NDIS package for daily activities, others are required to provide these supports. At the time of interview, Participant 3 was still waiting on the outcome of a review/appeal as her application for the NDIS was rejected. She explained that she often had to ask her children to help with these tasks but that she found this difficult because they had work and school commitments as well as their

own lives. She was concerned about what would happen if her two youngest children were to move out of home. Similarly, without NDIS supports, Participant 1 describes how her daughter would take her to the bathroom in the morning before school and then once her daughter went to school, she would spend the day laying down. She would have nothing to eat until her daughter returned from school.

While Participant 9 now has access to the NDIS, the funds provided for her supports are not enough, which means that her sister is still largely assisting her with daily living activities, personal care and domestic support. She explains “I’m having two hours domestic a week and sorry, where the patient – as my situation, sometimes [my sister is cleaning] the bathroom four or five times a day. She has to take me for the shower a couple of times, three times a day. After she showered me, she has to clean up the bathroom and to clean up my place and it’s not easy for her. But, poor her, she’s a human being; she needs a couple of hours rest, because at night, sometimes, she can’t sleep”. Participant 7 similarly explained that should she not get sufficient funding in the NDIS package for her son then it would mean that she would be unable to have some respite from caring for him.

c) Burden on friends or loss of friendships

Participant 3 explained that having people over and socialising is an important part of her Pakistani culture. However, it is difficult for her to invite people to her house to socialise because she is not able to keep her house tidy. Participant 9 explained that she had isolated herself from her friends because she felt like they did not understand and that they would judge her as a burden. She explains “I haven’t got any other family members helping me and from friends [... I’ve eliminated] my friends. Sometimes if you want to call someone a couple of times, they’re going to look at you, you can’t do it, why you taking a doctor appointment. They do not understand you need to see the doctor or you have to or something”.

d) Feelings of blame and questioning of disability legitimacy

Participant 1 explained how she felt that the NDIA were implying that she was the cause of her impairment and that she was unwilling to help herself. This caused her to have “a fairly bad breakdown”, resulting in hospitalisation. She explains how appealing the decision was difficult because she ended up having a breakdown after they rejected the independent OT assessment, despite the OT acknowledging that Participant 1 has a significant condition and requires help. She says: “They didn’t even listen to her ... So then they’re saying all these really bad things about me, they’re saying I should put my washing machine up on the wall where I can reach it and that’s why I made myself like this, I made myself like this because I must be doing things around the house that’s making me like this. So then I had to say ... I have been like this, with a spine problem, in my late teens, early 20s. I have been having this for a long time, it didn’t just happen now.”

Many consumers also felt that by rejecting their application the NDIA did not believe that they had a disability (Participants 9 and 11). While many mentioned this, they also sought in the interview, either by their choice of words or by offering for the researchers to view their medical

documentation, to convince the researchers that their disability was legitimate. For example, Participant 3 often encouraged the interviewers to look at her paperwork, that she was telling the truth about her conditions and the impact of them. Participant 11 explains how the rejection affected him and how it felt like his believability was being questioned. He stated: “It affected me heavily because when you are disabled and in this country, you can see there are people who provide services and you need to be with them and then they reject you, they don’t give you any importance, they don’t believe you, although they could see. This is making me feel very sad and miserable.”

The assumption that the NDIA did not believe that consumers had a disability was reinforced when consumers made comparisons between the income support and disability support systems, particularly when consumers received the DSP. The income support and disability support systems use different definitions of disability to determine eligibility for support. Yet, the process to apply for the DSP is arduous and requires the applicant to prove that they have at least one type of disability that entitles them to receive the DSP. A few participants were confused about why Services Australia (formerly Centrelink) found them to be eligible for the DSP but they were not eligible for the NDIS (Participants 3 and 6). One consumer who was angry at the discrepancy stated: “If the Government thinks I am disabled, why doesn’t NDIS?” (Participant 6) This statement is echoed by a second participant who stated “... the disability pension is the authority of the Government to allocate the funds to people who are deserving, who has a disability. Then what sort of disability NDIS people are looking at?” “I don’t know what these people [use to determine disability]. The people who are on the disability pension, they have already been tested and checked by their own independent doctor. Centrelink is not stupid, they give you the disability pension [and there’s no way] without verifying everything. But I don’t know what the NDIS – their standard is” (Participant 3). As the consumers note, their eligibility for the DSP and the process to prove their disability to Services Australia is not considered when applying for a NDIS package. As such, they are frustrated by the lack of consistency. In addition, according to an advocate from MDAA, Services Australia is able to access information from other agencies should it require it. Therefore, if NDIS applicants give consent, the NDIA should access existing client information in support of a NDIS application.

e) Living in pain

Several participants spoke about how they felt unsupported by the NDIA and that being denied the NDIS meant that they were living with ongoing pain. Participant 1 states that it was “terrible how she was treated [by the NDIA] really bad” and that she “was crying every day” with her pain and she was “not getting any help.”

f) Feeling discriminated against

One consumer also felt that he was being discriminated against because his application for NDIS support was rejected. Participant 6 states: “They discriminate against me because of my name, because of my face, because of my religion, and my human rights have been taken and I’ve been discriminated against.”

6.6. Emotional impact of rejection

Rejections had an emotional impact on consumers too. They spoke of feeling upset, helpless, frustrated, and angry.

a) Upset and helpless

Participant 3 described feelings of helplessness and despair because she has lost her independence, she is in pain and is unable to access supports. Participant 9 was upset by the NDIA’s decision to reject her application for the NDIS on multiple occasions. Participant 5 also found the constant rejection of her NDIS application “upsetting” and, after her third rejection, she almost decided not to pursue her application. This was a common reaction to multiple rejections (Also Participant 9).

Participant 9 explained: “It affect me badly because you’re looking forward for someone to give you a hand, to help you, to support you then and you find a little light coming through a little hole from a door, then someone close it. So, no light going to come through to your room. So hard ... It is so hard when you have hope, to have an assistance from someone or to continue in having a better life what you are in, for the situation you’re having than you’re having the door closed at the front of you. It is big shock.” They continued, “[it is] like someone trying to show me you’re not valuable anymore in this life. Why you are continuing your life and we give you help for – yeah, something like that. I feel myself that’s it, it’s the end of my life, no-one like to help me anymore ... it is so hard. It’s very hard feeling. I can’t describe it to you. When I used to have my rejection in my hand, I said that’s it, that’s the end of the world, that’s the end of my life. No-one wants me anymore, why I’m here for in this world? Now when I’m getting sick, so no-one want to help me, look like you’re no value to me. They didn’t show value to the person.”

b) Angry and frustrated

Some consumers were angry and frustrated that their application for the NDIS had been rejected. For example, Participant 6 said: “I am very angry with them ... I’m extremely angry to the maximum, how they’re treating me. I’m not a second-class citizen in this country. We’re not living in a third-world country. We’re living in a developed country and they’re treating me like this, like I’m a second-class citizen. They can go to hell.” Participant 7 describes how the rejection of her son’s application for the NDIS made her feel “very frustrated” with the department and the system. Participant 4 found the need to constantly explain and provide documentation frustrating.

The rhetoric surrounding the access criteria should be changed. Additionally, when someone’s application is rejected, they should be provided with information for other organisations or supports so as not undermine the individual’s disability. Such information should include advocacy organisations and mental health support.

This section of the findings has examined why people apply for NDIS support, consumers experiences with applying for the NDIS, the barriers to applying and the reason for and impact of rejection. It has also briefly explored why people seek a review of a decision or appeal a decision. While the purpose of this research is to evaluate the NDIS review and NDIS appeals processes for people from CALD backgrounds with disability, these findings about

applying for and being rejected for a funding package or further supports provides insights into the NDIS application process and why people seek a review of a decision or appeal a decision. These insights will be built upon in the following findings section which presents an exploration and evaluation of the NDIS review and NDIS appeals processes for people from CALD backgrounds with disability, their families and/or carers.

NDIS review and NDIS appeals processes

The previous section established that people seek a review of a rejected NDIS application or of decisions which award insufficient funding and supports. This section of the findings will explore how consumers found out about the review and appeals processes, their experience of both processes, the impact of seeking a review or appeal on them, how they dealt with rejection, barriers to appealing and whether they would appeal again. This section concludes with reflecting on MDAA’s role in assisting consumers.

6.7. How consumers knew to seek a review or appeal

There were two main ways consumers found out about the ability to review or appeal a NDIA decision. The first was via the NDIA (Participants 2, 4, 6 and 11) and the second way was on advice from someone such as an advocate at MDAA (Participant 1, 2, 4 and 5). Participants explained that information to appeal was provided by the NDIA in the letters they were sent (Participant 2, 4) or was emailed to them (Participant 4). Several MDAA staff members explained how some consumers were not aware they could have a decision reviewed (Interviewees 3, 4 and 5) and that as an advocate it was their job to provide consumers with that information as “this is [an] opportunity ... available to them so their rights can be supported. So they can access the system with full understanding, they have covered every step to gain the goals they so wish to achieve” (Interviewee 4).

However, Participant 7, when seeking a support service to help her with reviewing a NDIA decision, explained how she had to contact multiple people and was transferred during those calls, which meant she contacted approximately 20 different people in her quest for help with a review. This was time consuming because it took ten days of calling, leaving messages, waiting for a call back, getting provided with the “right” contact number before she could successfully find an organisation (i.e. MDAA) to assist her. She described this experience as “painful” (Participant 7) and noted that the contact details of organisations to assist with appeals should be easily accessible to those whose applications have been rejected. These details could be provided on the bottom of rejection letters and on the NDIA website. Such organisations should include advocacy organisations who assist with appeals like MDAA, legal support services which are easy to access and that are genuinely able to assist in the review, appeal and tribunal processes.

6.8. Experience of review and appeals processes

There were several common themes emerging about consumers’ experiences of having a decision reviewed or appealed which are discussed below.

a) Labour intensive

Participant 4 spoke about how labour intensive it is for someone to ask for a decision to be reviewed or to appeal a decision. He found this particularly time consuming because he had to find out the information required to appeal, “where to go, who to contact, how to fill out the form and then what documents to prepare” (Participant 4). He explains “I have ... waste a lot of time to prepare ... these things” for an appeal of his daughter’s funding and supports. While he had assistance seeking a review, he conceded that he still had to collect the information, and while the NDIS appeals officer at MDAA helped, there was still a lot of work required by the applicant.

Furthermore, the removal of layers of bureaucracy that he encountered in appealing a NDIA decision was also identified as an area requiring improvement (Participant 4) because the layers of bureaucracy meant that the process was time consuming. He explains: “Like when I went through the tribunal and then they’ll ask me, okay go and negotiate with the NDIA first, which is good but they ... want to send me a list of questions, which I replied. Then a different person from the NDIA, they came, and they gave me another – about 50, 60 questions and then have to get those answers from a different provider. Then go back and follow up with them, then after that ... so many meetings so many times. I know they all get paid, but not me. Everyone gets paid for doing those things and I’m asking for the support and then they are giving me the things [to do] which I have to spend extra time [doing]. I have to work, I have to look after the people with disability, then I have to do those extra things” (Participant 4).

Additionally, every time the applicant was required to attend the tribunal, they had to take time off work. He explained to the interviewer how he told the tribunal that he could not continue taking time off work. The tribunal asked him when he would be available to attend, and he explained he worked Monday to Friday during business hours. Given that the tribunal does not sit after hours or on weekends any accommodations made still meant that Participant 4 had to take time off work. This features in his consideration of whether to appeal again as he has to attend a lot of meetings, take time off work and there was no outcome from the meetings. Similarly, Participant 11 when asked whether he found the process of collecting medical evidence time consuming and stressful replied “of course” and then “I reached the stage where I stopped answering the calls because it was just going around in circles. I thought they were just trying to say they called for the record. But they were not really intending on progressing or doing anything”.

Another consumer also spoke about how collecting evidence to support the review of a NDIA decision was physically difficult because she needed to “run around” and ask all her son’s previous health professionals for copies of old reports. This was exacerbated by the fact that some treating or assessing doctors were no longer at the health

service making it difficult to trace relevant reports. This could also be difficult for migrants or refugees who may not have copies of medical records or a medical history in Australia.

b) Lengthy process

Consumers described various stages in seeking a review and/or appealing a NDIA decision as lengthy and this was reiterated by staff. Not all interview participants made a distinction between how long applying for the NDIS took and how long a review or appeal took. Furthermore, some consumers appealed on multiple occasions, applied on multiple occasions, and applied on multiple occasions but stopped applying in-between their applications. Nonetheless, they generally gave some indication of how long the process took.

Outcomes from appeals were said to take one, two or three months (Participants 2, 4, 5 and 10), close to a year (Participants 1, 3 and 4) or even longer (Participants 1 and 5). Some participants were still waiting on the outcome of their appeal when interviewed and it was not clear when a decision would be made.

One consumer explained that the process of applying for the NDIS and appealing a decision has been “extremely difficult” and that they have been “struggling with NDIS for two years or more” (Participant 11), explaining that the appeals process took “one year and four months. Because I received the refusal in April 2019 and only in August this year [2020] I heard back from the tribunal granting me access. But I still, of course, don’t have the access. I have to provide the five things that they requested” (Participant 11). Another explained that “it took more than one-and-a-half years from the decision [the] NDIS made to until the tribunal case was finalised” (Participant 4).

For Participant 9 it took her three years to be able to access NDIS support. She explains this was “because they been rejecting my application so many times and [keep giving] me reasons. We kept trying our best and sending all the documents and everything [in new] and all the doctor’s reports, the hospital’s, my sickness, support letters and they still – it takes me three years to get in”.

Another consumer explained that while the appeals process did not take very long for them, between seven to 10 days with assistance from a MDAA NDIS appeals officer, applying for the NDIS and acquiring everything that is required took 18 months (Participant 7). It seemed to be a trend with the assistance of an appeals officer peoples’ appeals were processed quickly and requests granted (Participant 10).

Nonetheless, MDAA appeals officers described the process as too prolonged – staff suggest this is why some people from the CALD community cannot be bothered or are deterred from accessing the NDIS (Interviewee 2). People with psycho-social disabilities, for example, are commonly required to have an OT assess their mental health and daily living as part of the appeals process, which prolongs the process (Interviewee 2). Interviewee 2 stated: “[I]t’s just a really long process that [... Legal Aid lawyers] try to get ... occupational therapists to assess [... the consumer’s] mental health and their daily living” (Interviewee 2). Furthermore, some consumers with psycho-social disability struggle to meet requirements – they can be forgetful, miss meetings, have a bad day and be unable

to attend appointments, be unable to give consent, struggle to comprehend what the system demands etc. This can prolong application processes and time without necessary supports (Interviewee 1).

The lengthy process has an impact on people with disability. For example, consumers suggested that the length of time that the process can take, especially if the case goes to the tribunal, does not recognise how their needs may have changed from the original claim lodged with the NDIA which is being appealed (Participant 4). This point is crucial given that if a person is appealing for more funding, they are at the tribunal level and their existing package lapses, the tribunal will extend their current NDIS plan at a pro rata rate. Yet, the appeal is based around the inadequacy of the current plan and the need for more funding. Consumers cannot have a new plan until the appeals process is complete. This also proves difficult for consumers whose needs change. For example, a person with a vision impairment undergoes an operation and requires more support. If the case is still at the tribunal, the NDIA will not increase the funding and support until the matter has been resolved at the tribunal. It also does not take into consideration that the person may be in pain (Participant 3). Participant 3 explains that in her experience “the [tribunal] people, they take time. They don’t think the person is in pain, they are just taking their time”.

Staff confirmed the review process could be lengthy. One staff member commented that for some requesting a review, the review can take a significant amount of time and for some a scheduled review of their original NDIS plan was due anyway making a NDIS appeal redundant or less appealing (Interviewee 5). Additionally, further delays were likely when the review had not been assigned to a NDIS reviews team.

It is worth noting, however, a MDAA staff member suggested the lengthy processing time has improved since the initial years of the scheme. For example, “Back in the days when we were first doing it sometimes the NDIA just wouldn’t reply or they would take a really long time to reply” (Interviewee 5).

Nonetheless, consumers explained how the time it took to appeal a decision made by the NDIA would deter them from appealing again (Participant 4) and staff note that some consumers want to withdraw from the appeals process because it is too prolonged and requires too much effort (Interviewee 2). In one example, Participant 4 explains how the timeframes set by the tribunal to collect and collate the requested information were too long because he was able to meet their requests in a lesser amount of time. This was frustrating because he really needed the support for his daughter and the long deadlines to provide the requested information meant that his requests for support were being delayed even further. Lengthy time frames were also given to the NDIA to respond to the requests and they would take the amount of time given to them to respond to the request which meant that an outcome was further delayed (Participant 4). He conceded that even when one of his appeals was fast-tracked it still took five to six weeks (Participant 4). Thus, although, Participant 4 had been granted a NDIS package for his daughter, the process of acquiring the reasonable and necessary supports following the planning meeting and OT visit was lengthy. He describes a six-month waiting period between the funded OT visit, submitting the OT report to the NDIA and when

they actioned the supports. This was despite several follow up emails and calls by the applicant. Another consumer explained when they took the matter to the tribunal, they were granted access, qualifying as having a disability. However, the NDIA’s lawyer requested more information and documentation, which their specialist noted could take up to six months to write (Participant 11).

The tribunal lengthens the process of the appeal and requires the consumer to engage with lawyers who represent the NDIA. One MDAA staff member suggested that the length of this process and the unequal power dynamics that operate between the lawyers representing the NDIA and the consumer from a CALD background with disability, their families and/or carers leads them to believe that appealing is not “really beneficial for some clients” (Interviewee 2). One staff member often suggests to their client that it would be best to re-apply rather than appeal. This is because sometimes re-applying takes less time and is less stressful than going through the appeals process, which can take years. One appeals case Interviewee 1 is working on has gone for two and a half years and is yet to be successful/complete.

There is also a lack of easily accessible information about the appeals process and the length of time it can take provided to consumers. Some people lived under a false assumption that a case conference will resolve their NDIS access issues. There is nothing easily accessible that communicates what the process looks like or the longevity of a typical case. This should be clearly communicated. The legislation should provide a specific time frame for NDIA responses, like the ones they impose on applicants. Furthermore, the NDIA should provide consumers with someone throughout and after the tribunal who can contact medical professionals on behalf of consumers to ensure their future claim meets evidence requirements. Questions to participants about the application or requests for further evidence should also be made more accessible so that they are understood by everyone making answers easier to provide. There is a disjuncture between legal knowledge and medical knowledge and recommendations and how evidence is interpreted and communicated. If the person gives informed consent, the NDIA should communicate with medical professionals on behalf of consumers. This would help to alleviate the emotional, economic, labour intensive and lengthy burden of providing further evidence during a review or appeal. Additionally, changes to allow only non-legal advocates to appear in NDIS reviews and NDIS appeals may also help to alleviate some of the stress and unequal power dynamics in the tribunal between NDIA lawyers from firms such as MinterEllison and Clayton and Utz and the person from a CALD background with disability, their families and/or carers.

c) Complicated and complex process

The appeals process has also been described as complex and complicated, particularly for consumers. Most of Interviewee 2’s consumers have expressed they would not go through the process if they did not have MDAA assisting them because they lack confidence to navigate the system and its complexities. Staff felt it was only through gaining more experience with the process that they were able to understand what was required in the review and appeals applications and they were able to streamline the process. They recognised the importance of an OT report and including a lived experience statement, which is a statement by the applicant that educates the NDIA about

their life and how they manage their everyday life. They also realised that the lived experience statement needs to be backed by evidence to be accepted – for example a carer statement or OT report, however, this requirement is not made clear or in many cases, not communicated altogether (Interviewee 1).

With regards to the case conferences, one staff member expressed that 90 per cent of their consumers in case conferences have a lack of understanding of the proceedings that occur. As such, consumers participate without having real knowledge of the happenings (Interviewee 1).

Furthermore, throughout an access appeal a consumer is left in limbo because they are not eligible for any supports (Interviewee 1). This complicated aspect of the process needs to be considered and rectified.

d) Inaccessible and insufficient information in correspondence

Staff also explained that the lack of detail about why the consumer was rejected in the initial rejection letter can also make the process of applying for a review difficult. They explain that on the initial rejection letter applicants are briefly alerted to the appeals process and the reason for the rejection. However, this is usually explained in reference to the NDIS Act and legal terminology is used which can be vague and difficult to understand the specific reason for rejection. Alternatively, rejections following an internal review are more detailed. Staff report that this letter explains in two to three pages why the applicant’s review of a decision was unsuccessful (Interviewee 3). Therefore, rejection letters need to be more explanatory and transparent as opposed to merely stating an area of legislation that has not been met. They should be written in a way that is accessible for people with disability (e.g. informal language and images). Rejection letters should include a list of requirements to tick off for the application to be successful next time. The NDIA should also distinguish their letters from other government correspondence because all government correspondence is formal and similar in appearance/format making it hard for some to discern what action is required or where the letter has come from if they are interacting with multiple systems.

e) Lawyers

Lawyers can be involved in several stages of the review and appeals processes which can make the processes complex, complicated and unequal. The NDIA legal team and a case manager from the NDIA can be involved during a case conference before the tribunal phase and during the tribunal phase. This is particularly intimidating, confronting and stressful for consumers appealing decisions, particularly for those who do not have legal representation or an advocate to support them or whose primary language is other than English. One staff member described how the tribunal is “very confronting for consumers going through the process” especially when “working with a lawyer who doesn’t know how to work with people from a CALD background, or a person with disability” (Interviewee 2). They described how lawyers would often use legal terminology and read legislation out to consumers, which is difficult to understand for those without a legal background. Furthermore, they would not give a chance for any interpreter to interpret and translate what they were saying to the consumer. As an NDIS appeals officer

commented: “[T]hese lawyers ... don’t seem to have the training in relation to disability and ... CALD communities. It’s really stressful for our consumers” (Interviewee 2). It can also be particularly stressful for consumers who have psycho-social disabilities, which can be exacerbated by the process. Therefore, this part of the process is intimidating, particularly so when it is the person with disability, their families and/or carers “versus the lawyers trained to protect the NDIA” (Interviewee 2) and seemingly favours the government organisation consumers are appealing against.

Getting legal representation can be complicated. Although legal support is provided through a joint program with the Legal Aid and the tribunal at the first session (usually 30mins), CALD people with disability, their families and/or carers going through the appeals process rarely know this until MDAA informs them. Additionally, this support is not ongoing and leaves the person without legal assistance after this first session. If Legal Aid is further approached for assistance, which occurs frequently, often the case is refused representation. The ‘Advice and Rights Centre’ is also regularly approached and sometimes advice but no representation is given (Interviewee 5). Therefore, while the applicant may be able to access a free solicitor for the duration of their case, this can be a long process. Staff describe the process as unequal and unfair given that the NDIA “is allowed to have their legal representation but not everyone can afford to have a lawyer to accompany them during tribunal” (Interviewee 5). This is also compounded by the fact that the AAT is a no-cost jurisdiction.

The NDIA should provide funding for consistent and ongoing legal representation of the appellant, that is, the tribunal process should be made more fair by having readily available legal representation for those who need it. The lawyers who are hired from external law firms for the tribunal to represent the NDIA should have training, knowledge and experience working with people from CALD backgrounds and disabilities. Alternatively, the AAT should be a jurisdiction where lawyers are not permitted because early on lawyers set the precedents for the AAT which is problematic. Instead, just skilled non-legal advocates should be allowed. This would alleviate the unequal power relations and recognise the no-cost jurisdiction of the AAT.

f) Timeframes

Additionally, applicants are given a time frame to submit documents or complete tasks otherwise their appeal is cancelled which complicates the process. For people with psycho-social disabilities, who have good and bad days, who also may have the added complexity of not being able to write in English, this presents as a difficult and sometimes impossible task. Interviewee 2 speaks of one client who had an OT appointment booked but was unable to attend because it was not one of their good days – they were experiencing trauma. MDAA got billed for this assessment because the consumer was not able to inform anyone they would be absent. As such, any timeframes imposed, and any actions taken when a timeframe cannot be met should consider the circumstances of the applicant.

6.9. The impact of the review and appeals processes on consumers

The appeals process has a significant impact on consumers. Considering the impact of appealing on consumers is important because it shows how the process could be exacerbating existing conditions or causing further harm. Additionally, such experiences could shape whether consumers are likely to seek a review or appeal again.

a) Exacerbates mental health and retraumatizes

According to staff the process exacerbates mental health, consumers’ disability/ies and retraumatizes. Consumers have to re-tell their stories and revisit medical professionals that have written initial reports, which can reignite traumas already experienced causing or adding to mental and emotional distress (Interviewee 2). In one case Interviewee 2 said his consumer did not want to return to his psychiatrist or psychologist to meet further evidence requirements because of the re-traumatisation it will cause. Realistically, however, this is his only option other than withdrawing his application or having it cancelled. Similarly, one case Interviewee 1 had, who has a psycho-social disability and physical disability, did not want to go through a psychiatric assessment because they already had a comprehensive report from their psychiatrist which detailed their struggles and because their health is compromised when in the community. The assessment was pushed upon them and caused traumatisation to the point that they could not continue the assessment. This trauma, largely caused by the experience of applying for the NDIS, is now ongoing (Interviewee 1). Interviewee 2 also had one consumer who had to increase their medication due to the stress and trauma the tribunal process caused.

Having to re-tell one’s story over and over to new case workers compromises wellbeing and is exhausting. It can also raise hope only to have this squandered by another rejection which exacerbates exhaustion and is overwhelming. Many consumers felt like there is always another hurdle (Interviewee 1). This supports the recommendation that the NDIA should focus on collecting the medical evidence on behalf of consumers when requesting it and should assess the impact of traumatisation and exacerbation of existing impairments when making such requests.

b) Provokes anxiety and feelings of overwhelm

Interviewee 2 explains how the tribunal can provoke anxiety because consumers are not told how to prepare for the case conference, just that they have to attend it on a given date which is communicated through a letter. They are told to write a statement of lived experience without explanation of what this is. This can be a difficult and depressing task. Additionally, in certain cultures, this type of information is private and not spoken about (Interviewee 2).

The process also creates feelings of overwhelm particularly when the review involves a lawyer. As established consumers do not know the process and what the first case conference means. Furthermore, they feel unsupported by the system, that their rights have been disregarded, and overwhelmed that more evidence may be required for their application. This causes further distress as they may have to pay for this evidence and collecting and collating the evidence could be time consuming. For some consumers,

it is difficult to cope with being ill, having a disability, having to deal with rejection and face a case conference or the tribunal.

c) Stress invoking and intimidating

Staff additionally say that for many the tribunal process is stressful and intimidating especially for someone who does not have a NDIS advocate or who cannot afford to have a lawyer accompany them during the tribunal. Confronting a lawyer who may use vocabulary that is difficult to understand is daunting for anyone, but particularly for those for whom English is not their first language. As a result, this process causes discomfort for the consumer (Interviewee 5). Interviewee 1 describes that the tribunal process is extremely stressful and overwhelming for people to try to understand and go through – what it really means to go through an appeal is unexplained.

One of Interviewee 2’s consumers was required to get an OT evaluation as part of the evidence required through the appeals process. The OT “forced” the consumer to perform a “range of motion test” despite the consumer vocalising she was “uncomfortable doing it”. This caused the consumer pain, but they were fearful to challenge the authority of the OT further.

d) Frustrating

Staff also explain that consumers feel frustrated by the appeals process because sometimes they have to recollect the evidence and they are unsure how to improve their evidence because no guidance is provided.

6.10. Dealing with rejection

According to one staff member, some consumers experience great highs and lows throughout the appeals process. For example, magistrates can present as being on a person’s side and the case seems promising and then the NDIA can reject the case asking for more evidence (Interviewee 1). This is emotionally destabilising and disheartening. The same staff member also identifies that rejection can be invalidating and demoralising. They have had a number of cases that once rejected the consumer questions “what more [evidence] could they possibly need?” (Interviewee 1)

The effect of the appeals process on people should be recognised and accommodated for.

6.11. Barriers to seeking a review and appealing

In summary, there are several barriers which can be identified to seeking a review of a decision or appealing a decision.

a) Medical evidence is costly and inaccessible

Medical evidence was described by both staff (Interviewee 5) and consumers to be expensive (Participant 3). Staff express that internal reviews are frequently too costly for their consumers because the onus is on them to fund each of the reports required to meet evidence requirements (Interviewee 2). Additionally, Participant 7 found that one health provider required her to pay per page for print outs of relevant historical reports. When asked why she did not have copies of her old reports by the interviewer

she explained “you don’t keep every single old report. When you keep your house clean, you chuck them. I never expected that I’m going to apply NDIS when he was a baby” (Participant 7). The cost of requiring further medical evidence should be absorbed.

Additionally, accessing medical evidence could be a barrier to seeking a review of a decision and appealing a decision. Participant 11 suggested that he found it difficult to get the required medical evidence from a specialist because specialists are busy, and it is difficult to make an appointment with them.

Parents found it difficult due to privacy and confidentiality laws to get access to their children’s medical reports (Participant 7). Participant 7 was encouraged to seek these records out by a MDAA staff member when appealing a decision in case the medical evidence provided in the original NDIS application was not sufficient.

b) Evidence requirements are unclear and meeting them is time consuming

Participants were also confused about requests for further evidence (Interviewee 2) and what that evidence needed to include. One staff member explained how consumers felt that they had already explained their story to the NDIA and wondered why the NDIA asked more questions and required more evidence. In some cases, consumers would have countless medical reports yet were required to collect more evidence.

Nonetheless, given the centrality of evidence in the process of applying for the NDIS, one consumer expressed that they wished they had knowledge about the type of evidence required and included this in their initial application. This would have prevented them from needing to appeal and going to the tribunal (Participant 4) or continually asking their treating medical professionals for new evidence. For example, in July 2020, Participant 9 was found to be ineligible for the NDIS because her condition was not determined as permanent by the NDIA. So, with the support of her treating medical practitioners and MDAA she provided the NDIA with new letters from her doctors which had the key words “This is permanent.” Her application was successful. She said: “That’s what makes my doctors laughing ... they said, oh my god, must mean they are looking – they are looking everywhere to find the word permanent. So as they can’t see the word permanent, ... they didn’t take you.” By knowing the importance of such wording to a successful application, Participant 9 and her doctors could have ensured that these specific words were included in her original application.

Participant 11 also found that he was denied access to the NDIS because of his conditions and the lack of evidence. He explains: “In this country, they have a lot of services. They have the human rights and all the [ethics] are high but every time that they hold these sessions with me over the phone, and I’ve spoken to about four or five people, they continuously repeat the same thing. They, for example say, you have glaucoma, this does not impact on you to NDIS. You have damage in your knees, you need to replace the joints but that’s not enough for you to be on the NDIS. But I keep telling them, but my hand, I have a permanent disability with my hand. I don’t have the fingers; I was shot in the hand, so I lost bones and muscles and my hand is

deformed and it is disabled. But they say no, you need more evidence. So actually, I took the matter to tribunal and they said according to section 24 you do qualify as disabled and, on that basis, they gave me access. But then their lawyer requested that I provide some information or documents from my medical team and the specialist said that it could take six months to get a report because he doesn't specialise in writing reports" (Participant 11). However, Participant 11 was able to secure a 10-minute appointment after two and half months so that the specialist could "take a look and see if [he] can provide" the relevant documentation.

Participant 5 explains: "Yeah, it was time consuming because there's just sometimes I had to call up my rheumatologist, put an appointment with him and go down to actually ask him to do another report for me. Even though I see my GP regular[ly] I had to re-ask her to do another report for me to fill out the other form. She even started to get cranky with filling out the forms. She's like, 'how many times do you want me to fill out this form for you and they keep knocking you back? I think you should just stop applying for it because they're not going to give it to you anyway. They're just rejecting you this many times." She felt that while her rheumatologist had experience completing NDIS applications, her GP was less familiar with the process and what was required. While her GP had completed the paperwork for many of her patients, many of her patient's applications were getting denied.

Participant 9 provided the NDIA with different medical reports that documented how her condition would get worse at times. Her doctors were also frustrated because they could see their patient should receive NDIS support but was being denied. Participant 9 explains: "Yeah, my doctor wasn't happy at all, was very sad and upset about the decision, how they are reacting back to me because they said it's not right, because you need it. You're living alone, you are a single woman."

To address this, rather than the proposed independent assessment, applicants should initially apply for funding by stating their disability. The NDIA should then respond with the relevant medical evidence required, the relevant medical professionals who can provide medical evidence and the possible supports available to the applicant. Although it may lengthen the initial application process it will significantly reduce appeals and the entire application process and time it takes to receive funding. This may also help the medical profession to understand what type of evidence is required.

c) Inadequate communication

Some consumers found the communication from the NDIA difficult to understand (Participant 5). Participant 5 for example, explains how she found the letters from the NDIA detailing why her application was rejected incomprehensible. This made it hard to address the NDIA's requests for further evidence. As explained above, she has "brain fog" from her medications, which makes it difficult to interpret and understand information even if she reads it multiple times, and the way the letters are written made it difficult for her to understand how to improve her application.

When discussing how her application for her son for NDIS support was rejected, Participant 7 explains that although she was given an explanation of why he did not qualify, this was explained referencing sections and subsections of the Act. She describes this as "some odgy-body things they said", not "in a normal way", "whatever nonsense" and using "stupid words where nobody can understand". She later qualifies "they'll use these legal words which only they understand". She concedes this could act as a barrier for people from CALD backgrounds with disability: "I think people with culturally-diverse, linguistically different backgrounds, they're going to find it hard and they keep quiet, because they don't know what else to do." As such, the words and phrases used in the rejection letters should be more understandable, rather than a reliance on legal terminology because this can be "intimidating" and can deter someone from applying for the NDIS, seeking a review or appealing a decision. She states: "Who cares about section 32(4)? You [should] care about the human being [and] treat them as a human, not too much legal lingo."

Another communication barrier that was identified by staff and one consumer for CALD communities was the need to understand English. Staff say there is a lack of interpreter services available through the NDIA, which makes communications for CALD communities with the NDIA challenging and, at times, impossible if they are not working with a support service or advocate who can supply this service. When an advocate or an advocacy agency is able to provide these services, this can be at the cost of the support service such as, MDAA (Interviewee 5). One staff member (Interviewee 2) also suggests that many from the CALD community are unaware of the resources available to them, and even when aware, have difficulty understanding and accessing them due to language barriers. Additionally, one consumer emphasised the importance of needing to understand English for negotiations and communications with the NDIA and emphasising to them what supports are needed (Participant 4). He also acknowledged that while he can write in English, it takes him a long time to complete the forms (Participant 4) because English is his second language. He explains that sometimes it is difficult because he cannot use the word he wants to use and explain points in the way that he wants to. He also has had the experience where people have said that they do not understand what he said and that he does not want to listen. However, on an occasion when he used an interpreter, he was not happy because the interpreter's abilities in English were equivalent to his own.

Other consumers who speak English also identified language as a particular barrier to people whose first language is other than English. Participant 3 states: "For example, I can understand English. But some people from other communities, culturally diverse background, they – still don't understand the NDIS system. They are unable to file an application and appeal properly. They are really in very desperate situation. They are language barriers."

Staff (Interviewee 4) also noted that the paperwork sent to the consumer is always in English, so letters of rejection are written in English. She suggested that this could cause people from CALD communities with disability to discontinue reading once they read "not approved", which

means that they miss the information at the end of the application about the ability to appeal a decision. As such, she wished that the NDIA would consider and understand the history and background of the person and whether English is their first language when rejecting an application. If this is not the case, she suggests that the NDIA should do an informal notification by telephone using an interpreter to inform the person in their language that the application was rejected, why the application was rejected and explain their options for seeking a review or appealing. This informal call could then be followed with a letter, which they should also be notified about in the phone call. This means they can be empowered by the process and start to action a review or appeal themselves, rather than having to take the rejection letter to an advocacy agency to find out what can be done.

Additionally, one consumer felt that the NDIS did not communicate in a way which takes into consideration the impact of their decision on the applicant. Participant 9 states: "They don't think about others dealing, I don't think so. They should – having better way – how to communicate with others and respect others' value and feeling, because it hurt very emotionally, really bad." Consideration should be given to the impact of a rejection on consumers and the contact details of support services should be provided.

d) Culture

Furthermore, some consumers are reluctant to appeal or will not appeal because culturally it would be perceived as being ungrateful or as causing undue 'trouble', even when they feel as though their plans are inadequate. Some consumers are also fearful that supports will be taken away completely if they appeal and are grateful for any supports they receive and thus choose not to. For example, Interviewee 5 (at the time of interviewing) was supporting a consumer who wanted to make a complaint about the NDIS and the NDIA anonymously out of fear that if they were identified, their funding would be cut.

6.12. To appeal or re-apply?

Given the lengthy process of an appeal, in some cases consumers and staff detail how the best option for an applicant is to re-apply, rather than ask for a decision review or appeal. Participant 5 explains, "a couple of times I was told not to review just to start all over again because my process would be a lot easier and I'll get a quick call back a lot quicker. Because if I did a review that the process is going to take more than three or four months to get a phone call back". She said that advice was provided to her by the NDIA.

Some consumers who had been through the review or appeals process were motivated to appeal again (Participant 7). One consumer explained they would appeal a decision again because they needed the supports available via funding and that their condition was "bad" and "legitimate" (Participant 1). This was a theme amongst consumers who felt that the denial of the application was a denial of their disability. One consumer stated: "Until the day I die, I'm going to fight them. I'm going to appeal them. I'm going to beat them because as I told them, everything is a lie" (Participant 6). Another explained "I kept appealing for so many times because they kept sending things back and I didn't give up, because I'm in a really bad condition" (Participant 1). Nonetheless, "It's very draining and it's very

bad on your mental health because when you know that you ... have so many impairments with your body and they say to you there's nothing wrong with you, that's really hard to fight" (Participant 1).

However, another consumer said he would appeal again but the time-consuming nature of appealing does deter him (Participant 4). He said: "We are going to ask because we are not supported but then this is completely extra work for us ... so that's why I may not go for the appeal because I already don't have time and this completely extra time." He explains that while he appealed one aspect of his daughter's plan because there was not enough funding provided for supports, he left a second appeal process halfway through because it was too time consuming. Thus, he concedes that it is too much work for him to go to the tribunal and fight each time a required support is found by the NDIA to be unreasonable or unnecessary.

Participant 11 indicated he would be unlikely to appeal again. He explains: "I'm really tired of all of this. It's not that I'm asking for any financial privileges, I am only asking for assistance from one of these organisations in my daily life. If I'm going to struggle to get the service or get the assistance, then that's it, I don't want it, I'll just rely on God and my family members."

An underlying theme, however, became lack of choice that some had to appeal decisions. Participant 2 states: "Oh, it's not that hard to decide ... if I have to appeal or not because I know my son's needs and condition. So whatever he needs, ... I really have to find something for him." Participant 10 similarly states: "Very simple, we think it's not enough support for [redacted] and we do lots of things and the funding is not enough. If we appeal, we may get more, but if we don't appeal, we get nothing."

6.13. MDAA assistance with appealing

Consumers were appreciative of the help provided by MDAA staff with their appeals (Participant 1). Consumers generally named the NDIS appeals officers and the capacity building and support officers, however, generally highlighted how MDAA staff ensured all the required information was included and documented and how MDAA staff advocated and supported their applications (Participant 1). For example, one consumer explained how someone from MDAA went to a doctor's appointment with them seeking the required medical evidence necessary for them to apply for the NDIS and another spoke about how the NDIS appeals officer gave her support and documented everything she wanted included in her reply to the NDIA (Participant 1). Furthermore, MDAA staff are valued for the way they break the requirements down into manageable steps and explain to the consumers what the NDIA requires. Participant 5 explains: "If I was stuck on a question, I didn't know how to answer it, like he sort of broke it down for me and helped me understand what they were going on about". In sum, consumers saw the assistance provided by MDAA staff and the expertise of the NDIS appeals officers as integral to their NDIS appeal, and often successful outcomes.

This highlights the important role that MDAA staff generally, and NDIS appeals officers specifically, play in navigating the appeals process and the NDIA. For example, one

consumer explained how they tried to appeal themselves, but they did not know what information was required or how to communicate with the NDIA in a way which would lead to a successful outcome. They suggested that it was only through being supported to appeal by an NDIS appeals officer who knows and understands the procedure and can communicate in the way required by the NDIA that the NDIA took their appeal “seriously” (Participant 10). Participant 10 explains: “Like us the first time we did appeal, but we don’t know what NDIS need to get, even we actually doing all the things like speech, OT and psychology, but we still don’t know how to communicate with them. But as long as one person know the procedure ... they know how to communicate with them and NDIS take it seriously and maybe better, I think.” She concedes it would be difficult to do without support (Participant 10).

Participant 5, for example, explains how the NDIS appeals officer from MDAA, called her and helped her complete what was required for her appeal. She says: “Within two weeks I heard back from them. It usually takes three months to hear back, and then they usually say oh, sorry, you’re denied the NDIS.” Instead, “they said to me that you’ve been approved.” This sentiment was echoed in the staff interviews where staff explained the key role that the appeals officers have in successful appeals given their experience and knowledge of the procedures. One staff member explained how “having a dedicated team like the one at MDAA really increases your chances of getting ... what you deserve in your plan ... I’ve come across many ... people [who] have tried to do it on their own and it’s just been really difficult for them. So, having that support, I think it makes a big difference” (Interviewee 5).

Additionally, another staff member explained how consumers have admitted that without the support provided by MDAA they would have “drop[ped] out completely” because “they would just not have the confidence to navigate the system. There’s too much red tape around it. The legislation is too complex”. The assistance provided was emphasised as crucial particularly for consumers who are not “tech savvy or can’t speak English” (Interviewee 5).

Given this, it is important to question how accessible the process and procedure of appealing is for those who do not have access to support like that provided by MDAA and whether those without support are likely to succeed in their appeal. This generates two important recommendations.

People with disability, their families and/or carers who are appealing a NDIA decision should be provided with adequate support to do so. For example, information on the appeals process should be communicated more clearly and in a way which is accessible to people from CALD backgrounds with disability.

It is crucial that roles like the NDIS appeals officers continue to be funded as well as organisations like MDAA.

However, while consumers were appreciative of the work of MDAA, they raised some minor concerns. Firstly, one consumer found it difficult when she had an urgent matter she needed to discuss with someone at MDAA because she needed to make an appointment (Participant 8). Secondly, staff turnover was identified as a concern (Participant 10). One consumer felt that during the time she has been dealing with MDAA she had three people dealing with her son’s case and it was confusing, particularly in relation to whether anything has been actioned. It was also difficult because she then needed to explain their case all over again. These minor concerns could be mitigated by an increase in award rates and guaranteed funding for organisations like MDAA.

7. Recommendations and Conclusion

Overall, this report has found there are significant barriers to applying for the NDIS, seeking a review of a NDIA decision, and appealing a NDIA decision for people from CALD backgrounds with disability. As such, the following recommendations are made. The recommendations are organised under subheadings, which pertain to areas of relevance.

7.1. Applying for the NDIS

The following recommendations and commentary relate to applications for the NDIS.

1. Information about applying for the NDIS should always be made accessible to people from CALD backgrounds with disability, their families and/or carers. This information should be in a range of formats and languages.
2. If LACs are assisting people from CALD backgrounds with disability to apply for the NDIS or are doing outreach to CALD communities to encourage people with disability, their families and/or carers to apply for the NDIS, LACs should have connections with CALD communities and have the training, knowledge and experience of working with people from CALD backgrounds with disability.
3. Culture shapes understandings, definitions, and experiences of disability which impacts whether people apply for the NDIS and how they apply. The way culture shapes understandings, definitions, and experiences of disability must be considered and addressed in the NDIS. Consultation with and genuine listening of the experiences of organisations such as, NEDA and MDAA to develop strategies in this regard is important.
4. The age limit to NDIS applications is arbitrary and bureaucratic. The age cut-off of 65 years of age should be scrapped in line with the actual requirements of people with disability.
5. MDAA provides a fundamental role in initiating contact with crucial support services and the NDIS for people from CALD backgrounds with disability, their families and/or carers. It is important that this work by MDAA is supported and funded on a permanent basis.
6. Many applications for the NDIS are denied based on insufficient or inadequate evidence. Greater clarity must be provided to applicants and treating medical professionals about the type of evidence required by the NDIA and how this evidence should be presented for NDIS applications. Alternatively, procedures for applying for the NDIS could change so that when someone is initially applying, they state their disability. Then the NDIA could respond by detailing the relevant evidence required, which medical professionals can provide this information and how this evidence is to be presented.
7. There should be clear guidelines about who can and who cannot access the NDIS. The guidelines should detail specific eligibility requirements based on disability type and the evidence required. These guidelines should not be designed to make it harder for people to apply but to acknowledge how difficult it may be for some impairments to meet the eligibility criteria, despite requiring NDIS support. For example, the difficulty someone with a psycho-social disability may have demonstrating a functional capacity reduction or permanency.



MDAA staff member and consumer

8. There should be some recognition of the cost of evidence for the applicant.
9. Some applicants who receive the DSP but who are denied the NDIS are frustrated by the inconsistency in the application processes. Given the arduous process to apply for the DSP and achieve a successful outcome, the information and evidence that Services Australia holds as part of that application process should be able to be accessed by the NDIA in support of a NDIS application if NDIS applicants give consent. Furthermore, consultation should ensue with relevant bodies about the application processes for both systems and how the application processes can be less arduous and unclear.
10. Denying access to the NDIS or increased supports has implications for the care and support people with disability receive. This should be considered when applicants are rejected or applications for more funding and supports are denied. Referrals, information, and the contact details of other support services should be included in rejection letters. This should include the contact details of appropriate advocacy organisations and mental health support services.
11. Initial rejection letters need to be more explanatory and transparent and all rejection letters should clearly explain the reason for rejection, rather than reference a section of legislation.
12. Rejection letters should include a list of requirements to tick off for the applicant so that their application is successful next time. They should also show what medical professionals/specialists reports the participant should acquire to provide further evidence. As well, information should be provided on where to go and the contact details of who to talk to about the rejection and seeking a review or appeal.

13. Rejection letters should be accessible for people with disability and people from CALD backgrounds with disability. Letters could include informal language and images and be written in languages other than English. Alternatively, if letters cannot be provided in languages other than English then when an application is rejected and the person is from a CALD background whose first language is other than English, the NDIA should do an informal notification by telephone using an interpreter to inform the person in their language that the application was rejected, why and explain their options for seeking a review or appealing. This should be followed by a letter.
14. NDIA letters have a standard format which is like other letters by other government departments. For those interacting with multiple systems this can be confusing. The NDIA should distinguish their letters from other government correspondence.

7.2. Seeking a review or appealing a NDIA decision

Many consumers sought a review of a decision to deny their NDIS application or the funding and support requests in their plan. With regard to seeking a review or appealing a decision the following recommendations are made.

1. The balance between the interests of the NDIA, service providers and the person with disability, their families and/or carers needs to be sought without compromising adequate, timely and appropriate support for the person with disability, their families and/or carers.
2. People with disability should be awarded enough funds for the reasonable and necessary supports they require, covering how often they require such supports. This may deter people from overestimating their initial requests in the hope that they may receive supports which are close to meeting their needs.
3. The NDIA through the Operational Guidelines, their website and the NDIS Act provide definitions of reasonable and necessary supports. However, this information on the website does not appear to be provided in languages other than English. This information should be in multiple languages and should also be clearly communicated to and understood by applicants so that they do not need to seek a review or appeal a decision when the supports they require have not been funded. Such changes could prevent them from applying for such supports which are unlikely to be funded.
4. People who are seeking a review of a decision or appealing a decision are left without any support or with their existing inadequate funding and support package. This needs to be considered and rectified.
5. The contact details of organisations who can assist with review and appeals applications should be easily accessible to those whose applications and requests for more supports and funding have been denied. This information should be provided in multiple languages. These details should be provided in rejection letters and on the NDIA website. Such organisations should include

advocacy organisations who assist with appeals like MDAA, legal support services which are easy to access and that are genuinely able to assist in the review, appeal, and tribunal process.

6. There should be an indication of an approximate duration of how long a review or appeal will take and clear and accessible information should be provided about what the review and appeals process looks like, including what an applicant is required to do, the process and what is involved.
7. Timeframes are usually placed on applicants. Some applicants can gather the information required and provide it to the NDIA or AAT before the due date. Others are unable to meet the timeframes. Any timeframes imposed and any actions taken when a timeframe is not met, should consider the circumstances of the applicant.
8. For internal reviews, the legislation and operational guidelines should mandate a specific timeframe in which a decision must be made.
9. For a case conference there is no consistent AAT Conference Register or Member assigned to a case. This means that applicants may have to tell and retell their story to different AAT Conference Registers or Members. To avoid this, there should be continuity on cases.
10. Questions about a participant and the supports and funding they require which are sometimes given to applicants when requesting a review or by the tribunal should be written in a way that is accessible, easy to understand and considerate of people from CALD backgrounds with disability. This would make answers easier to provide.
11. To alleviate the emotional, economic, labour intensive and lengthy burden of providing further evidence during a review or appeal, with informed consent, the NDIA should communicate with medical professionals on behalf of applicants to ensure that the required evidence is provided appropriately. Similarly, the NDIA should provide consumers with someone throughout and after the tribunal who can contact medical professionals on behalf of consumers to ensure that their claim and any future claims meet evidence requirements.
12. To alleviate some of the stress caused by the unequal power dynamic between NDIA lawyers and the person from a CALD background with disability, their families and/or carers in the tribunal, there could be changes to allow only non-legal advocates to appear in NDIS review and NDIS appeals matters, making the AAT a lawyer free jurisdiction. Alternatively, the NDIA should provide consistent and ongoing funding for legal representation of the appellant. This would make the tribunal process fairer.
13. NDIA workers and all lawyers working with the NDIA should have training, knowledge and experience working with people with disability, people from CALD backgrounds and people from CALD backgrounds with disabilities, their families and/or carers.

14. The review and appeals process can be difficult, particularly if the outcome sought is denied or rejected. The effect of this on people should be recognised and accommodated for by providing them with support through this event. This could be as simple as initially providing them with the contact details of support services.
15. Organisations like MDAA and their appeals officers have a fundamental role in the review and appeals process for people from CALD backgrounds with disability. Organisations like MDAA should be funded on an ongoing basis.

7.3. Independent assessments

While the introduction of independent assessments may mitigate some of the concerns raised in this report, the independent assessments as proposed cannot be accepted without consideration of the critiques in this report, the concerns raised by disability advocacy organisations (see Australian Federation of Disability Organisations, 2021) and genuine consultation. Three-hour independent assessments by privately contracted organisations are inadequate for understanding a person's lived experience, functional capacity, and medical history, especially if conducted by professionals whose qualifications may not be appropriate. Furthermore, concerns have been raised in submissions to the Parliamentary Committee Inquiry into Independent Assessments about the capacity of independent assessments to be conducted in a culturally appropriate way for people from CALD backgrounds with disability (Stayner, 2021). Although the introduction of independent assessments has been 'paused', the following recommendations pertain to independent assessments.

1. The introduction of independent assessments should cease entirely until genuine consultation and listening has occurred between the government, the NDIA, disability advocacy organisations, people with disability and their families and/or carers. Reforms to the current structure of independent assessments should be based on these discussions.
2. Once this consultation has occurred, should any model of independent assessments be introduced, assessors must have adequate training, experience, and knowledge of CALD communities.

The fact that so many people with disability and their families did not want the proposed assessment process illustrates a larger issue. That is, significant changes to the NDIS should not go ahead unless there has been a genuine consultation process.

Finally, Australia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and was one of the first countries to ratify it. Article 26 of the Convention stipulates in part the following:

“States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services” (UN CRPD, 2006).

The experience of NDIS applicants and participants and the often-arduous review and appeals processes seem at odds with what the UNCRPD stipulates above. Applying for the NDIS, the NDIS review and NDIS appeals processes should be reshaped to be more in line with the aims and objectives of the UNCRPD.

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