Engaging CALD communities in the NDIS

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Table of Contents

1. Executive summary

This report gives voice to the experiences and insights of CALD community leaders and CALD people with disabilities to shine a light on cultural and systemic barriers preventing engagement with, and access to, disability support services. It is hoped the report will help to give greater prominence to the concerns of CALD communities in the implementation of the NDIS. It is further hoped that it will provide a resource to advocate for scheme modifications.

The primary research found that the key factors impacting CALD engagement with formal disability services are: 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. Systemic limitations in the NDIS model for delivery are also shown to pose challenges for CALD clients with disabilities. Many clients are not fluent in English, require greater support in planning and purchasing of services and do not meet scheme expectations of client capacity for self-advocacy. These are significant and complex challenges.

Guided by the insights of CALD communities and individuals with a disability, the report provides evidence for strategies which will strengthen engagement, advocacy, organisational capacity and disability service delivery for people from CALD backgrounds. To help identify strategies to strengthen organisational capacity and practice, it also enlists those on the frontline of service delivery, by drawing on the experience of AnglicareSA disability and mental health workers who provide support services to CALD people with disability.

To meet the needs of CALD clients with disabilities and engage with the strategies suggested in this report, considerable organisational effort on behalf of AnglicareSA will be required. The importance of rapport building with CALD clients, particularly with service providers who can establish relationships based on trust and cultural awareness, has been one of the strongest themes to emerge from the primary research. This was found to be the case particularly for new and emerging communities who face the greatest barriers to accessing support services.

A total of 55 people participated in the primary research for this project through a series of one-on-one interviews and focus group sessions. Interviews were held with: 10 CALD people with disabilities and their family members from a range of established and newly arrived communities, some of whom are existing clients of AnglicareSA; and seven community leaders from newly emerging CALD communities from the Asian, Middle Eastern and African regions. Four focus group sessions were held with 30 AnglicareSA disability and mental health coordinators and support workers, and one focus group session was held with community leaders from over twelve different African countries.

The themes emerging from the primary research are organised under five main topics: Cultural Barriers to CALD Engagement with Disability Services; NDIS Systemic

Limitations for CALD Communities; Strategies for Engaging CALD Clients; Culturally Appropriate Service Delivery and Preferences; and Building Organisational Capacity.

Five corresponding recommendations are provided to address each of these topics. These are underpinned by a series of suggested actions for implementation that respond to the key primary research findings, which are also identified below.

Key Findings and Recommendations

Topic 1: Cultural Barriers to CALD Engagement with Disability Services

➢ CALD communities face significant difficulties in understanding the NDIS model and access points. Research participants were found to have low awareness of where to find NDIS information and available services.

➢ There are cultural and systemic barriers to accepting services, influenced by longevity of time in Australia, fluency in the English language and established relationships with providers, which diverge between clients and non-clients.

➢ There is an identifiable need for a finer-grained definition and understanding of CALD communities along with corresponding engagement strategies which are specifically targeted to newly arrived and emerging communities.

➢ Varying degrees of stigma attached to disability are evident amongst the CALD communities, but stigma surrounding mental illness or psychosocial disability is reported as being the most difficult to overcome.

➢ The family is seen as the primary care providers to CALD people with disabilities.

➢ There is a significant community-identified need for an education and information campaign in collaboration with CALD communities, focusing on: the consequences of ignoring or refusing support; benefits of early intervention; available service options; and the importance of qualified, professional support beyond the family.

Recommendation 1
Work in collaboration with CALD community leaders to build capacity and enhance knowledge of disability and available services.
• Develop volunteers and staff from CALD backgrounds as community liaison assistants to the AnglicareSA NDIS Customer Advocate Team (NCA) and forge relationships with key members of CALD communities as cultural brokers, with attention given to newly emerging CALD communities.
• Utilise existing CALD clients of AnglicareSA disability services as ambassadors to enhance knowledge of disability and service options within CALD communities.
• Provide information on other community service support programs, including any ILC funded programs, for CALD community organisations to disseminate to individuals, particularly those from refugee backgrounds who are not eligible to receive NDIS support.

Topic 2: NDIS Systemic Limitations for CALD Communities

➢ There is a significant need evident for translation services to be incorporated into existing plans of CALD clients to assist with delivery of funded supports.

➢ The need for translation services varies amongst CALD communities, signalling that divergent responses are needed.

➢ Communication following planning sessions and support with purchasing services is inadequate for CALD people with disability.

➢ Additional funding for support coordination is needed for CALD clients who face cultural and systemic barriers to self-advocacy.

➢ Awareness of and access to available disability services amongst CALD people with disability is greatly aided through established rapport with a trusted provider and support workers.

➢ The role of advocates is essential for CALD clients, particularly those from new or emerging CALD communities.

Recommendation 2 Develop an advocacy position for NDIS policy and funding changes that focuses specifically on the challenges facing CALD communities.
• Develop an advocacy position that disaggregates 'complex needs' clients, giving specific focus to CALD people with disability engaging with the NDIS.
• Establish a strong advocacy position on the inclusion of funded translation services within individual NDIS plans/service packages for CALD clients where required (including those with existing plans without triggering a review process) to better support individuals from a CALD background.
• Ensure advocacy for increased funding of coordination support explicitly includes clients from CALD backgrounds, who face specific cultural and systemic barriers to understanding and negotiating the planning process and purchasing of NDIS services.
• Request the NDIA make it compulsory for support coordinators to undertake a follow-up visit to CALD clients following plan finalisation to ensure that support services have been purchased and are culturally or otherwise appropriate.
• Employ a Customer Advocate from a CALD background as part of the NCA team and encourage all AnglicareSA staff to build rapport and establish relationships with existing and prospective CALD clients to improve access to the NDIS.

Topic 3: Strategies for Engaging CALD Clients

➢ Written information on the NDIS, especially individual support plans, needs to be presented in first languages of cultural groups or converted to Easyread format.
➢ Easyread has wider potential uses, for example de-mystifying the terminology around disability, explaining medical tests and diagnoses to family members, and outlining house protocols to CALD clients in supported accommodation.
➢ As CALD individuals are less likely to attend general NDIS information sessions conducted by the NDIA, targeted information sessions through established community organisations need to be provided.
➢ Approaches to engage CALD communities need to include both one-on-one support, including home visitation (sometimes after hours), and community-based information sessions.
➢ Engagement strategies need to involve families and the broader community, as well as respected leaders from the community and churches.
➢ There are a broad range of referral points to the NDIS for individuals with disability and parents of children with disability that could provide a connection point for service providers to identify need and disseminate information.

Recommendation 3
Create a CALD engagement and communication strategy to encourage greater awareness and utilisation of disability and other support services.
• Develop marketing material targeted specifically to CALD communities with attention to cultural diversity in visual representation, in the languages used (Easyread wherever possible) and inclusion of a CALD contact name on promotional material for the NDIS.
• Ensure all information on disability services and the NDIS, including the organisational website, clearly explains what is meant by 'disability' and corresponding services provided for each form of impairment, using visual representations.
• Assess the organisational website for simplicity and cultural relevance and include a section specifically for prospective and current CALD clients with links to translation services, contact numbers for CALD staff champions, and other support services relevant to CALD communities.
• Build rapport with CALD communities through staff attendance at cultural events and festivals and by ensuring NCA engagement is framed around CALD preferences and needs, such as after-hours, one-on-one and home visits.
• Schedule a series of information sessions on AnglicareSA disability services and the NDIS, utilising existing CALD cultural groups and associations as the entry point with priority given to new and emerging CALD community associations engaged through this research.
• Establish a procedure through AnglicareSA's representation on the Centrelink Advisory Group to refer newly arrived people from CALD backgrounds to a primary health provider.
• Maintain regular contact with and provide information to all CALD referral agencies on AnglicareSA disability services and relevant community and accommodation programs.

Topic 4: Culturally Appropriate Service Delivery and Preferences

➤ There is a reported lack of consideration given to cultural concerns in NDIS planning.

➤ A preference amongst CALD communities for disability support staff from CALD backgrounds and for carers to be of the same gender as the client is evident.

➤ The emphasis of CALD communities on inter-dependence and the role of the family in the care of people with disabilities influences care preferences and needs to be accommodated in the service approaches of support agencies, and in the planning processes for the NDIS.

➤ There is general support for the underlying principle of individual goal setting within the NDIS but only within a framework of broader cultural understanding of the role of the family and communal values.

➤ There are varying degrees of willingness to accept disability services externally, but a clear preference for formal care to be provided in the family home.

➤ Supported accommodation for CALD family members with disability is not an option that was generally accepted as culturally appropriate.

➤ 'Respite' support is predominantly interpreted as being care provided outside of the family home and is rejected by most CALD participants in the research.

Recommendation 4
Co-design a CALD service policy with CALD people to ensure that services provided to CALD clients are culturally appropriate and relevant.
• Co-design a CALD service policy with CALD volunteers, AnglicareSA staff, clients and community leaders.
• Assess funded programs through ILC for any gaps in coverage of CALD communities, with consideration given to a program supporting CALD families of people with disabilities.
• Incorporate CALD service considerations into the mainstream by establishing a network of CALD champions in each portfolio area to support the Principal, Multicultural Services and provide advice on culturally appropriate service delivery.
• Promote best-practice examples of AnglicareSA culturally appropriate service delivery and workplace practices on the organisational website and amongst staff, with links provided to research, articles and information on cultural awareness sessions.
• Identify preferred CALD service providers to enable referrals where appropriate or collaborations when required.
• Foster cross-portfolio service connections and referrals for CALD clients as part of developing organisational strategies, such as the disability accommodation strategy.
• Provide tailored information to CALD clients and potential clients on AnglicareSA services provided in the home, including explanation of the range of respite and accommodation services available that focus on 'in-family' support.

Topic 5: Building Organisational Capacity

- ➢ There is strong support amongst staff for a policy that will build capacity across the organisation to deliver specialist CALD services.
- ➢ Staff demonstrated solid experience in disability service delivery to CALD clients and displayed a strong commitment to respectful and inclusive practices in caring for CALD people with disability.
- ➢ There is broad awareness of issues of cultural competency evident amongst staff, but also an identified need for an extension of formal cultural competency training.
- ➢ There is a low level of expertise with using translator services amongst staff. Cost, accessibility and lack of knowledge of what is available are cited as barriers.
- ➢ There is a good level of cultural diversity in the disability and mental health services workforce, but a targeted approach may be required.
- ➢ Additional funding beyond existing scheme parameters will be required to meet the needs of CALD clients with disability and undertake targeted engagement and outreach strategies.

Recommendation 5
Embed commitments to cultural inclusivity throughout the organisation, in strategic documents and initiatives to enhance cultural competency and workforce capability.
• Set a clear strategic objective on the role of CALD clients in AnglicareSA business development planning and client growth opportunities within the NDIS framework.
• Up-date and centralise data on CALD clients and staff to underpin strategic decisions on translation of materials, engagement approaches and the development of a CALD service policy.
• Establish relevant CALD workforce and client representation targets in the organisational goals of each service arm and the KPIs of relevant Senior Managers.
• Pursue a pilot CALD workforce project with the Department of State Development to increase the number of CALD disability support staff in targeted service streams of AnglicareSA (involving the Newly Arrived Youth Service).
• Implement compulsory cultural competency training for executive staff and members of the NDIS Customer Advocate team. Consider extending this training to an identified CALD leader within each disability, accommodation and community service team.
• Create a 'Translator Database' of bilingual AnglicareSA staff and a 'Preferred Translator' guide to suitably experienced translation services.
• Investigate funding provisions for translation services as part of NDIS pre-planning, plan development and service provision to ensure maximum use of funded supports, and prepare a schedule of funded services for staff and CALD clients.

2. Key terms

List of abbreviations and acronyms

ABS	Australian Bureau of Statistics
CALD	Culturally and Linguistically diverse
CDC	Consumer directed care
COAG	Council of Australian Governments
CRPD	United Nations Convention on the Rights of Persons with Disabilities
ILC	Information, Linkages and Capacity Building
LBOTE	Language background other than English
LOTE	Language other than English
NCA	NDIS Customer Advocates
NDIS	National Disability Insurance Scheme
NESB	Non-English-speaking background
NESC	Non-English-speaking Countries
OESC	Other English-Speaking Countries (e.g. New Zealand, Canada, USA, UK)
PCA	Person Centred Approach
SDAC	Survey of Disability, Ageing and Carers

Key organisations

ABS	Australian Bureau of Statistics
AFDO	Australian Federation of Disability Organisations
COAG	Council of Australian Governments
DANA	Disability Advocacy Network Australia
DSS	Department of Social Services
EDAC	Ethnic Disability Advocacy Centre
FECCA	Federation of Ethnic Communities Council of Australia
MDAA	Multicultural Disability Advocacy Organisation
MRC	Migrant Resource Centre of South Australia
NDIA	National Disability Insurance Agency
NDS	National Disability Services
NEDA	National Ethnic Disability Alliance
NILS	National Institute of Labour Studies
PC	Productivity Commission

3. Introduction

The National Disability Insurance Scheme (NDIS) has been one of the most ambitious social policy reforms in recent times. The policy is a national approach to improving the lives of people with disability, their families and carers, founded on disability rights, consumer directed care and person-centred philosophies. The implementation of the NDIS moves away from traditional block funding, to individual, self-managed funding and support to promote choice, social inclusion and independence. In the current NDIS landscape, service providers are led by the consumer in a framework designed to enhance client control over support services.

The roll-out of the NDIS has presented several advantages and challenges for customers and services providers. A key area that presents significant challenges for the NDIS rollout and implementation is the response from people from non-English speaking backgrounds. While the rates of disability amongst people from culturally and linguistically diverse (CALD) backgrounds are similar to Australian-born people, the uptake of disability services in CALD communities is significantly lower (Zhou, 2016). The NDIA reported that the lower rate in CALD communities is being replicated in the early rollout of the NDIS (NDIA, 2016). In the literature, this under-representation is attributed to systemic issues, particularly language barriers and a lack of familiarity with Western healthcare policies and systems. Cultural barriers are also highlighted, with cultural norms and beliefs about disability having an impact on willingness to seek and receive service support. It has also been identified that there is a disjunction between collectivist orientations of CALD communities and more individualistic disability supports, which underpins the imperative of the NDIS scheme to enhance independence (Sotnik & Jezewski, 2005 and Pooja Sawrikar & Katz, 2008). This cultural difference impacts perceptions about the responsibility of the family, extended family and community in the care of people with disabilities and the role of outside agencies. It can also affect the capacity of people from CALD backgrounds to effectively engage in services through self-advocacy and the exercise of independent choice.

This research engages with CALD clients and communities, and with service providers, to extend the foregoing evidence base and make recommendations in regards to the appropriateness of NDIS policy, funding and services for CALD communities.

4. Background
The NDIS

Launching in 2013 under the Gillard Labor Government, the NDIS was a major legislative reform of disability services in Australia. The NDIS has radically altered the way in which people living with disability access support by allowing for individualised, tailored support. The NDIS estimates that the scheme will provide support for up to 460, 000 Australians living with disability (who are under 65) (NDIS, 2017). Beginning with key trial sites,

11

currently the NDIS is being gradually rolled out across Australian states and territories. To provide a background to the development of the NDIS, the table below outlines some of its key, milestones from 2008 -2013.

2008	Australia ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2016)	
	Key outcome Contributing to the global effort to promote equal and active participation of people living with disability. • Protecting, promoting and fulfilling human rights of people with disability • All underpinning principles of CRPD are factored into policies and programs associated with people with disability, families and carers • Reporting responsibilities	
2010	Productivity Commission inquiry into Disability Care and Support (Productivity Commission, 2011)	
	Key findings • Existing disability support is underfunded, fragmented, inefficient • People with disability have no choice and certainty of support	**Key recommendation** • New scheme established (c.f. Medicare) called the NDIS • Long-term high-quality care and support • Increased choice and tailored care packages
2011	Council of Australian Governments (COAG) *2010 – 2020 National Disability Strategy* (DSS, 2011)	
	Key outcome Unified approach to supporting people with disability, their families and carers	
2013	NDIS Act 2013	
	Key outcome Legislation passed to create the NDIS and the NDIA as the agency responsible for delivering the scheme	
2013	First launch sites established. Trials and rollout commenced in states and territories progressively	
	Key dates in SA 2016 NDIS available to young people aged 0-14 years (February) 2017 NDIS available to young people aged 15-17 years (January) 2017/18 State-wide roll-out to adults aged 18-64 years based on where they live (1 July 2017-30 June 2018)	

The NDIS promotes flexible supports across an individual's lifespan with an emphasis on early intervention and investment for those who have permanent and significant disability. The NDIS is informed by three key imperatives: the human rights agenda associated with the CRPD; the social agenda which addresses issues of social exclusion, and the economic

agenda which encourages people with disability to be active and productive (DSS, 2011). Based on these imperatives, the NDIS is goals orientated. Within the terms of the scheme, individuals work at outlining and working towards goals that allow them to achieve more independence and self-reliance, greater social participation in community life, including employment, education and training opportunities and overall improved social and emotional wellbeing (NDIS, 2017).

The NDIS is guided by the philosophy of Person-Centred Approaches (PCAs) which promote "individualised, self-directed funding and supports" (DSS, 2011: 13). PACs alters service delivery, funding and support to be more consumer-directed (Iannos & Goodwin-Smith, 2015). Consumer-directed care allows the recipient of services to participate in the planning of their care and support to enhance the level of choice and control they have over their lives. PCAs is a strengths-based approach, encouraging the individual to be at the centre of everything to enhance independence and autonomy (Van Dam, Ellis, & Sherwin, 2008). In CDC approaches that are person-centred, funding for support can either be self-managed by the individual or their nominee, or outsourced to a registered service provider.

Critique of NDIS

Early evaluations of the NDIS conducted by the National Institute of Labour Studies (NILS) suggest the consumer-directed, person-centred approach has benefitted people with disability, through customised services, which provide enhanced choice and control over their care and greater autonomy. It is also noted that there has been a general increase in support and more say over the timing and location of the support (Mavromaras, Moskos, & Mahuteau, 2016). NILS has reported that in general there is an increase in satisfaction for most NDIS participants. However, there have been several negative aspects reported in the NILS evaluation. For instance, the NILS evaluation highlights a key weakness the lack of group support because of the NDIS's individual focus (Mavromaras et al., 2016). NILS also reported that some early users of the NDIS experienced poorer outcomes, due to the complexities associated with the NDIS processes and a shortage of services. Both these factors indicate a high level of unmet demand, particularly in rural locations.

The recent Productivity Commission report, *The National Disability Insurance Scheme (NDIS) Costs*, released in October 2017, found that CALD people with disability are one of several key cohorts that may not be getting the full benefits of the NDIS or may have less positive experiences when they do engage with the scheme (Finding 3.2). Unfortunately, however, while some broader recommendations may benefit CALD clients, including appeals for additional block funding and greater resources for Information, Linkages and Capacity Building initiatives, no specific recommendations are provided by the Productivity Commission in this report to target engagement and service improvements for people with disability from a CALD background.

Unmet demand or underutilisation of disability support services is a known issue with some groups in Australia, particularly the most vulnerable groups, including women with

13

disability, those that are culturally and linguistically diverse and Aboriginal and Torres Strait Islander people with disability. The disability services sector, long before NDIS, has been critiqued for reflecting white, Anglo-Australian values and thus being difficult for people who are from diverse cultures to understand and access (Harris, 2004). The design and delivery of services and the characteristics of the workforce are also influenced by this Anglo-centric approach. Soldatic, van Toorn, Dowse, and Muir (2014) argue, that there has been a historical marginalisation of CALD and ATSI people in the disability support system in Australia. This critique has continued as the NDIS has been rolled out across Australia. It has been led by key advocacy groups, including FECCA, NEDA, EDAC and AMPARO.

It is expected that the NDIS will provide "reasonable and necessary" support to 460,000 people with significant and permanent disability, approximately 10 per cent of the disability population.[1] Those people with disability who do not meet the eligibility criteria will be referred to other services through the LAC (Local Area Coordinators) contracted by the NDIA (Purcal, Fisher, & Meltzer, 2016). The narrow boundaries of the NDIS has led to questions regarding support for the disability population who do not meet the NDIS eligibility requirements (Mavromaras et al., 2016). The definition requiring a disability to be significant and permanent, to warrant support, has resulted in criticism of the NDIS for excluding fluctuating, episodic or periodic severe mental illness (Williams & Smith, 2014). According to Fisher (2016), the ways in which the NDIS defines permanency also does not align with the 'recovery paradigm' that frames the mental health sector (Williams & Smith, 2014). This narrow definition has led to questions regarding support for the disability population who do not meet the NDIS eligibility requirements (Mavromaras et al., 2016) In response, the Productivity Commission has recently recommended that a psychosocial gateway into the NDIS be implemented with use of specialised staff and targeted approaches that include face-to-face engagement, outreach services and better linkages to other services and supports outside the scheme (2017).

The shift away from block to individual, self-managed funding has also meant that the approach to service delivery has become more market driven (Hallahan, 2013). Individuals are now able to 'shop around' for service providers that more adequately meet their needs and align with their values and goals, which has led to enhanced competition in the market. The changes have had a significant impact on the nature of care, support workers (Macdonald, 2016) and service providers (Gilchrist, 2011). For instance, the introduction of the NDIS has meant that service providers will have to invest considerably in modifications to their systems, including IT and assets, training staff and alternative marketing and costing approaches to ensure they are more competitive and attractive to consumers (Gilchrist, 2011; NDS, 2015). In general, this means that service providers must offer services that are more flexible and can be responsive to the needs of individual clients. However, this enhanced flexibility for-sale can alter, and increase, the demands on an already casualised,

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[1] The recent Productivity Commission Report, *National Disability Insurance Scheme (NDIS) Costs*, notes that the NDIS is expected to involve assessment of the disability service needs of slightly more than this estimation, at about 475,000 people. (2017:8)

underpaid workforce (Mavromaras et al., 2016; NDS, 2015). Additionally, the NDS (2015) has highlighted that the small, specialised organisations that are not able to spend and invest in competition and change innovation are at risk and thus the sector may become less diverse, with larger providers that provide less specialised disability services being more likely to dominate the market.

The structure of the NDIS relies on individuals both proving their eligibility and how receipt of certain services and support will eventually allow them to reduce their dependence on formal support. However, as Soldatic et al. (2014) emphasises, this relies on individuals being literate in the concepts of 'self-activation', choice and decision making. This assumed reliance on individual conceptual literacy has led to a critique of equitable access, particularly for people who have multiple and complex needs, people with intellectual disability, Aboriginal people and CALD people. The ability of marginalised groups who do not have relevant skills, fluency in English, informal support or find they require additional resources and support to navigate the complexities of CDC approaches, is being questioned (Purcal et al., 2016). The reliance on self-activation does not allow for recognition and response to these specific needs as part of the systemic process, and so may not be appropriate for CALD people (Soldatic et al., 2014). There is greater likelihood that already marginalised groups will not initiate their packages and fail to adequately advocate for their needs, hence underutilizing available services (Purcal et al., 2016).

An additional critique of the NDIS is that it values and privileges individual orientations and ignores the collectivist approaches arguably valued by non-Western cultures. As Hasnain, Sotnik, and Ghiloni (2003) suggest, the Western view regarding the significance of independence is not shared by many cultural groups. They argue that this disjunction between Western and non-Western ideals are a barrier to participation for CALD people and communities (Pooja Sawrikar & Katz, 2008). As Soldatic et al. (2014) suggests, the individual focus of the NDIS may reinforce exclusion or enhance marginalisation for CALD people with disability who rely on community or familial provision of care and support.

Understanding and defining CALD

There is ongoing debate regarding an appropriate label and conceptual definition of multicultural diversity in Australia (P. Sawrikar & Katz, 2009). As per the acronym used in this report and in government and policy frameworks, cultural differences are defined as "culturally and linguistically diverse" or CALD. The characteristics of this definition are straightforwardly outlined by the ABS as; (1) country of birth, (2) main language spoken at home (other than English), (3) English proficiency and (4) Aboriginal and Torres Strait Islander status (ABS, 2014). This definition encompasses the previously used terms of NESB or LBOTE, which capture the importance of language and country of origin. However, these terms were dropped from many public and government discourses in favour of the term CALD because country of birth and language were not seen to be adequate alone as indicators of the complexity of cultural identity (ABS, 1999). Moreover,

these terms do not adequately acknowledge the fluidity of cultures across time and space, particularly in Australian society as cultures are exposed to changing expectations, experiences and ideas.

Recent Australian public policy discourse has also highlighted the diversity in the definition and understanding of the concept of CALD. This is particularly evident through advocacy groups who highlight the differences within and between CALD groups (Ethnic Communities Council of Victoria (ECCV), 2012). For example, the phrase 'new and emerging communities' has been more widely used to identify a specific group within CALD communities who have shared characteristics. The shared characteristics include but are not limited to; the number of years since arrival, the countries of origin which have not historically been a part of Australian multiculturalism, for example the growing body of African communities settling in Australia over the last two decades. These communities have similarities from their relatable journeys to Australia which might have included fleeing trauma and stresses of war and conflict. However, not all CALD people have a history of trauma or are disadvantaged as Australia has a history of welcoming skilled and semi-skilled migrants from many nations including English and non-English speaking regions. Often these people or families arrive from backgrounds of education and high income, indicating that not all CALD people have experienced poverty and marginalisation.

Given the known issues associated with conceptualising CALD people, Sotnik and Jezewski (2005) argue that culture is best defined as a system of interconnected elements which may or may not include the following;
-   Normative codes (ways of dressing, embodied practices, behaviour, practices associated with food and eating and so on)
-   Communication codes (including verbal and non-verbal communication cues)
-   Knowledge
-   Problem-solving strategies
-   Relationships (including those with family, neighbours, kin groups etc.)
-   Ways of transmitting or informing culture to younger people

Given the diversity and variation that can inform how cultural status is defined, this project will be informed by both the narrow (official) and broad (conceptual) view of culture considered above, noting that this research does not include Aboriginal and Torres Strait Islander people. Additionally, this project will seek to highlight the voices of CALD people with disability from newly emerging communities in South Australia. This emphasis is justified by the significant additional disadvantage that confront these communities and act as barriers to realisation of effective engagement with the NDIS. It also reflects the mission of AnglicareSA to ensure that those most disadvantaged and marginalised are represented in service provision and support.

Disability in the CALD community

For CALD people with disability, there is ongoing recognition of the multiple and intersecting disadvantages which fortify barriers to accessing suitable services and support. These barriers can be categorised as cultural constructions and as systemic barriers which result in people being trapped in cycles of disadvantage (NEDA, 2009; Pooja Sawrikar & Katz, 2008). The barriers and challenges associated with accessing services for CALD people with disability are commonly: language differences; differences in cultural norms; and lack of information and knowledge being delivered appropriately (Selepak, 2008). Awareness of the low uptake and utilisation of services by CALD people has been problematised in the disability advocacy space long before the introduction of the NDIS (N. E. Groce, 1999; Nora Ellen Groce & Zola, 1993; Harris, 2004; NEDA, 2009; NSW Government, 2012). The following section addresses some of these general[2] barriers that are repeated in the literature and considers how they have been managed to date.

Cultural barriers

Culturally perceived causes of disability are factors influencing understandings and attitudes towards people with disability, as well as the acceptance of services by people with disability and their carers (Mortensen, 2011). Due to the diversity of disability and their cultural perceptions, often there are different explanations and responses for different disabilities. For example, in some cultures, certain disabilities would evoke pity (de Torres, 2002) or fear that the disability may be contagious (Lind, Winter, Scholossar, & Clark, 2012). In other contexts, some would not view themselves as having a disability, particularly in terms of mental health (Williams & Smith, 2014).

Ideas of causation appears to inform the notion of responsibility and blame that is present in the literature. In a Western context, cause might be attributed to a medical explanation such as genetic mutations. Often, there are gendered elements associated with the rationale which blame women or men for pre-conception and pregnancy behaviours and lifestyle choices (Delany, 2011). In other cultural landscapes, cause may be perceived as karma, bad blood or a punishment for an offense or sin against a God or deity, highlighting a link between culture, religion and disability that is frequently referred to in the literature (de Torres, 2002; N. E. Groce, 2005; Nora Ellen Groce & Zola, 1993; Lind et al., 2012).

Belief systems regarding what constitutes a disability, and its cause or rationale, influence the way medical intervention and care are viewed. For example, Kim-Rupnow (2005) explains that in Korean culture, when blame is associated with a disability or a disability is associated with supernatural consequences, families are less likely to seek support and more likely to leave the person's future to fate. Others might view disability with no permanency

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[2] While this project acknowledges the diversity between and within cultural groups the report is written to reflect some of the reoccurring themes in a broad, overarching sense to reduce the volume of the report. While labels such as African or Syrian may be used, the report acknowledges that these groups are heterogeneous, with characteristics and values varying within these groups.

and expect, in the case of young people, that they might 'grow out of it'. It is also a commonly shared tendency amongst several CALD communities to categorise disability as acquired (i.e. through injury, accident or illness) or congenital (lifelong from birth), with the former being considered a result of bad luck or misfortune and the latter a result of sin or wrongdoing of ancestors (Kim-Rupnow, 2005; Liu, 2005).

Stigma and shame is covered across much of the literature addressing the experiences of CALD people with disability and can be linked to attitudes and perceptions of disability discussed above. The stigma attached to disability in some contexts results in people refusing to look outside of their immediate or extended family for support. Fear of discrimination and social isolation from ethnic and other communities has multiple layers (Selepak, 2008) and may influence help-seeking behaviours (Bronheim, Goode, & Jones, 2006). The associated negativity around disability, will often mean that disabilities remain unreported in some contexts. This may be based around the nature of the disability, for example an obvious physical or intellectual disability may result in unwanted attention. Thus, some research reports that there is a reluctance for families to seek support with a preference for hiding the family member and managing the care privately or maintaining a "family secret" (Liu, 2005: 69). On the other hand, a person with disability may be avoided or ignored due to social unease or an uncertainty around how to behave appropriately (Kim-Rupnow, 2005).

The presence of disability in a family also has a significant influence on immediate and extended family. Due to beliefs that disability may be a punishment for wrong-doing or misdeeds, family may work at distancing themselves from associated evils (de Torres, 2002). Moreover, the family may also be the subject of community gossip and speculation which threatens positive reputations, resulting in exclusion, or the family being ostracized (Lind et al., 2012), or the person with disability being hidden in private (Australian Human Rights Commission, 2010). The concept of shame may be directed towards one person, for example the mother or the head of the family, or to the person with disability (Liu, 2005).

Care and support for people with disability can also be understood very differently in CALD families and communities. For instance, in some cases, there may not be a primary carer for a person with disability, instead all family members equally contribute to care (Selepak, 2008). However, care within the family can often be the responsibility of women, particularly the primary responsibility (typically mothers), in the immediate family (Pooja Sawrikar & Katz, 2008; Shang & KR, 2016). Alternatively, there may be a reluctance for men to seek support due to cultural constructions of masculinity or a value placed on boys and men which means that resources are directed away from girls or women with a disability (N. E. Groce, 2005). In some contexts, this may result in the young person being viewed not as a resource in the family but a drain on resources, which can result in neglect (Nora Ellen Groce & Zola, 1993; Lind et al., 2012).

Ideals around care and support for people with disability also emphasises the variations between collectivist and individual orientations, in many cross-cultural considerations of

18

disability (Sotnik & Jezewski, 2005). Particularly important here is the perceived role of the individual, the family and the community. For example, the 'norm' in most cultures is viewing the family not as immediate or nuclear but as intergenerational and extended (N. E. Groce, 2005). As Kim-Rupnow (2005) outlines, in a Korean context *interdependence* is more valued than *independence*. In certain contexts, emphasis on interdependence may result in the individual with disability being expected to be a contributing member of the family unit. These views may also lead to conflict when decisions regarding service support and care are focused on the individual, to the exclusion of the wider family (N. E. Groce, 2005; Sotnik & Jezewski, 2005).

Depending on the cultural influences, the presence of a family member with a disability may result in an intensified sense of obligation and overprotection. In a Western approach, the overprotective nature of family may be interpreted as infantilizing or reducing the agency of the person, reinforcing dependency. In context of Vietnamese norms of mutual care and obligation, as Hunt (2005) explains, however, people do not see any need for a person with a disability to live alone or apart from their family. These types of cultural approaches to care may also reduce the likelihood that families are accessing respite services (Australian Human Rights Commission, 2010: 21; NEDA, 2009).

Systemic barriers

Language and literacy are often presented as the largest barrier to engagement and participation in services for CALD people with disability (Liu, 2005; Zhou, 2016). Many of the critiques argue that the language and literacy barriers is due to unsuitable delivery of information, such as providing written materials to people with low or no literacy skills (NEDA, 2009) or the provision of information in inappropriate language formats. Lack of information regarding the services available is often related to information being delivered in the dominant language or a limited range of languages (FECCA, 2016). Additionally, there seems to be an overreliance on family or children as informal translators which is inappropriate in many situations particularly due to the accuracy of translation, conflicts of interest and confidentiality concerns (Australian Human Rights Commission, 2010; FECCA, 2016; Selepak, 2008).

Distrust or suspicion of authority, government and services based on experiences in people's country of origin often hold them back from accessing services (Selepak, 2008; Soldatic et al., 2014). The notion of confidentiality and privacy becomes significant when some families fear certain officials or others fear community retribution because personal information may not be kept confidential (Pooja Sawrikar & Katz, 2008). Lack of awareness of Australia's privacy laws and mandatory reporting laws may also compromise some group's access to services and support.

Social exclusion. Bronheim et al. (2006) indicate that families caring for a person with disability encounter many negative financial consequences and have low income, associated with lost or limited opportunities to participate in paid employment. In general, CALD

19

people with disability typically have low income, low economic participation and housing instability (NEDA, 2009; Soldatic et al., 2014) and low engagement in education. Shang and KR (2016) report that in China, the attitudes towards people with disability influences parental expectations of young people with disability. Their findings show that parental expectations that schools will not accommodate young people with disability means that many do not send their children to school.

Geolocation, transportation and housing are also represented as barriers for social inclusion and accessing disability services (Australian Human Rights Commission, 2010: 26; Pooja Sawrikar & Katz, 2008; Stone, 2005). The importance of suitable, secure and affordable housing has been acknowledged as a concern due to high unemployment, low income and associated poverty of people with disability and their links with homelessness (Tually, Beer, & McLoughlin, 2013) and poor health (NEDA, 2009). The NDS (2015: 23) estimate that up to 120, 000 NDIS participants "may encounter barriers that restrict their ability to secure accessible, affordable housing."

For those homes that may be available there are concerns about their suitability for people with disability. The associated issues regarding suitable housing were addressed in a 2015 Senate Standing Committee on Economics inquiry on affordable housing (http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Economics/Afford able_housing_2013/Submissions). The submissions to the inquiry acknowledge that the changes introduced around the NDIS, which emphasise enhanced independence, will increase the demand for suitable housing. This increased demand suggests an additional challenge to service providers to develop more inclusive, appropriate housing design models (Nix, 2016) that incorporate the needs of CALD people with disability.

Underutilisation and low access rates. It has been widely reported that CALD people with disability underutilise services (AMPARO, 2016; NEDA, 2009; Robertson & Travaglia, 2015). According to Zhou (2016), the access rates for CALD people with disability is disproportionate to their presence in the community, highlighting a care service access gap. He suggests that this may be due to the role of families, providing informal care which reduces the reliance on the formal system. Alternatively, the preference may be for intervention to come from natural remedies, rituals or healers, with whom people are able to put more faith (Hunt, 2005; Kim-Rupnow, 2005).

Soldatic et al. (2014) argues that underutilising services could also be due to a lack of sociocultural literacy of the systems in Australia which may limit people's knowledge of health care and other support systems. Moreover, the complexities and confusion associated with these systems may also discourage people from engaging with them (Mortensen, 2011). Anxiety associated with large volumes of forms that require completion, care and health plans and ongoing paperwork may also dissuade people who are not literate or cannot understand the forms (Mortensen, 2011). Other factors may include unfamiliarity with disability support because such a service did not exist in country of origin. Hasnain et

al. (2003) suggests that the underutilisation of services is due to a lack of outreach efforts and a direct result of having inappropriately trained staff.

Intersecting disadvantages. People from various CALD backgrounds from new and emerging communities are also experiencing settlement issues which influence their access to disability services. Often, there is a priority given to housing, employment and language education during the arrival and settlement period, resulting in disability support and service being considered peripheral (AMPARO, 2016; Selepak, 2008).

Best practice models

Mortensen (2011) stresses the importance of services (and service providers) to adjust to the needs of CALD people with disability. NEDA supports this position by arguing that there is a need for enhanced cultural responsiveness and the delivery of culturally competent services and support to attract CALD people (NEDA, 2009). The following section highlights some of the key approaches to providing specialised disability services currently recommended or that are being employed in disability service organisations to enhance outcomes for CALD people with disability. Although these solutions are pre-NDIS, there is little evidence they have been factored into the development of the NDIS. Thus, they continue to require attention in its current rollout and beyond.

Developing a cultural diversity strategy. According to Zhou (2016) there is a gap between the disability services offered to CALD and mainstream people with disability. To bridge these service gaps, advocacy groups are promoting the development of cultural diversity strategies to facilitate equal outcomes (AMPARO, 2016; NEDA, 2009). This involves prioritising and planning for CALD disability service clients the same way as mainstream clients. The outcome of this equitable framework would be the same level of access for CALD *and* mainstream clients (NEDA, 2009).

Cultural competency approaches and training. Cultural competency is covered extensively in the literature as a method to enhance access to services by CALD families and people with disability (AMPARO, 2016; Lind et al., 2012; Robertson & Travaglia, 2015; Sotnik & Jezewski, 2005; Stone, 2005). Understanding the diversity of values and beliefs across cultures will allow organisations and service providers to respond more appropriately to the needs of individuals with disability and their families. Pooja Sawrikar and Katz (2008) argues that services which are marketed to white, English speaking families are less likely to attract CALD clients as they do not demonstrate their cultural competence. Based on marketing material, depicting white homogeny, CALD users frequently assume services and supports are not suitable for their needs (see also NEDA, 2009; Robertson & Travaglia, 2015; Pooja Sawrikar & Katz, 2008).

Initial findings from NDIS evaluation indicate that current approaches to training staff on cultural competency is "not yet adequate, too generic and too short and hence lacking

profundity" (Mavromaras, 2015: 63). This finding suggests that more higher quality work needs to be done to enhance the cultural competency of service providers.

Appropriate language provisions. Systemic language support services for CALD people with disability are needed to ensure the effective communication of important information and delivery of quality and suitable services (Liu, 2005). Appropriate language can be provided through easily accessible, inexpensive, qualified translation services (FECCA, 2016; Lind et al., 2012). A small number of organisations suggest using TIS (Telephone Interpreting Services), which include access to a large catalogue of languages and dialects and is available 24 hours a day 7days per week.

This service is purported to be freely available by the NDIA to support CALD people with disability to initiate planning activities within the NDIS. On 17 October 2017, the NDIA announced that through a partnership with TIS, people with disabilities who have English as a second language (ESL) are eligible to use free translation services to "implement funded supports in their NDIS plans when engaging a provider." According to their announcement, participants should be able to receive "NDIS-funded supports in their primary language". However, there are restrictions on the use of translation services for plan review purposes. What's more, while it is clearly stated that these services focus on "*implementation* of funded supports", there is a lack of clarity around whether translation can be used during service provision as part of ongoing delivery of support and care services.

Capacity building. The promotion of choice and the notion of self-directed funding relies on decision making skills and help-seeking behaviours that many Australians may take for granted. As NEDA (2009) emphasises, to encourage CALD people to understand the notion of choice and control, they also need to be equipped with decision making skills which enable them to engage with appropriate services specific to their needs and values. The promotion of capacity building will attend to providing such skills as the ability to seek and receive help, choice and decision making, significantly reducing the systemic barriers preventing CALD peoples from accessing services. (AMPARO, 2016). Building on CALD people's health literacy so that they can adequately communicate their health and support needs (Bronheim et al., 2006) is also an important aspect of capacity building.

Cultural brokering. Cultural brokering is defined by Jezewski and Sotnik (2005: 37) as "bridging, linking or mediating between groups of different cultural backgrounds" to reduce possibilities of conflict, misinterpretation or enhance knowledge exchange, to bring about change. Cultural brokerage has been applied internationally (Bronheim et al., 2006; Jones & Thomas, 2009; NCCC, 2004) to reduce inequality and improve access and outcomes for CALD people with disability. According to Mortensen et al. (2014) relationship building and developing trusting relationships within the community is a vital aspect of the success of cultural brokerage. Cultural brokerage is community driven (NCCC, 2004), allowing the community to be experts in their own lives (Harris, 2004).

The key benefits cultural brokers have on both CALD families and service providers are outlined below (Mortensen, 2011; Mortensen, Latimer, & Yusuf, 2014).

Benefits to CALD families	Benefits to service providers
• Improved access to relevant services including health care and support	• Improved cultural knowledge and understanding
• Reduction in isolation	• Linking families to other services
• Increased knowledge regarding systems and ability to navigate them	• Improved relationships with clients and communities, establishing trust
• Improvements to accommodation circumstances (enhanced ability to access more suitable accommodation)	• Streamlining processes
	• Advocacy

5. Research methods

Research design

In response to the barriers to accessing disability services and the critique of the NDIS discussed above, this project explores the gaps in providing culturally appropriate service delivery and policy design for CALD people with disability accessing the NDIS. Furthermore, given changes to the disability sector brought about by the new policy framework and delivery model of the NDIS, and the need for service providers to enhance their marketing and engagement strategies to keep and attract clients, this project will provide a better understanding of CALD communities, their needs, values and preferences. This project will address the following key research questions:

- Do services under the NDIS meet the needs and preferences of CALD people with disability?
- What will help achieve the best outcomes for CALD people with disabilities receiving NDIS funding?

Overall, the project findings will inform NDIS service development and contribute knowledge to its design, approach, advocacy, engagement and marketing activities.

Sampling & recruitment

The sampling approach for this research was detailed and comprehensive. The project conducted many different discussions to gain an in-depth picture for individuals, families and communities involved or soon to be involved with the NDIS. The project included the following groups through purposive sampling approaches:

1. **Research Group A:** CALD recipients of NDIS funded services or who are eligible in the current and future NDIS rollout. This group included both existing AnglicareSA clients (A1) and non-clients (A2). As the rollout to date has included adult CALD people with disability above the age of 17 and young people aged 0-5, this group of participants included CALD people with disability as well as their parents or guardians.

   This group explored the suitability and appropriateness of, and/or the barriers preventing them from accessing NDIS services which suit their needs and preferences. The project also explored non-client participant's general awareness of NDIS disability services and provision, as well as understand what attracts or deters people with disability from engaging with service providers.

2. **Research Group B:** This group included CALD leaders/community representatives or their nominees to explore how disability is framed in three specific cultural groups: African, Syrian and Bhutanese. Contributions from these three communities ensured coverage of perspectives from Asia, Africa and the Middle East, representing Australia's new and emerging communities. Although not a specific criterion for this project, new and emerging communities were given priority h, as they are potentially the most likely to face barriers to engaging with the NDIS and therefore at higher risk of underutilising disability support services (see above). This group also serve as a reference point to providing a general overview of cultural attitudes and barriers towards disability as well as an opportunity to encourage community led consultation and feedback. Already established relationships with community leaders were relied on for consultation.

3. **Research Group C:** Group C engaged with AnglicareSA community inclusion co-ordinators, disability support and mental health workers. This group focused on AnglicareSA staff as this project explores how well equipped they are at working with CALD people. It is particularly interested in how they engage translators and interpreting services and any suggestions they may have for service adaptions and organisational support for improved engagement with CALD clients. The focus on staff in this group, is important because any weaknesses and strengths they discuss contributes toward informing a policy for service provision and more effective engagement of CALD people with disability.

Recruitment strategy

Recruitment for the research groups was conducted as follows:

1. The engagement process began with Anglicare staff (Group C). This group was identified from the AnglicareSA database and through direct contact with AnglicareSA Managers of disability support services, mental health and children's disability. Staff focus groups were held during scheduled staff meetings to maximise availability of staff.

As part of recruitment, attention was given to ensuring that the staff involved had experience with delivery of services to CALD people with disability and some staff from the children's program who had experience of the initial roll-out of the NDIS, which began with children and young people.
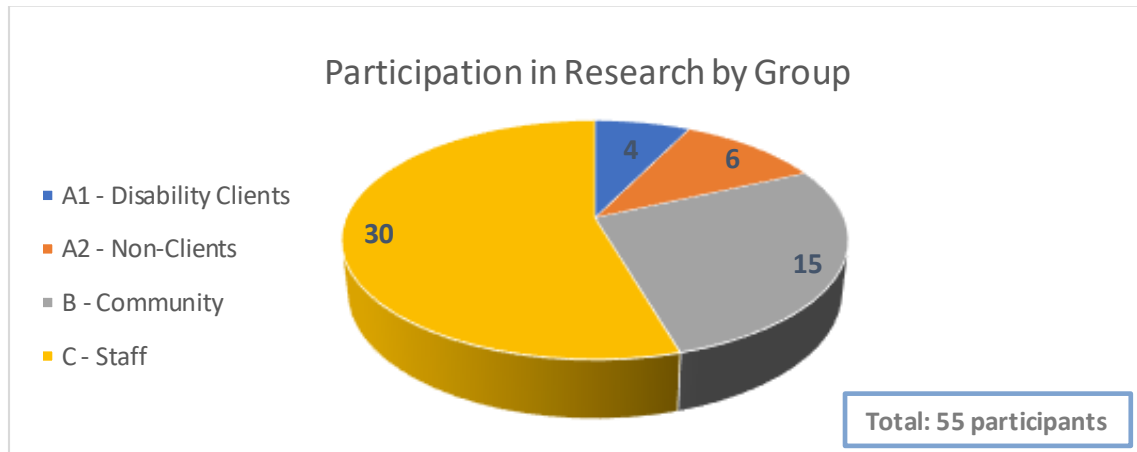
The rationale for starting with this group was that staff in direct contact with CALD clients would have highly relevant insights, which could help shape the individual client interviews. It was also deemed important to include staff from the outset to meet the objectives of this project to identify possible barriers to engaging with CALD communities, any need for training or development and to ensure their input into the identification of potential service changes which they may implement.

2. One-on-one interviews were arranged with Community Representatives (Group B) who have existing relationships with AnglicareSA through the work of the Principal, Multicultural Services. These interviews sought to understand the cultural views of disability specific to three identified regions (African, Bhutanese and Syrian) and the services, support and information these communities might require. An additional focus group was also organised with the African Communities Council, which provided the opportunity to the garner insights of leaders from over twelve different African countries and to arrange individual interviews. Each of the community leaders interviewed are highly regarded and respected in their communities and largely come from professional fields as medicine, engineering, accounting, academia, the education system and various roles in the human services, including in mental health and disability support. Building rapport with community representatives was an important to identifying individuals with disability within their communities who may require service support (Group A2).

3. Recruitment of CALD individuals with disability for Group A was conducted in two ways to form two subgroups:A1 and A2:

   Sub-group A1 was formed of existing AnglicareSA clients identified by AnglicareSA Managers of disability support services, mental health and children's disability. AnglicareSA currently has over 900 clients with disabilities (including psychosocial), 162 of whom are identified as CALD (as defined by their non-English speaking background -NESB). Managers were asked to identify CALD clients to be interviewed, including families of children in receipt of NDIS services in the first roll-out.

   Sub-group A2 was formed of non-AnglicareSA clients identified by community representatives. These non-AnglicareSA clients were required to have targeted follow up with all community leaders after their individual interviews. Each of the three main cultural groups representing the regions of Asia, Africa and the Middle East provided the contact details of individuals with disability from their communities. Engagement with this group involved, where possible, the attendance of one member of the AnglicareSA Customer Advocate (NCA) team. This was to ensure that technical detail

about the NDIS could be provided to potential clients and relationships developed if individuals required further follow-up or connection to services.

Participation in Research by Group

- A1 - Disability Clients
- A2 - Non-Clients
- B - Community
- C - Staff

4
6
15
30

Total: 55 participants

Interviews & focus group discussions

The approach to data collection was carefully considered to ensure the appropriate dynamic when interacting with CALD participants. The participant's role in the dynamic was considered instrumental to identifying the location of, and who they would prefer present during interviews (Ritchie & Ormston, 2014). Due to the centrality of the family, and the nature of disability, the researcher ensured the preferences of the person with disability was at the centre of these research decisions while incorporating the involvement of family, parents, guardians or carers.

Research Method by Group

Focus Groups | With Family present | 1:1 interviews
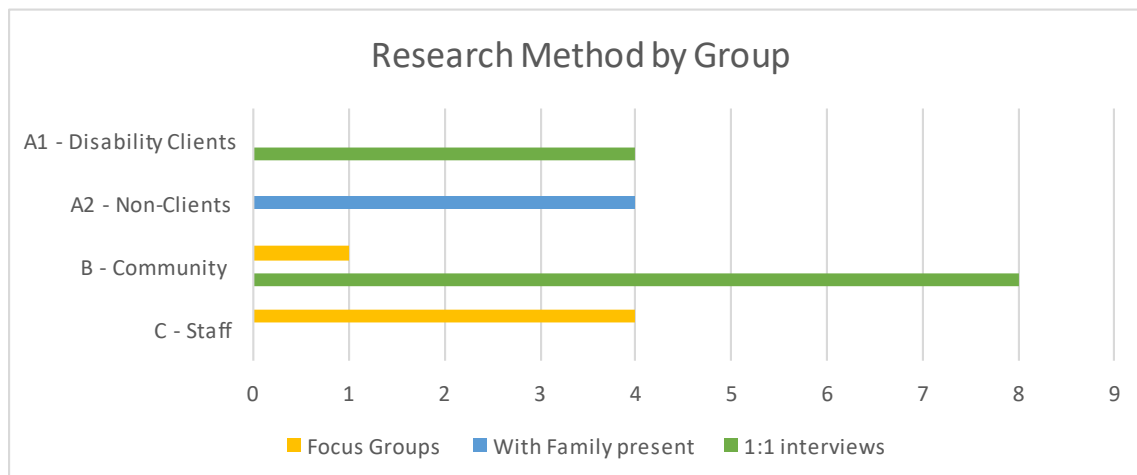
Location

Interviews with CALD people with disability were conducted in the home or at an AnglicareSA support service or supported accommodation site. Focus group discussions were held with staff at AnglicareSA offices and a focus group with the African Communities Council was held at their regular meeting place as part of a monthly meeting. Interviews with community representatives were held at a public or workplace location of their choice.

Interpreters and support

The assistance of interpreters was used for three individual interviews: two held with Syrian families and one with a Bhutanese family. A member of the AnglicareSA NCA team was present at two individual interviews: one with the Syrian family and one with an African family. Both families requested and were provided with technical information on the NDIS, and advice on support services. The inclusion of the NCAs in these meetings was agreed to by the participants and was of benefit to both parties, with staff also expanding their cultural competency and confidence by engaging with these two emerging community groups.
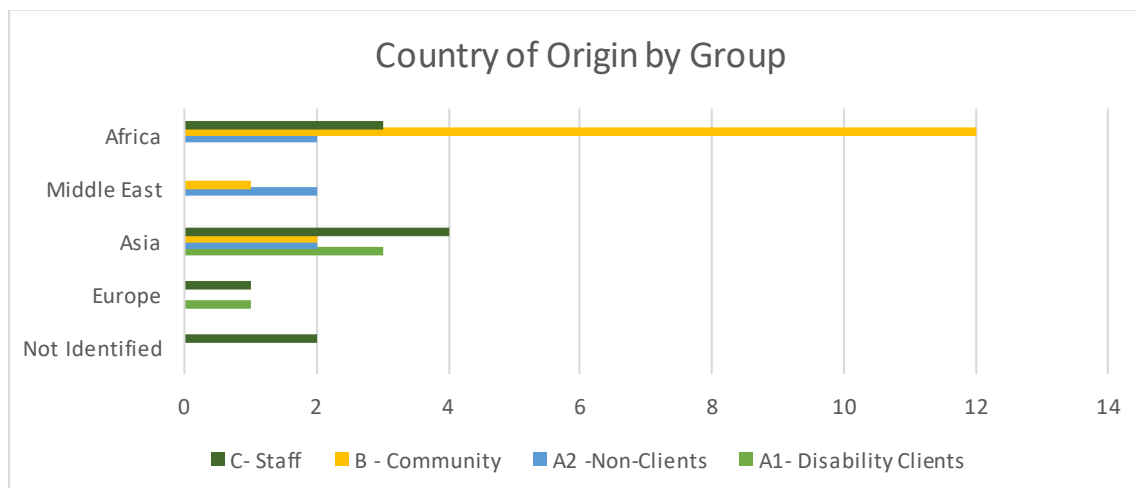
*Note: The African group was represented by a diverse array of countries including Nigeria, Ghana, Liberia, Sierra Leone, South Sudan, Burundi, Kenya, Madagascar, Tanzania, Uganda, Somali, Congo which explains the larger number of participants from this continent.

Topic guides

Interviews and group discussions were informed by topic guides to ensure the data collected was generally informed by the same or similar ideas (Arthur, Mitchell, Lewis, & Nicholls, 2014). The topic guide was largely built up from the literature review, issues that arose from the NDIS critiques and consultations with community representatives. While these broad topics framed the specific interview questions asked, they were modified for each participant group and for focus groups purposes.

27

Interviews and focus groups were audio recorded, with participants' permission, and field notes were prepared following each session. These recording techniques were essential for the lead researcher to recall and record themes with precision when verbatim transcription were not available. It was also important to have audio recordings that could be compared to field notes recorded following the interview. Notes taken during the interview, also do not allow researchers to be devoted to listening and engage in responsive questioning, thinking about the respondents and managing the dynamic (Arthur et al., 2014) and thus are likely to be brief or incomplete. Therefore, the interviews were not transcribed. Rather, the lead researcher made basic handwritten notes during the interviews and detailed field notes, following the sessions.

Data analysis

The interviews and focus group sessions were re-listened to and key quotations were recorded to inform the framework for thematic analysis. Where required, the audio recordings were listened to alongside the notetaking to capture and reiterate researchers' thoughts and interpretations (Fasick, 1977). This process provided a *general* overview of key (and repeated) themes with direct quotations from participants ensuring that the voices of CALD people with disabilities and their families, as well as CALD community leaders, would be clearly present in the research findings and report.

Thematic analysis in this research attended to the patterns which emerged from the topics discussed by the participants. Analysis began with data management which involved sorting and categorising to generate a framework of reoccurring themes and concepts (Spencer, Ritchie, Ormston, O'Connor, & Barnard, 2014). This method was intended to generate broad and overarching, rather than abstract themes. However, the method allowed for sufficient detail about the complexity of participant's experiences, including their perspectives and beliefs about disability and the disability services associated with the NDIS. The framework for analysis was built around the interview schedule and literature but was also open to emerging themes.

The methodological approach used in this project follows an adaptation of the iterative approach by Halcomb & Davidson (Halcomb & Davidson, 2006).

Step 1: **Combined audiotaping and note taking at interview/focus group**
The researcher records important details and impressions of an interaction. As the interaction is concurrently being audio recorded, verbatim responses can be considered following the interview/focus group to provide greater depth in reporting.

Step 2 **Reflective field notes immediately following an interview/focus group**
This step is an opportunity for the researcher to expand on initial impressions of the interaction and to record and begin categorising ideas and issues raised.

Step 3   Listening to the audiotape to amend/revise field notes and observations
The audiotape is reviewed in consultation with the researchers' notes to ensure the notes provide an accurate reflection of the interaction.

Step 4   Preliminary content analysis
This step is used to draw out common and reoccurring themes between interactions.

Step 5   Secondary content analysis
The analysis from Step 4 is reviewed by a researcher who is not involved directly with data collection. This allows for themes to be validated. Due to project constraints, input into this step will be limited.

Step 6   Thematic review
This last step involves reviewing details from Step 5 and applying any modifications to the themes developed. It also involves matching themes with illustrative examples from participant interviews to illustrate the meaning of their perspectives.

Saturation

Saturation is reached when no new data informs the thematic analysis. This is considered to have occurred when instances described by participants are repeated, in subsequent interviews, and no new information arises. The researcher thereby determines the evidence collected is saturated (Seale, 2004).

Limitations

Recruitment: Reach and Limited Returns. Contact through Managers of disability and mental health support services to recruit individual CALD clients with disability (Group A1) resulted in a lower than anticipated response rate: only four existing clients were interviewed when the initial target was for ten clients. The participation rate of AnglicareSA disability clients is considered low because AnglicareSA currently has 162 CALD clients (as reported by Managers and defined by their non-English speaking background (NESB). It was anticipated that there would be difficulties in the recruitment of non-client people with disabilities (Group A2), which relied upon liaison and establishing rapport with community leaders from emerging communities. This group achieved a total of six participants, again from an original target of ten, which included two family members and four individuals with disabilities.

While the original target from each group was not achieved, ten interviews with individuals or their family/caregivers overall was a representative sample of CALD voices from individuals who directly experience disability, enabling robust thematic analysis and research

findings. A range of different disabilities and a diverse spread of cultural backgrounds was evident in the interviewees. As Group A was divided into two sub-groups A1 and A2 (clients and non-clients), comparisons could be made about their respective awareness of the NDIS. This comparison yielded a key finding of the research: an existing relationship with a provider is of great benefit to CALD people with disability to understand the services and negotiate the NDIS process.

The numbers of interviews held with community leaders (Group B) well exceeded anticipated recruitment targets. These representatives provided rich data on cultural views of disability and insights into community awareness of disability support systems within the three emerging communities in South Australia. As advocates for their communities, leaders were able to articulate some of the cultural and systemic barriers, preventing individuals with disability engaging and utilising disability services. The data retrieved from this research group supported and corroborated the specific and more personal, insights of individuals with disability by framing them within a broader cultural context.

Methodology. This research seeks to elevate the voices of individuals from CALD communities, particularly those who belong to newly arrived or emerging communities. However, while the report is focussed entirely on CALD communities and is undertaken to better inform engagement and service practices for CALD individuals with disability, the lead researcher who conducted the interviews and recorded the findings is not from a CALD background. To mitigate this limitation and ensure that the research has been conducted in a culturally appropriate manner, the lead researcher on this project has been advised and supported by the Principal, Multicultural Services, AnglicareSA throughout the recruitment process, during many of the interviews and in the framing of this report and its recommendations. Moreover, while each of the research groups have informed the findings of the report, attention has been given to ensure that CALD community representatives and CALD people with disabilities are heard in each of the main components of the report analysis and recommendations. In most of the sections, substantial direct quotes are used to ensure that representation of diverse views is captured and reflected as accurately as possible.

6. Findings & Discussion

This report aggregates the data from the three research groups, A (1 and 2), B, C, into five main topics: Cultural Barriers; NDIS Limitations; Engagement Strategies; Service Delivery; and Organisational Capacity. A recommendation is provided after each topic, addressing these main areas of focus in the research.

Following the five topics are the dominant research themes and key findings which emerged through consideration of the interviews and focus groups held with community leaders, CALD people with disabilities and AnglicareSA disability and mental health support coordinators and workers. The key findings reflect the stories and experiences of all

research participants in the project across the three research groups. Some findings call more heavily upon one research group over another. However, this is due to the topic rather than a view point. The contributions of each group are specified as appropriate.

The key findings are not unexpected and, in many respects, reflect the literature and reinforce the documented concerns of CALD advocacy groups. This congruence in themes from the primary research and the literature is significant because it suggests there is strong evidence underpinning the known barriers facing engagement of CALD people with disability services and a sound basis behind arguments for tailored NDIS approaches. This research confirms that enhancing the capacity of CALD clients to engage with this new reform framework, and ensuring that culturally appropriate services are made available to CALD clients, will require a concerted effort on behalf of service providers in collaboration with CALD communities.

Topic 1: Cultural Barriers to CALD Engagement with Disability Services

Understanding disability – a complex and unfamiliar system

The NDIS is a complex reform, posing challenges for government, service providers and disability and mental health support staff. Despite the proliferation of communication about the NDIS, the greatest challenge arguably lies with potential clients and their families who must navigate through a new assessment process within a service provision model that is constantly evolving.

A key finding of the primary research is that within the CALD communities interviewed, there is considerable difficulty in understanding the NDIS model and access points, with scant awareness evident amongst research participants of where to find information on the NDIS and services available.

Community leaders from each of the three emerging communities, African, Syrian and Bhutanese, all emphasised the need for their members to be better informed about the NDIS and disability services that are available. They reported that there is a distinct lack of information "on where to go and who to contact". One community leader said that while community members had heard the acronym, they "don't have any idea of how NDIS works." Another leader from the Ugandan community said that his community members know "nothing about it."

It was reported that when the NDIA or service providers do have contact with CALD communities, the information is not presented in a way that is clearly understood. The differences in service offerings between multiple providers, adds to the complexity. One representative said: "I can see many organisations come around [to provide information to CALD communities] and they [community members] are confused about where to go."

31

While lack of clear information and appropriately explained guidance is concerning, two further reasons emerged as predominant factors influencing low levels of awareness amongst the CALD communities consulted: the unfamiliarity of Western disability support systems and cultural views of what constitutes a disability. Both are raised in the literature as likely to lead to underutilisation of services (Soldatic et al.: 2014 and Mortensen, 2011).

One Bhutanese community leader explained that in many cases it is not understood that services are available in Australia because there is no formal support provided in Bhutan. Similarly, an African representative reported that experiences with disabilities in home countries, where formal support is limited, and disabilities are taken for granted as 'incurable', can limit awareness that support services will improve the lives of those with disabilities. According to this same representative, community members do not "have any idea of the NDIS or whether it will be better as they can't compare with anything else."

Within all three emerging communities, community leaders reported that disability is defined in divergent ways. The Bhutanese community representatives explained that the Nepali word for disability covers all forms of disability, including psychosocial disabilities. For the Syrian communities, the Arabic term for disability similarly includes both mental and physical disabilities and translates as "people of specific needs." However, in African communities, disability is generally seen as being physical in nature, requiring visual confirmation before an individual is classified as disabled. In discussion with the African Communities Council, this belief was seen to be commonly shared across the more than twelve African countries represented. As one participant noted, "Disability means physical disability." Psychosocial disabilities are immediately excluded from this narrow definition of disability with mental health "not even part of it." Moreover, it was explained that even within one African country, there may be multiple terms to explain each type of physical impairment but that none of these would be referred to as a disability.

This understanding of disability as purely physical, and the complex multiplicity of terms available in African languages, is problematic in terms of the NDIS framework when communication is based on one, inclusive definition of disability in the dominant language. When a disability is not specifically defined it is assumed that the term is accepted and immediately understood by all cultural groups, when it may instead involve implicit exclusions. If an individual or family do not recognise they have a 'disability' as it is understood in their language, the likelihood of the individual seeking services or support is minimal. As one African community representative said: "Someone may have a disability but people around them don't identify it as a disability. It needs to be made clear so people realise they are included." These types of difference in language and disability identification have implications for communication of the NDIS to CALD communities, which is considered further under Topic 3 later in the report.

It was also found that the views of individuals in research group "A" diverged in their familiarity and knowledge of the NDIS, despite all participants being from CALD

backgrounds. This divergence can be attributed in large part to the composition of the two subsets of this group. As outlined aboveA1, was comprised of existing clients of AnglicareSA, each of whom were from cultural communities with greater longevity in Australia, and A2 was comprised of non-clients who were from newly arrived or emerging communities. As would be expected, with longer time spent in Australia, those interviewed from subset A1 had greater familiarity with, and acceptance of, Australian health and medical systems, comfortability and fluency with the English language and, as existing clients of AnglicareSA, established rapport and trust with a provider. Notably, a key finding of the research is that subgroup A1's factors, enabled enhanced understanding of the NDIS and therefore greater ability to negotiate the complexity of the NDIS. One client from this group said that he understood that the NDIS is: "About equity. Helping disadvantaged people. Making choices." This client also noted that he had attended seminars on the NDIS and knew many people within AnglicareSA who could advise him.

The greater awareness of existing clients reconfirms the extent of the barriers facing emerging CALD communities and newly arrived individuals. It also highlights the need for a finer-grained definition and understanding of CALD communities along with corresponding engagement strategies, specifically targeting newly arrived and emerging communities.

The prevalence of stigma - 'disability' and mental health as pejorative

Within the CALD communities consulted, social stigma surrounding disabilities is prevalent and seen as having a direct impact on willingness to seek service support. Community representatives (Group B) confirmed the proposition, in the literature that negative perceptions of disability are a significant barrier to CALD engagement with disability service provision, particularly in relation to mental illness.

In the languages of those interviewed, the term 'disability' is most often seen as having negative connotations: It either entails some form of judgement or is viewed as a weakness. This was most marked in the conversations with community leaders from African communities. Despite the wide variance in languages spoken and great cultural diversity even within individual African countries, it was reported by one African community leader at a large focus group session that "one general assumption" is possible: "You will not find any positive understanding to any sort of disability." This was emphatically supported by other leaders from over twelve African countries at the focus group session, all of whom emphasised that disability was viewed negatively in their home countries.

"Any disability is negative and is seen to be a shame, so nobody accepts the idea that their child is disabled. You don't even talk about. Once you do it causes conflict … leads to fighting as seen as rude. You don't really talk about it." Community Leader

As suggested in the literature, community representatives from all three emerging cultural backgrounds confirmed that cultural views of disability are informed by societal treatment of disabilities in home countries. As one Bhutanese representative explained: "In terms of cultural things, back home there is a hatred for people with a disability most of them get from other people." Leaders described how people with disabilities are at best tolerated in home countries, but more often excluded and ostracized. One leader explained that the care of people with disability "comes down to the family but is still seen as a shame. No-one wants to take them out." One of the individual clients with disability (sub-group A1) cited the high level of discrimination against people with disability in his home country as the main motivation for his decision to come to Australia. He explained that there are no support structures outside the family for people with disability and that "people are treated like fourth or fifth class down the hierarchy".

A respondent in the Staff focus groups noted that from their experience, providing services to CALD clients, some families may not see that the disability requires medical intervention or support services, while others treat disability as something that should be hidden away or treated with embarrassment. Religious belief was also cited by staff as an important influencing factor for CALD communities, with some CALD people seeing disability as evil or as a curse, while others may view it as a blessing. This view also reflects the interviews with community representatives, who noted that disability is often understood within a religious or spiritual framework as either a "gift or a punishment from God". As demonstrated across many studies in the literature, community representatives in the research interviews also reported that these beliefs of religious or spiritual causation can influence how people with disabilities are cared for. As one representative explained: "They are looked after, not by loving them but to please God." Alternatively, they may reject Western medical intervention if it is believed that the disability may have been caused by 'witchcraft' rather than genetic or biological causes (de Torres, 2002; N. E. Groce, 2005; Nora Ellen Groce & Zola, 1993; Lind et al., 2012).

The research found that the stigma attached to disability is especially apparent with mental illness. African community leaders explained that people suffering mental health issues in African countries are marginalised and treated harshly, sometimes violently, particularly if their illness is evident in overt, anti-social behaviours. There is no medical intervention available in these countries, and people are often left to fend for themselves outside of communities and families. The Syrian community leader interviewed also explained that: "Culturally and religiously, depression is not a favourable word that is used at the dinner table." He explained that while many Syrian people suffered from post-traumatic stress arising from conflict and trauma, and depression because of dramatic changes in status and lifestyle, there "are a lot of reservations even in Australian society to talk about these issues", especially amongst men.

A parent of a child with disability (sub-group A1) noted that there are changing attitudes toward disability amongst CALD communities both in home countries and in Australia. He explained that his community's beliefs are in a transition because the values of the older

34

generation, who have been informed by the traditional way of life, lower educational attainment and religious perspectives, are beginning to have less prominence in the way that children are now being raised.

Nonetheless, in relation to mental illness, the stigma from home country experience amongst all three emerging communities is viewed as the most difficult to overcome. Even living within an Australian context, a community leader explained that: "The hiding component is still there. Nobody wants to come out and discuss about the sort of difficulties they have." Another leader, who works in mental health services, reported that there is little understanding amongst members of his cultural community that human service professionals are bound by legal confidentiality. Due to this lack of understanding about legal confidentiality, there is fear within the community that others will become aware of their personal situation. This fear of disclosure prevents people from seeking help or following through on referrals. That people do not seek help for fear their community will know a family member has a disability, reinforces the evidence in the literature that fear of discrimination and social isolation is a powerful barrier to help-seeking behaviours. (Bronheim, Goode, & Jones, 2006).

This reluctance was most clearly apparent in an interview with an African family, who are non-clients (sub-group A2) and were referred by a community leader to discuss the psychosocial disability of their son. During the interview, the father revealed, for the first time beyond his immediate family, that he too suffered with significant mental health issues. Despite an emergency intervention ten years ago, and hospitalisation for six months, he explained that he is currently taking medication for his symptoms (provided by a local GP). However, there has not been any sustained follow up or psychological support provided since his release from Glenside. This lack of support can be attributed in part to his reluctance to speak about his condition, even within his immediate community. He said: "If you say you have a mental problem, people start to get scared of you ... so I swallow it and keep it to myself ... I've never had anyone in the African community ask whether I have a mental health problem." His daughter, who participated in the interview, confirmed that her father feared the judgement of his peers, noting that the issue of mental health "is everywhere in the African community ... [but] it is very hard to ask for help."

Cultural norms and values: inter-dependence and responsibility for care

In addition to different cultural views of disability and its stigmatisation, the literature also suggests that those with disabilities in CALD communities may be less likely to access formal services because they are being cared for by families within the home (Zhou 2016). While this cannot be concretely substantiated without a broader quantitative study, it is certainly apparent within each of the cultural groups interviewed. A community representative explained that: "In Middle Eastern communities the attitude to wellbeing and care is different. The family would look after the person, not a stranger. Full stop."

Participants cited the secrecy and stigma surrounding disability in home countries as reinforcing cultural practices of family-based care. One community representative (group B) noted that in his home country it is only when family members are hospitalised that the care would extend beyond the family. Still, now in Australia, he said "the first support comes from the family. It is the family who takes the clear lead."

The belief that responsibility for the care of people with disability lies with the family, rather than an 'outsider', was also evident in client interviews (sub-group A1). One parent of a child with disabilities reiterated throughout the interview that he felt that caring for his child is his responsibility alone. He expressed that while he is comfortable receiving services to support him, he is very reticent about greater personal care services being undertaken by others. He was adamant that he does not see the care of his son as a burden, emphasising throughout the interview the pride he has in his son, who he described as "his gift from God". The second parent of a child with disability from a South Asian background also insisted that "it is a family thing when it comes to any type of disability."

In addition, two of the individuals with disability interviewed had not received any service support from outside the family, apart from emergency intervention. One of these two individuals have lived in Australia for 10 years and the other is newly arrived just under a year ago. As noted in the methodology for this research, these interviews with newly arrived non-clients (A2) were attended by an AnglicareSA customer advocate to ensure that questions could be answered and information provided on the NDIS. Following the interview, the recently arrived individual has been offered assistance by AnglicareSA. However, he has yet to accept these services despite expressing in the interview that he is in desperate need of formal support, and has a funded NDIS plan in place. The context of his eagerness to receive outside support is important, though, as his clear preference expressed throughout the interview was for his care be undertaken by his wife. His requests for formal services focused specifically on the duration of time when his wife was due to be hospitalised and absent from the home for a lengthy period, hence reinforcing his clear preference for in-family care.

The difference between Western notions of autonomy and individualism and CALD alignment with community and collectivism identified in the literature was also emphasised by community leaders (group B). That leaders emphasised this cultural difference was seen to reinforce the notion of familial and community responsibility for the care of family members with disability in CALD communities. CALD clients and non-clients (group A) also reported that their cultures place a higher value on social norms of *inter-dependence* rather than independence. A main difference highlighted by each emerging cultural group (groups A and B) is the raising of children. It was reported by community leaders and people with disabilities and their families that in contrast to the focus on freedom and independence in Australian culture, for CALD communities even when 'children' are adults they remain under the care of the parent. It was noted by one leader that "in [my] culture until you get married you can't make decisions, you stay with your family." A Syrian family of a child with disability (sub-group A2) identified that the greatest challenge for the family, apart

36

from language barriers, is the different freedoms provided to Australian children. The parent noted that: "In our culture even though you are 50 or 60 you are still under your parents' living [care] and you must respect them and their rules."

"Australian people are more individuals than community because where I come from everything is about the community, your friends, your cousins, your relatives." Community Leader

The literature also emphasises that for CALD communities the notion of 'family' is much broader than Western notions, extending well beyond the nucleus of immediate relatives. The emphasis on community, friends and family was strongly evident in two of the cultural communities (Bhutanese and African) and less in the third (Syrian). While leaders from Asian backgrounds specifically listed all family members as care providers, the Middle Eastern community leader immediately said that the responsibility lies with the mother. Even when asked about extended family, he reiterated the response that the mother alone is the primary carer. In contrast, amongst African communities, the broader community networks were more strongly emphasised, including extended family and neighbours who play a role in the raising of children and family life. Similarly, for an individual with disabilities from Bhutan, the support she had received from her cultural community included financial support for the family's medical travel and other expenses, as well as highly valued emotional support. She noted that "our community is very, very special."

Even those individuals with disability from more established communities, emphasised that the community orientated nature of their cultural background is still central to the way CALD individuals interact and support one-another. One AnglicareSA disability client (sub-group A1), stated: "That's how Greeks are, we stick together ... You find that many people from the Greek community become like social workers. Many visit and help people who don't have anyone to turn to."

This importance placed on community support can mean, then, that care becomes the responsibility of community members rather than outside service organisations, as indicated by one community leader:

"Because we are a communal society a lot of disabilities are taken care of by the community themselves." Community Leader

Participants in one staff focus group also raised concerns that the 'collective culture' of CALD communities is a chief reason for the underrepresentation of CALD communities in the NDIS. This was confirmed by one of the community representatives who also suggested that by channelling funding directly to the individual, rather than providing systemic support mechanisms, the NDIS model could further exacerbate the reluctance of CALD people with disabilities to identify themselves as having a disability. He explained that this form of exposure to government through identification as a person with disability

37

or mental health problems, will "stigmatise people even more." In addition, he believed that that the NDIS model of individualised care not only conflicts with the care practices of CALD families and communities but may even undermine them. By monetarising care and support provided by families, he suggested that the NDIS could thereby change the communal care provision of families. He said that when the funding didn't come directly to the person, the family "would support that person no matter what ... making it a natural thing." However, when an individual is allocated money for additional support tasks, the family can then say, "now you have to pay me to look after you."

Combatting the underutilisation of services

All community leaders interviewed for this research specifically expressed concern that there are members of their communities with disabilities who are not receiving any formal support services. A Bhutanese community representative said that he believed that there are "many people" in his community without formal care, while an African leader reported that "there may be some members who have no support at all, but it is hard to tell. We don't have any statistics."

Concern was especially evident for CALD people with psychosocial disability because this form of disability is harder to detect and identify. One community leader noted that: "Mental health is something that is eating our community alive." The incidence of Post-Traumatic Stress Disorder (PTSD) in CALD communities was reported as being prevalent, particularly within newly arrived refugee groups who have been through conflict and experienced trauma. Staff in the focus group sessions highlighted that mental health does not fit neatly into the NDIS framework because the recovery model for psychosocial disability is non-linear, involving relapses and periods of wellness. They cited PTSD as particular condition which is difficult to fit within the NDIS inclusions.

Community representatives of emerging or newly arrived communities, also suggested that there are large numbers of refugees, for example from Syria, who have suffered injuries through war or conflict and torture in their home countries. Although many have severe physical limitations and ongoing pain, they are not eligible for the NDIS. Information and contact with support agencies is equally important for these vulnerable members of communities who are refugees, suffering injuries through war, conflict and torture and need access to other community or disability support services outside of the scheme. It is suggested that AnglicareSA review programs currently funded through ILC funding to consider any opportunities for possible collaborations. In South Australia, there is one such program that is being undertaken by the Migrant Resource Centre, which may provide another vehicle for AnglicareSA to ensure information on program support is made available to recently arrived community groups.

In the research interviews, community leaders recognised that people in their communities do not openly discuss disability and mental health and may not acknowledge that they have a disability due to specific cultural understandings of disability and conceptions of

38

responsibility for provision of support services. As discussed, these perceptions may prevent CALD people from seeking and accepting services. However, all community leaders interviewed also insisted that despite reluctance to seek assistance due to cultural barriers and stigma, it was essential that "the knowledge is put out there even if it is not taken up." The process of beginning the conversation is seen by community leaders to be of pivotal importance: "It is something that as a community we need a lot of information and discussion about", one community leader said.

In the literature, it is contended that underutilisation of disability support services in CALD communities is further frustrated by the absence of outreach efforts and a lack of staff who understand the cultural dimensions of how disability is viewed (Hasnain et al. (2003). One community representative emphasised that in the process of taking information to CALD communities, it is essential that advocates and staff have some understanding of cultural perceptions beforehand to ensure that the outreach approach does not act as a further deterrence.

"If you do not have the overview of what disability means to this particular culture, from a different context it might look like its offensive and that may deter people from easily coming out and saying this is helpful for me … it may be more insulting for me." Community Leader

The research confirmed that while general information is needed on services in the communities consulted, overcoming the hurdle of stigma and misunderstandings regarding what constitutes a disability needs to be addressed first or as part of a complementary outreach strategy. There is a significant need identified by community representatives in the research for an education-based campaign that focuses on the consequences of ignoring or refusing formal support, the benefits of early intervention and the importance of qualified, professional services beyond the family. As one community leader said: "Trying to fight that stigma will open up opportunities for the families and the disabled person … then they will be able to come out freely and access these services without shame ... That would be the best outcome." The need for this information to be undertaken in collaboration with CALD communities and, where possible, co-delivered by trusted members of the community, is seen through this research to be vitally important.

One community representative noted that there is a growing awareness within CALD communities that in Australia there may be better support systems available. There is recognition that having a disability is a barrier to the lives of people with disability and the hope that there will be better care options in Australia. Despite emphasising the role of family and extended care networks, all individual client (sub-group A1) and non-client (sub-group A2) participants expressed some willingness to receive some support from outside the family. As one community representative said: "They would be happy to receive services. The first to accept is the family. If the family understands that the person needs to be helped ... if the family has consented." Community and extended family networks are therefore important to enable community leaders and disability service organisations to

39

identify people who may need additional support beyond the community and can be utilised as the conduit for information about disability services and support beyond the family.

The suggested strategy of utilising community representatives as advocates or cultural brokers, which is proposed in the literature and employed internationally with CALD communities (Jesewski and Sotnik (2005: 37), (Bronheim et al., 2006; Jones & Thomas, 2009; NCCC, 2004) was given resounding support by all participants in the interviews and focus group sessions. Staff focus groups (group C) emphasised the need to engage with respected cultural leaders as conduits to different CALD communities before service providers can offer information about available services. It was noted by an African community leader that community representatives are essential in assisting with identification of people who may need support, particularly those with more hidden forms of disability, because "each community leader knows their people" and "it is easy from mouth to mouth to get information about someone." Moreover, another community representative said that "they understand the unspoken words. People who know the context better find it easier to identify (people who need help)." In a similar process to the recruitment for this research, the involvement of a community leader prior to a service provider, will allow for a transferal of trust and an opportunity to build rapport within the context of the community. The important aspect of this use of cultural brokers is that it must be a collaborative process, driven by the community (NCCC, 2004, Mortensen et al. 2014).

Community representatives highlighted that it would be important to carefully identify those members who would act as "entry points" to the community. It would be necessary to ensure there are a variety of people available who may have different connections into the community, that they have a passion for the area, and that their roles are clearly defined. It was suggested that there are members of CALD communities who have done training in the NDIS who would make it easier for people with disabilities to "open up", after which they could provide a knowledgeable insight into the available services. One representative said: "They may not be happy to answer questions to somebody out there that they do not know, but they may be happy in an informal form of conversation about their challenges that come about as a result of disability … allowing a community member to point out that there are services available and where to go."

In addition, community leaders suggested that it would be very effective for CALD individuals with disability who have already accepted and utilised formal disability services to advocate for the benefits of seeking support. They expressed the view that this approach would encourage a shift toward more positive goal-setting for individuals with disability and move away from focusing on the negatives of disability or mental illness. While it was acknowledged that it would be a challenge "to find someone who has overcome mental health issues to come and talk about it, but it would be a very good thing."

40

Recommendation 1
Work in collaboration with CALD community leaders to build capacity and enhance knowledge of disability and available services.
• Develop volunteers and staff from CALD backgrounds as community liaison assistants to NCAs and forge relationships with key members of CALD communities as cultural brokers, with attention given to newly emerging CALD communities.
• Utilise existing CALD clients of AnglicareSA disability services as ambassadors to enhance knowledge of disability and service options within CALD communities.
• Provide information on other community service support programs, including any ILC funded programs, for CALD community organisations to disseminate to individuals, particularly those from refugee backgrounds who are not eligible to receive NDIS support.

Topic 2: NDIS Systemic Limitations for CALD Communities

Language barriers and the risks of un-funded translation services in NDIS plans

In the literature, language and literacy present the greatest systemic barriers for participation in services for CALD people with disability (Liu, 2005; Zhou, 2016). Language was repeatedly the first barrier highlighted in both the interviews and focus group sessions with all three research groups. A newly arrived Syrian parent of a child with disability (sub-group A2) said that "language differences are most the challenging issue with coming to Australia." This language issue was also echoed by another parent from Bhutan who had lived in Australia for eight years, but still found English to be "much too difficult."

While the community leaders interviewed communicated fluently in English, three of the individual research participants with disability (sub-group A2) required translators. Two of the client participants, (sub-group A1) on the other hand, did not request translators. However, translation assistance may have enabled more in-depth discussion with these individuals as there were some difficulties explaining concepts and ensuring that meanings were accurately conveyed and understood. It is of interest, though, that both clients repeatedly referred to staff members at AnglicareSA who are assisting them with their plans and supports. That they were already receiving assistance from AnglicareSA may have aided their comprehension and confidence in negotiating the NDIS process without a translator. The three other individuals with disability interviewed had fluency in English: one non-client has lived in Australia for eight years (sub-groupA2), and two clients from Malaysian and Greek backgrounds who consider that English is now their first language (sub-group A1).

It was apparent through the interviews that several participants are quite conscious of wanting to improve their comprehension and fluency in English, by stating that they are undertaking classes or online courses. Community representatives were also keen to point

out the efforts made by their community members to learn English and adapt to Australian society. A Bhutanese leader noted that when people from his community first arrive in Australia, they feel quite lost amidst the different cultural practices and social norms. However, within six months most had begun to adapt and gain an understanding of how to operate within this new cultural context and "learn to do things by themselves." The Syrian community leader also emphasised that while many in the community have "very little English, many have improved significantly as it is a very hardworking community … within a year and a half there is immense progress." African community leaders also insisted that while some members may have difficulty expressing themselves in English, there are high comprehension levels within this community: "Most of us have no problem in understanding." Another African leader suggested that there would only be as few as 10 or 15 members who cannot understand any English.

Despite this eagerness to emphasise how CALD communities are endeavouring to overcome language barriers, two of the emerging communities strongly argued that translation services are still needed for CALD clients to better understand the NDIS and disability service provision. The research found that the need for translation services is very important for two of the cultural groups: Bhutanese and Syrian. However, it found that it is less important for community leaders and clients from an African background. The Syrian Community leader who was interviewed explained that the necessity for translation services is particularly important in a medical field, like disability, where complex terminology and tests need to be understood to gain consent and proper treatment. He said that without fluency in English, "people agree to things they wouldn't otherwise because they didn't understand well, or didn't have the full picture or just thought to be quick and brush things off." A Bhutanese Community representative also expressed a strong preference for disability support staff who can speak the Nepalese. He said: "Some of the staff speaking English, who will the community be trusting? One of the solutions for us is to have the person who speaks the Nepali language."

Presenting information verbally, in English about the NDIS is also seen as an additional barrier by many community leaders and individuals with disability who are newly arrived. When asked if it is important at NDIA forums and information sessions to have translators available, one of the Bhutanese representatives answered: "Yes, language is the most important. People have not understood what the NDIS means, even me."

The literature contends that if information on government and formal service support is presented to CALD communities only in English, it creates a significant barrier to access for CALD communities (FECCA, 2016; NEDA, 2009). This was confirmed in the research with two non-client participants (sub-group A2). Both individuals required translators to conduct the interview and yet, their NDIS plans were presented in English without supplementary use of Easyread conversion or links to information in appropriate language formats. In addition, neither participant had translation services 'woven into' their NDIS plans or attached to the service products in their plans, making their utilization of services difficult. One family already receiving services under the NDIS for their child (sub-group

42

A2), considered that the service being provided is not at all effective for their son without the assistance of a translator. This family has accepted services from a provider who assists their blind son with self-care tasks such as dressing, toileting and eating. However, a translator is not part of his current plan, and his success is limited by his inability to understand the carer. The parents expressed concern that their son would not achieve the desired outcomes of greater independence through support services through the NDIS without translation services being embedded in that care.

> *"He is not benefiting from their visits. He keeps forgetting because he didn't get the meaning." Parent of Child with Disability*

The family explained that they had a translator initially but that this ceased, and that the provider advised that 'next time' they can organise with the NDIS to get an interpreter as part of their plan (presumably when it is reviewed in 12 months). However, the parent said that "they don't provide an interpreter as they are treating us as Australian people not in need of interpreting services."

The Syrian Community leader made it clear that all service provision for CALD people with disabilities comes down to communication. He said that "as long as it's simple and there is a [phone] number if you have an issue and there will be an interpreter on the end of the line they will do it [seek services]." He explained that when clear procedures and systems for funding translation services were put in place with other support programs for his community, "many people took advantage of that, made phone calls ... providing they know that the person on the other end can answer and be able to explain things in their language."

The literature also contends that it is an unacknowledged expectation that family members or friends will act as translators for clients when they receive documentation that hasn't been adapted for cultural specificity (FECCA, 2016; Selepak, 2008). This research provided some support of this unacknowledged expectation as it was noted that many people relied upon family members, especially children to translate and act as their conduit to understanding Australian society more broadly. In the absence of materials which are translated or in Easyread, or funding for translation services, the reliance upon inexperienced family members with little knowledge of the disability system becomes the only available option. Having to rely upon inexperienced family members, particularly children, risks potential misunderstandings, loss of the client's own autonomy, and can contravene the rights of individuals to confidentiality, even amongst family members (Australian Human Rights Commission, 2010).

Recent announcements in October 2017 from the NDIA regarding translation services and an agreement established with Translating and Interpreting Services (TIS National) for provision of free translators for NDIS clients was raised earlier in this report. As mentioned, this announcement seems to suggest that free services can be used by clients to "implement funded supports in their NDIS when engaging a provider." However, while

this statement appears to address some areas of CALD client's needs in the negotiation phase of the NDIS process, and during the purchasing of services, further clarification is required on in-service provision of translators. Specifically, it is not clear whether translation services can be used during delivery of services to assist CALD people with disability to understand the support they are receiving, and the instructions being given by carers. This lack of policy clarity means that the provision of a translator for CALD people with disabilities is done on a case-by-case basis, requiring individual advocacy that is unsupported by a robust and equitable framework.

Moreover, the NDIA's announcement indicates that there are restrictions on use of translators when an individual wishes to seek a review of a plan outside of the yearly review process. Specifically, a translator is not able to be funded by the NDIA if the review request relates to a form of support that is not currently in the plan. The unfortunate irony here for CALD people with disabilities, then, is that the request for translation services to be included in a plan would not attract the assistance of a translator.

The research thus confirms the need to ensure that translation services are incorporated into existing plans of CALD clients where required, as part of what is deemed by the NDIA to be "reasonable and necessary" supports. There is an urgent need for clearer guidelines on how translation services can become an embedded component of funded supports within a plan and, therefore, an intrinsic part of care delivery. It is important that this issue be given priority in advocacy undertaken at an organisational level to ensure that the inclusion of translation services in plans doesn't rely upon individual negotiation and self-advocacy, and that the only potential window to address this inequity is during yearly reviews only.

Lack of funded coordination support

The NDIS is a complex reform with ambitious aims and a tight timeline for implementation. The recent Productivity Commission report, *National Disability Insurance Scheme (NDIS) Costs* (2017) notes that the pace of the roll-out of this reform means that the NDIA has focussed on meeting participant intake targets, which has been to the detriment of adequate preparation of clients and quality planning processes. The Commission claims that this has resulted in "poor outcomes such as confusion for many participants about planning processes; rushed phone planning conversations; inadequate pre-planning support for participants … and a lack of effective communication with both participants and providers" (2017: 2).

The research with community representatives and individuals with disabilities from CALD backgrounds highlighted several examples of inadequate communication following planning sessions, and a lack of support with purchasing services or requests for additional supports to be included in existing plans. Community leaders from the Bhutanese community cited several examples of community members who had started the NDIS planning process and been promised assistance or equipment but had not heard back from the NDIA and do not know who to contact. Another reported that in the recent roll-out to adults with disability

in the northern suburbs, that he had received many complaints from the community about lack of follow-up and poor communication. He said: "I have been hearing of some issues that when one organisation takes their queries and then never come back, what's happening, what is the plan?"

Within the African communities, similar concerns are being raised with community leaders that individuals have sought services and finalised plans but then received insufficient information on timelines and the purchasing of services. The chief concern one African leader reported is that after overcoming hurdles to initiate the NDIS process, members of the community with disabilities are "not accessing services that they are supposed to be and so the risk is that their support is reduced every year because they are not using them."

Interviews with non-Anglicare clients (sub-group A2) also suggested that unless there is significant involvement of a supporting agency, the purchasing of services is likely to be further delayed or not actively pursued by individuals. This was apparent with one recently arrived individual with disabilities, who had a plan undertaken in one meeting with the support of the MRC, but had not received any services or equipment, such as a scooter which was specified in his plan. Despite a translator present, during the planning meeting he had minimal knowledge of what would happen next.

"I do not know what sorts of support or helps I can have from the NDIS." Adult with Disabilities (Non-Client)

The potential risk of underutilisation of services evident in these examples from the research has also been highlighted by Anglicare Australia in its *Submission to the Productivity Commission's Issues Paper on the NDIS (Costs)* (2017). While administrative failures (focused mainly on the NDIA portal) have been identified as causing delays in customers being contacted by providers and accessing services, it is also asserted that there is a lack of package funding for support coordination in plans. The Anglicare submission makes it clear that without support coordination being adequately funded within plans, clients may struggle to understand and enact their plans, leading to "delays in service purchasing and delivery" and eventual underutilisation of entitlements (2017: 5).

The Productivity Commission has recommended (Recommendation 10.1) that the NDIA should allocate support coordination to participants in their plans based on need (and not for a fixed period) in determining whether it is a reasonable and necessary support. The barriers identified in the literature and confirmed in the primary research highlight that the need for CALD clients to attract additional funding for support coordination should be considered exceptional and that CALD communities, particularly those that are newly arrived, warrant specific advocacy efforts.

Current advocacy on behalf of exceptional needs clients and those with psychosocial disability emphasises that more time is required to build rapport with these vulnerable client groups to understand the complexities of their needs and thereby achieve successful

45

planning outcomes. Anglicare Australia has argued that the current NDIS assessment and planning processes (and funding model) doesn't accommodate the rapport building, necessary for clients with psychosocial disabilities, particularly (2017). The feedback from each of the research groups confirms that this concern and associated need should also apply to CALD clients. Staff asserted in the focus group sessions that understanding the needs of CALD clients and the cultural context required significantly more time:

"From my experience, you need to meet with them (CALD clients) a lot more regularly. Monthly and sometimes weekly meetings with the families as opposed to other families who you may speak to once on the phone." Staff Member

The staff focus group sessions reported that CALD clients may require longer or more meetings in both pre-planning and planning for the NDIS to build rapport, necessary for support workers to understand their cultural views and build the trust needed to assist them overcome any resistance to provision of formal support. Staff focus groups noted that generally the language of the NDIS is complex, the paperwork confusing and the collation of material needed for planning meetings poses a huge hurdle for many potential clients. However, for CALD people with disability there is the added barriers of a lack of flexibility to tailor NDIS information to different cultural languages, and the additional time a lack of translator adds to the already time-consuming process of guiding a participant through all stages of applying for and utilising the scheme.

This research gives credence, then, to the contention that targeted advocacy for funded coordination services for CALD clients is needed, which treats CALD people with disabilities as a discreet cohort rather than as a group that is included within the categories of exceptional or complex need clients. Intensive support is required by CALD communities to combat the cultural barriers identified in the research and to begin to address the already established evidence that there is significant underutilisation of services by CALD communities.

CALD capacity for self-advocacy

It is accepted that the NDIS provides a unique challenge for participants who must navigate through complex systems and make multiple choices between providers and a myriad of different service options. The Productivity Commission describes the participant as needing to make "the change from passive recipients of supports to informed consumers" (2017:10). As the literature also emphasises, the capacity for exercising self-direction and choice is a requirement for successful negotiation of the NDIS framework and planning process. Without this capacity, the likelihood of individuals receiving maximum service support is significantly diminished (Soldatic et al.: 2014; Purcal et al : 2016).

It is clear in the literature that CALD people with disabilities have multiple hurdles to overcome before they can be informed about the NDIS. These include: language barriers; cultural views of disability; stigma and shame; and lack of knowledge about Western health

care systems and reliance on models of familial care that may restrict outside intervention. The feedback provided by the three research groups offers further evidence that each of these barriers is likely to prevent active or assertive help-seeking behaviours amongst CALD people with disabilities. This is problematic when the NDIS model demands that individuals clearly articulate their needs and engage in the planning process in an assertive manner to ensure that they receive adequate service support.

"*Clients who can advocate are getting better packages and more funding. Language and lack of understanding is going to be interpreted as a decreasing amount of funding" Staff Member.*

Participants in the staff focus groups (group C) reported that CALD clients often tend not to articulate their health difficulties, with individuals from some cultures being quieter, less demanding or likely to assert themselves. This was confirmed by a staff participant from a CALD background who said that: "We Africans do not like to share our closed information. If I have an illness … I will keep it to myself …. So, if someone comes in, someone who is not close to my family, I will not say anything." In addition, it was noted that there are power imbalances often at play which can make it difficult for individuals to contravene the directions of those seen to be in authority. A participant noted that in her experience with CALD clients and families, the "moment you come in as a professional, the immediate response [of clients] is to say yes." Another staff member suggested that there is a reluctance to "bring up another layer of need" particularly amongst refugee communities who feel grateful to be in Australia and do not want to be viewed as 'complaining.'

It was also reported that those in need may be reluctance to ask for services due to a fear of authority based on experiences in their home country. Staff research participants (group C) noted that some individuals from a CALD background express reluctance to engage with government services, due to negative experiences in home countries with governments that are unhelpful or may have caused them harm. These types of negative experiences lead to a "fear of social services type involvement." This was confirmed by a community representative (group B) who reported that fear of government services is especially apparent with men who suffer from PTSD due to the war. He said that: "Many don't trust the agencies because they have been abused by the government …. if they are asked to write their name down they think 'no, I don't want to be [identified as disabled].'"

Two parents of children with disability (sub-group A1) interviewed both spoke of their lack of knowledge about autism when their children were first diagnosed. One said: "I didn't have anyone from my family or extended family with disability, which was challenging and complex." The confusing range of therapists and services provided through the NDIS was described as very "difficult to understand." In both families' situations, the immediate reaction to the introduction of a new disability service system was to remain with an existing provider. They reported that this was due to established relationships with support workers and therapy sessions that were already underway. In addition, remaining with the

current provider didn't require the families to seek any further information, make choices between providers or self-direct their care preferences.

For one of the parents of a child with autism (sub-group A1), it was apparent that he had negotiated a plan that didn't address his preferences or meet all his child's needs. He described his child's plan as "not very targeted." He explained that he would like a more comprehensive plan for his son, focused on social supports as well as speech and occupational therapies, and is very keen to have home visits for these services as the weekly scheduling of the current sessions at the service site is inconvenient. As a result, last year he said that he "could not use all of the funding that was approved … the way the provider provided the therapy wasn't according to the funding that was approved." He was quick to assert that this was the situation last year "because I didn't know anything about it" and that he planned to "transition to a new provider" in the coming year.

It is important to note that some of these difficulties are likely to be replicated within many families negotiating a complex and unfamiliar system for the first time and therefore may not be unique to this CALD family. It was clear that there has been a learning curve for this family who now realise that they can ask for additional services. As a result, they are now researching information themselves and seeking advice from Autism SA and AnglicareSA. That they are researching information themselves, signals their growing capacity to self-advocate, which is positive and possibly reflects their familiarity of the system, gained through developing the first plan.

Nonetheless, reluctance to assert control over the process and direct preferences for service delivery is reflected in the findings and evidenced in the literature as being particularly evident amongst CALD communities. It was interesting to note, given the discussion above on reticence amongst CALD people to self-direct care options and choices, that despite being quite clear on what changes this parent wanted to his son's plan, he indicated that his preference next year would be to have less control over the plan, not more. He stated that, "Last year, I had more control over what services came from which provider but this year I would like *them* to have more control."

Another difficulty with self-advocacy that became apparent through the individual interviews with families of children with disability (group A) is the reluctance to emphasise the extent of formal support that a child may require. Throughout his interview, the second parent of a child with autism, in this group (sub-group A1) was very reluctant to detail or embellish upon his child's difficulties. Instead, he stressed his child's strengths and capacities. The need to discuss plainly all the difficulties faced by this parent and his child to receive adequate services and maximise his funding allocation, was clearly a challenge that caused him great discomfort. That discussing his child's challenges caused him discomfort, may suggest a more general difficulty with parental articulation of a child's weaknesses, as it goes against a strong desire of parents to present their children in the best light. If this is the case, then it signals a limitation of the current NDIS model. However, it may also be

attributable to a fear of stigma and harm to the child through full disclosure of the limitations and extent of disability, reinforced by cultural beliefs.

The possibility of fearing disclosure was confirmed by another community representative who explained that the stigma attached to disability had influenced a family in his community to refuse to recognise that their child has a disability. He explained that the family's reluctance to identify their child's disability was because they did not want to take responsibility for the pain that the stigma may cause their child. He explained that: "They might know but they don't want to admit it as they may feel like they are letting their children down if they do that … they feel like if the school tells them then the parent is not responsible for making the decision." This reluctance was also evident in an interview with a newly arrived family of a child with disabilities (sub-group A2) who did not want to refer to their son's vision impairment as being a disability. They explained that they are careful to use sign language around their child when discussing his disability, refusing to use the word 'blind.' The father was particularly insistent that no-one else should refer to his child as blind either. The child's mother explained that the "can't cope with it" and wants to protect his child from the negative views of others.

Given these issues of stigma and reluctance to identify disability and the difficulties associated with supporting family members, then, people from CALD backgrounds are at risk of failing to advocate successfully for themselves or their families within the NDIS model. This reinforces the literature which notes that the promotion of choice and self-directed funding relies on open identification of disabilities and help-seeking behaviours that cannot be taken for granted within CALD communities (NEDA, 2009; AMPARO, 2016).

The research also found that in order to ameliorate these difficulties, the role of advocates and established relationships with trusted providers is essential for CALD clients, particularly from new or emerging CALD communities. Established rapport and a known contact within a complex and confusing system can provide a ballast against some of the possible risks of disengagement, underestimation of services and difficulties with self-advocacy which are identified as prevalent amongst CALD communities. Community leaders emphasised that government systems, like the NDIS, can seem even more impenetrable for CALD people, without someone who can understand their cultural beliefs and the types of assistance that may be required.

"People are easily intimidated by this set up of big offices …. you need to know somebody in there to help you." Community Leader

The benefits of an existing relationship with a service provider, based on established rapport that is developed over time, was evident in the individual interviews with clients who had been through the NDIS planning process and those who will be transitioning soon. Both parents of children with disabilities who are clients (sub-group A1) spoke of their regular contact with a AnglicareSA staff member, through the service their children

49

attended, noting that they have sought her advice on making changes to their children's plans, negotiating a new provider, and making transitions to schooling. One parent explained that because his child is at the service, he had become familiar with the staff and had spoken to them about strategies to find better services for his son and utilise all his NDIS funded supports. Both parents repeatedly stated throughout their separate interviews that "Anglicare will help with this." A further non-client interviewed (sub-group A2), who is not a parent, also spoke of her relationship with a social worker who was guiding her through her current support and to whom she would turn in future to find out more about the NDIS. Participants in the staff focus groups (group C) also noted that the familiarity of an already existing relationship between a client and AnglicareSA, staff would ease the way for clients to receive all services they need. For CALD clients and potential clients of the NDIS, then, the research highlights that established connections with support staff can assist with overcoming language barriers and identified cultural perceptions that can make self-advocacy difficult. Experienced Anglicare SA disability and mental health staff have the capabilities and potential to ensure that CALD people with disabilities can more easily navigate and negotiate their way through the NDIS. As one staff participant noted, when it comes to CALD clients within this new policy framework of the NDIS, "the stronger the advocate the better."

Given this powerful role of staff as advocates and the benefits for CALD people with disabilities that can accrue from established relationships with service providers, it is recommended that AnglicareSA seek to employ a customer advocate from a CALD background to add to the cultural competency of the existing team. In addition, it is recommended that other disability and mental health staff are also encouraged, with appropriate information and systemic support, to build rapport and establish relationships with existing and new CALD clients who may need assistance to negotiate the NDIS.

Recommendation 2
Develop an advocacy position for NDIS policy and funding changes that focuses specifically on the challenges facing CALD communities.
• Develop an advocacy position that disaggregates 'complex needs' clients, giving specific focus to CALD people with disability engaging with the NDIS.
• Establish a strong advocacy position on the inclusion of funded translation services within individual NDIS plans/service packages for CALD clients where required (including those with existing plans without triggering a review process) to better support individuals from a CALD background.
• Ensure advocacy for increased funding of coordination support explicitly includes clients from CALD backgrounds, who face specific cultural and systemic barriers to understanding and negotiating the planning process and purchasing of NDIS services.
• Request the NDIA make it compulsory for support coordinators to undertake a follow-up visit to CALD clients following plan finalisation to ensure that support services have been purchased and are culturally or otherwise appropriate.
• Employ a Customer Advocate from a CALD background as part of the NCA team and encourage all AnglicareSA staff to build rapport and establish relationships with existing and prospective CALD clients to improve access to the NDIS.

Topic 3: Strategies for Engaging CALD Clients

Communication and marketing

The research found information on the NDIS presented in first languages of cultural groups is very important for community leaders of two of the Bhutanese and Syrian groups, but less important for those interviewed from the African groups. The Syrian community leader emphasised that due to the complexity of the NDIS, brochures need to be presented in both English and Arabic but must also be "made simple" in both languages to make sure that complex systems, application processes and medical terminology are understood. He said that: "It is a difficult subject for them, unless it has been made simple through brochures in Arabic, through something that they can read and make sense of."

The role of support workers and providers in following up with individuals to ensure they understand the information presented, is also seen as important by community leaders. This emphasis mirrored both interviews with individuals/parents of children with disability from the Syrian community, who required a translator to conduct the interview and for service provision, as detailed in the previous topic. The Bhutanese community leader also stressed, as cited above, that "language is most important. People have not understood what the NDIS means, even me."

In contrast, it was emphasised by several community leaders from different African countries that many Africans living in Australia have a strong preference to communicating

in English. A Ugandan community leader said that: "Those who are here want to use English. We do understand English." Another leader from South Sudan explained that it was preferable in marketing materials to use English as: "At least one to three people speak English in the home. Maybe they might not read but they communicate with someone and take it [materials in English] to someone to explain it to them." In addition, it was emphasised by African leaders that the great diversity of language used within African communities and across multiple African countries makes the translation of materials difficult. For both of these reasons, it was asserted by one African leaders that translated materials for his community members "are sometimes not very useful."

The primary research provided an insight into three specific cultural perspectives on the requirement for translated materials. However, to ascertain a broader picture of the requirements, it would be necessary for current AnglicareSA client data to be verified and analysed, in conjunction with state-wide data on dominant languages amongst those of NESB to identify high-need languages and demand for translation services. FECCA emphasise that building a strong data set to analyse demand is particularly important, in high-risk areas, such as health services, and to enable effective planning for clients from new and emerging communities (2016: Executive Summary).

The research also identified that the use of Easyread (or similar) which utilises visual representation of concepts, is regarded as a vital tool to communicate more effectively with CALD communities. Community representatives from all cultural groups stressed the importance of using visual symbols, describing this form of communication as "most useful" and "very important." It was reported by community leaders that use of visual symbols could help to unpack any assumed definition of disability which does not accord with different cultural understandings. Unpacking assumed definitions of disability, is important to combat its narrow conception of physical conditions. It is also important to address the multiplicity of terms which are used to depict different physical impairments which are not seen as disabilities, particularly in African communities.

"If it is not clearly explained, it will limit many of the people in the community from accessing services from outside of the definition." Community Leader

Moreover, community leaders expressed the view that Easyread may more easily de-mystify disability terminology and better explain medical tests and diagnoses to family members. Staff focus group participants (group C) also emphasised the importance of Easyread documentation, for example in explaining house protocols to CALD clients in supported accommodation, medical tests or treatment options. They also suggested that its use may extend beyond marketing and informational material.
Cultural Relevance. In the critical literature, a strong argument is made for the need to review marketing and additional materials to ensure cultural relevance and relatability. The literature emphasises that CALD users can frequently assume, based on marketing material that does not contain any cultural diversity of those represented, that the services and supports are not suitable for their needs (see also NEDA, 2009; Robertson & Travaglia,

52

2015; Pooja Sawrikar & Katz, 2008). As one staff member in a focus group session asked: "What does AnglicareSA look like from the outside?" Key to answering people how people view AnglicareSA, it is necessary to assess all forms of communication from the perspective of cultural relevance.

The absence of CALD people in promotional materials was noted in the interviews by some of the community representatives. Not having images of CALD clients can exacerbate the perception that the services provided will not be targeted culturally or may not include CALD communities at all. One community leader indicated, however, that despite the importance of visual representation of CALD people, there would be reluctance amongst members of his community to have photos taken for this purpose. An additional strategy to achieve a more culturally diverse and welcoming brand is to include a CALD contact name on promotional material for the NDIS. This reflects the feedback through the research that there is often a preference to speak with someone in an official role who is from a similar, if not the same, cultural background. It was reported by an African leader from Burundi that there is an affinity amongst CALD communities, even across different cultures, due to the many shared cultural experiences, including common barriers and service preferences. As such, the visibility of carers, support staff and contact people from CALD backgrounds, even if they are not specifically identifiable as being from the same culture, may make CALD people with disability more likely to contact a service support organisation like AnglicareSA.

Another important message gleaned from the insights of community representatives is that many forms of communication, including the AnglicareSA website, assume not only a level of understanding of Australian service systems but also presume a shared cultural understanding of terminology. For example, organisational brochures on the NDIS, as well as communication on the website, begin their explanation of the NDIS scheme by asking the question, 'What is the NDIS?' This question presumes that there is a generally accepted understanding of disability, which therefore does not require any explanation. As a leader of the Ugandan community explained: "The issue of labels becomes important. For awareness to be made we need to unpack what disability is and tailor our messages according to each different form of disability."

To reflect the research feedback from community representatives, it is suggested that the AnglicareSA website and other forms of NDIS promotional material instead begin with the question: 'What is Disability?' As one of the Bhutanese leaders emphasised, the lack of awareness in his community of what is covered in the NDIS centres on this preliminary question, necessary before one can understand how the scheme works. The issue of eligibility and what forms of disability are covered in the NDIS is secondary to this question. It was suggested by each of the community leaders interviewed that CALD communities would value a detailed breakdown of each form of disability, using visual symbols, with a corresponding list of the full range of NDIS services.

53

As part of this approach to explaining disability, psychosocial disabilities required separate explanation. The research indicated that there may be confusion and the potential for CALD people with disabilities to be deterred from engaging with a support service organisation, when communication materials amalgamate psychosocial and physical disabilities. A specific example provided in the research is the conjunction 'intellectual disability.' It was reported by several of the African community leaders that the use of these two terms together is particularly problematic within African communities. As mentioned above, these communities perceive disability to be purely physical. An African community leader, who works in the education department, explained that African families often reject this term being applied for example to a child with autism. Because the child is physically capable it is believed they cannot be 'disabled'. He said that the parents' immediate rejection of the label "intellectual disability" is because "they don't see it". While this may be specific to one cultural group, it is relevant to note that the term 'intellectual disability' is used frequently on the AnglicareSA website and until the user delves deeper into the separate website links to different service categories, psychosocial disability appears as the primary form of disability for which services are offered. An awareness of the culturally specific meanings of terms is therefore important in understanding how an organisation is perceived externally by CALD communities, highlighting the need to review communications for unintended exclusions that may be deterrents for CALD communities.

The stigma attached to mental health, in all the emerging CALD communities consulted is another reason to ensure that both forms of disability are dealt with separately and clearly explained. This was proposed by one community representative who said that: "Packaging for different forms of disability should not be made the same because there are some disabilities that have more stigma than others, especially when you come to mental health." Mental health advocates have made it clear that the inclusion of psychosocial disability within the framework of the NDIS is problematic. The Productivity Commission recently recommended that a separate gateway for psychosocial disabilities needs to be established (2017). The creation of a separate gateway for psychosocial disabilities, if implemented, may assist with this cultural difference in communication, and have potential benefits for clients with psychosocial disabilities while also addressing the specific cultural dimensions for CALD people.

Staff focus group sessions (group C) also raised the need for general improvements in the organisational website, including updates to information, additional detail on services available, the use visual symbols (on the website and the NDIS portal), and improved public site navigation. From a preliminary assessment of the research input, it would be beneficial to include on the AnglicareSA website a section in the NDIS category for people from CALD backgrounds. This section could include a more detailed explanation of disability and service coverage using Easyread, with links to translation services and contact numbers of CALD support staff. Alternatively, the 'Newly Arrived' section of the AnglicareSA website that is focused primarily on refugee communities, could be updated and expanded to include all services which may benefit both emerging and established CALD communities, with each group differentiated as necessary.

Engagement approaches

The primary research found that approaches to engage CALD communities need to be varied and should include both information sessions held as part of established community functions or meetings, and one-on-one outreach support that includes home visitation. The increased involvement of Anglicare staff in CALD community cultural events and festivals was also seen as advantageous by staff participants in the research and welcomed by community representatives. One community representative noted that: "Anglicare is doing a great job but as far as putting their foot in other areas and communicating [this] may be something that they are able to improve on."

Information Sessions. A clear message from the interviews and focus group sessions was that engagement strategies need to begin with existing community organisations and seek to involve families and the broader community, as well as respected leaders from the community and churches. It was noted by participants in a community leader focus group that CALD individuals would be less likely to attend general NDIS information sessions conducted by the NDIA than targeted information sessions through established community groups.

The research with community representatives indicates that direct engagement with respected culture-based organisations is the best way to gain trust within CALD communities and overcome some of the stigma regarding disability. Direct engagement with respected organisations also provides the ideal mechanism to disseminate information to community members who may encourage individuals to pursue support options.

> ***"The area of disability is one of the key areas where we think we need a lot more information … If Anglicare can be of help to facilitate an information session around that, we would be happy to mobilise the community for this sort of activity … it would be definitely beneficial." Community Leader***

This approach has already been undertaken successfully at a recent forum with the Australians for Syria SA (AFSSA) association, which was organised through the research interviews conducted for this project. An AnglicareSA customer advocate was able to attend and provide information on the NDIS and services available as well as answer questions from the community. The community leader indicated that the session was well received by the community. For AnglicareSA, this initial contact personalises the organisation and enables the building of rapport with CALD people with disabilities who may need support services but do not have information on providers. Community representatives from all CALD communities consulted in the research were very supportive of this approach. One stated that the "problem is to communicate, that is it." He insisted that: "If we had a session on the NDIS, I guarantee that a lot of people would come because … there is a huge need for them to understand."

The reticence amongst CALD communities to share personal information and to openly discuss disabilities, especially of a psychosocial nature, has been discussed earlier in this report. Community leaders all acknowledged that this would be a challenge to overcome. However, they considered that it was important that information is delivered in an environment where people are comfortable, and presented in a manner that reflects understanding of the cultural context behind disability. As one community leader explained: "Providers do not understand the cultural context and so believe that the community does not want to receive services: they want the services but are not being told in an appropriate way."

Community representatives suggested that to assist presenting information in a culturally appropriate manner, it would be important that members of the community who are respected and listened to, such as priests or pastors and CALD health workers, be involved in information sessions with a provider. While concerns about confidentiality may prevent people from disclosing openly, community leaders considered that having a network of people known to the community available at these sessions provides an opportunity for more confidential conversations, later. In addition, a community leader explained that one successful session he had attended worked well because the nominated community members (or cultural brokers) were able to "take people to the relevant agencies and then interpret for them also …. this tends to calm them down and makes them more open to discuss issues." One community leader suggested that it would also be possible for community leaders to co-present information sessions, act as translators and introduce the topic of disability first in order to provide a direct explanation of why there is a need for open discussion within the community. Finally, it was considered essential that family members be encouraged to attend information sessions. As one community leader said: "If there is a workshop or something, they feel that people are talking about their kind of person … so it is important to involve the family."

"The biggest problem is that people don't understand what NDIS means and how the NDIS can provide better services for disability. If the session has been good, people will spread the word." Community Leader

One-on one support. Community leaders also emphasised that cultural barriers due to stigma and concerns about confidentiality (even within the cultural communities to which individuals belong), meant that information sessions would not work for all CALD people with disability, particularly those with psychosocial disabilities. It is considered vital, then, that there is varied engagement strategy for CALD people with disabilities. The role of cultural brokers has been discussed earlier, but community leaders also emphasised the need for community leaders to act directly as advocates by spreading awareness amongst the community and seeking to share information with families and people in need. Utilising these contacts as conduits for information to people with disabilities in need is a non-confrontational and confidential way to build knowledge in CALD communities.

Central to any engagement strategy with CALD people, based on the feedback in the research, is the need to frame engagement approaches around CALD preferences and needs, including after-hours visits, in homes and communities. As a community leader made clear: "One-to-one would work best particularly if individuals don't want their whole community knowing about their difficulties." Staff focus group participants (group C) also noted the importance of meeting individuals in their home where they have support people available and feel most comfortable. The NCA team within AnglicareSA is seen by staff to be providing an essential service to vulnerable clients who need more assistance in negotiating the NDIS, because they can focus on relationships and build trust before attempting to seek information from potential clients. The ability to meet clients in their homes, with family present, is pivotal to this rapport building.

The benefits of providing outreach visitation services and the important role of advocates was brought into clear focus through an interview with a non-client who had not previously acknowledged his disability beyond the family (group A2). As noted earlier in the report, this participant was able to disclose his psychosocial disability after suffering with its effects for over ten years due to stigma and negative perceptions of mental health within the African community. He expressed that his motivation for openly acknowledging his disability was an urgent need for more support and access to services as he faced a daily struggle with symptoms that were at times debilitating. Yet his knowledge of how to access these services was limited. He said: "We don't know. We are new to this country. We don't know much more about what is happening or where to go …. except to get sick, you go to the GP. I need to tell people because I couldn't get any help." This interview confirmed the vital need for *active* communication about services, through outreach methods direct to those in need, rather than *passive* modes of communication reliant upon self-directed contact which may never eventuate. The key factors aiding this individual's decision to disclose his disability in an interview, which are reinforced by recurrent themes throughout the research, are that: those in attendance were referred by a trusted community leader; the interview was in his home; he was surrounded by his close family; and he was offered accessible information from an experienced customer advocate who could immediately connect him to services and guide him through the NDIS process.

Partnerships with referral organisations

The research identified that individuals with disability and parents of children with disability were referred to the NDIS by their local GP, organisations such as Autism SA, childcare centres or schools, as well as through migrant resettlement programs or government organisations like Centrelink. These referrals occurred because a third party recognised that the person had a disability. One community leader stressed that the greatest barrier to service provision for CALD people with disabilities was identification of the disability, particularly children. He said: "This is the big issue. They may not know it is a disability until a third person notices it ... if it is not the teacher, it is the doctor but primarily it is the teacher…they know the behaviours of the children."

These points of contact for CALD communities are considered by this research to be highly valuable, particularly as these are the locations where diagnoses and referrals are made, and information provided on further support options. Staff members in the focus group sessions highlighted that they have had contact with new clients to AnglicareSA from newly arrived communities who have not had a formal diagnosis or any contact with a healthcare provider. It was noted that Centrelink may be the main government service that could enable identification of CALD adults with disability and offer the possibility of referral for formal diagnosis and medical assistance. Yet it was reported by staff in the focus groups that this was not a formalised process and may not always occur. As such, it is suggested that Anglicare's representative on the Centrelink CALD Advisory Group brings this matter to the group's attention to develop a procedure, ensuring that Centrelink refers all CALD people with disabilities to primary health practitioners.

It was repeatedly raised by community leaders in the research that schools and childcare centres are vital points of contact for identifying disabilities amongst CALD children and providing guidance to families about accessing support services. As one community leader said: "If a child has an intellectual disability, it is not until they are in a school that the teachers identify that there is something wrong and they are referred to psychologist or doctors, but within the family they don't identify it." Another parent of a child with autism (sub-group A1) was also alerted to a possible diagnosis of autism by a social worker at a mainstream childcare centre, before then being referred to AnglicareSA's Daphne Street support service.

In addition to GP surgeries and schools, community centres are another point of contact reported as being of central importance to some CALD communities. For the African community, particularly those from Burundi, the Lutheran Community Care centre in Davoren Park was mentioned as a place that is "very comfortable for many people, they go there, and they get support." Other community centres across South Australia that have regular contact with newly arrived communities include Morella Community Centre (CC), Pooraka Farm CC, Adelaide South West CC, Cooinda, Mitchell Park CC, Junction CC, Cheltenham CC, Kilburn CC, Wandana CC, Midway Road CH. All these centres are ideal locations for service providers to disseminate information about disability support. Further data on participation of CALD communities at these centres can be obtained through the peak organisation, Community Centres SA. The Northern Area Community Youth Service also has a large participant cohort from newly arrived CALD communities, and works in conjunction with three schools in the northern suburbs as part of a Family Learning Network. Connecting to this service may provide the opportunity for collaborative identification of families who are supporting children or older family members with disability, enabling the provision of information direct to CALD communities.

The primary research suggests that by establishing strong connections with these referral points through regular contact and provision of information on provider services, CALD people with disabilities may be identified, connected to services and have better access to current information about available support services.

Recommendation 3
Create a CALD engagement and communication strategy to encourage greater awareness and utilisation of disability and other support services.
• Develop marketing material targeted specifically to CALD communities with attention to cultural diversity in visual representation, in the languages used (Easyread wherever possible) and inclusion of a CALD contact name on promotional material for the NDIS.
• Ensure all information on disability services and the NDIS, including the organisational website, clearly explains what is meant by 'disability' and corresponding services provided for each form of impairment, using visual representations.
• Assess the organisational website for simplicity and cultural relevance and include a section specifically for prospective and current CALD clients with links to translation services, contact numbers for CALD staff champions, and other support services relevant to CALD communities.
• Build rapport with CALD communities through staff attendance at cultural events and festivals and by ensuring NCA engagement is framed around CALD preferences and needs, such as after-hours, one-on-one and home visits.
• Schedule a series of information sessions on AnglicareSA disability services and the NDIS, utilising existing CALD cultural groups and associations as the entry point with priority given to new and emerging CALD community associations engaged through this research.
• Establish a procedure through AnglicareSA's representation on the Centrelink Advisory Group to refer newly arrived people from CALD backgrounds to a primary health provider.
• Maintain regular contact with and provide information to all CALD referral agencies on AnglicareSA disability services and relevant community and accommodation programs.

Topic 4: Culturally Appropriate Service Delivery and Preferences

Culturally appropriate services

The research provided several insights into CALD preferences for disability support services and the factors affecting culturally appropriate service delivery. These insights could usefully inform development of a CALD service policy for AnglicareSA. It would be important to include CALD volunteers, staff, clients and community leaders in this policy development process in accordance with co-design principles. In many respects, the conduct of this primary research has initiated this engagement process with staff, clients and leaders, ensuring these groups actively contribute from the outset.

Despite the philosophy of person-centred care underpinning the NDIS, the research found that the cultural background of the client did not feature in the planning sessions of those interviewed. One of the parents of a child with disability (sub-group A2) was careful to point out that those who assisted them with their son's plan were kind and helpful (and an interpreter was in attendance), but "they didn't ask anything about our culture." Another

parent of a child with disability (sub-group A1) also confirmed that while he couldn't identify any specific concerns, he was not asked about his cultural beliefs or views, regarding the care of his son.

For participants in the research (group A), it was reported that it is most important that cultural and religious observances are acknowledged and respected by support worker staff. The Syrian community representative (group B) gave examples of such observances, including taking off shoes when entering the house, showing consideration to the women in the house (especially the daughters) by knocking before entering a room, and being conscious of when female members of the household may be changing or using the toilet. If the carer is a male this is especially important and would require the support worker to request permission before moving between different rooms in the house.

Other considerations from a cultural perspective included becoming aware of any festivals or celebrations that may be important to CALD people, seeking to understand traditions and customs, gaining knowledge about cultural beliefs, and acknowledging and respecting the role of family support. Staff focus group participants also noted the importance of being aware of experiences that individuals from a CALD background may have, particularly those who are newly arrived and may have experienced displacement, violence or trauma in their home countries.

Additional cultural preferences were revealed when participants in the research interviews gave an indication of what sorts of services they would find inappropriate or would rather have carried out by a close family member. For example, a community representative (group B) suggested that personal care such as showering would be difficult for members of his cultural community to accept from professional support workers. He described a stronger sense of privacy amongst CALD communities and a belief that care of the body by a stranger would be intrusive. This was confirmed by an individual with disabilities (sub-group A2) who had a strong preference for family to undertake personal care duties.

> *"When it comes to someone doing something for me like this (showering), the family is the preferred carer." Adult with Disabilities (non-client)*

Staff focus group participants (group C) noted that due to this sense of privacy there is potential amongst CALD clients to underestimate the support which is needed. Staff reported that refusals to accept support for personal services is more pronounced in CALD communities. Other staff participants noted that acceptance of assistance with house cleaning tasks may also prove difficult due to entrenched beliefs that professional support staff should not perform what are perceived to be menial duties. It was suggested that accepting these services from white carers can be inhibited due to the concept of white privilege, whereby the historical dominance of white people in home countries enshrines hierarchical roles based on race that are retained by CALD people in Australia. The difficulty a CALD person with a disability may already have in accepting support services

can be exacerbated by a reluctance to invert this entrenched power imbalance through being cared for by a white person.

Preferences in Disability Support Staff. There was general alignment in the research amongst the three research groups, regarding the preference for disability support staff to come from CALD backgrounds. Community leaders all expressed a belief that CALD people with a disability from their communities would have a preference for a CALD carer. Staff also emphasised the need for diversity in the disability support workforce to enable CALD people with disabilities to have the choice between carers of diverse cultural backgrounds. However, while some individuals with disabilities interviewed (group A) preferred a CALD carer, there were divergent views about support staff coming from CALD backgrounds amongst existing AnglicareSA clients with disability (A1).

Community representatives reported that in many cases, they believed people with disability from their communities would prefer a carer from their cultural background, mainly to assist with overcoming language barriers. The ability to speak Nepalese was viewed as being advantageous for the Bhutanese community representatives, one of whom explained that establishing trust between a carer and client begins with an understanding of the language. He said that "Some of the staff speaking English – who will the community be trusting? One of the solutions for us is to have the person who speaks the Nepali language ... and they need to have knowledge of disability too."

The representative from the Syrian community also immediately signalled that there would be a distinct preference within his community for a Syrian carer. As a medical professional, he has found that patients seek him out because they feel more comfortable asking questions in their own language and with someone who can understand their cultural concerns, for example, beliefs about nudity or the need for greater privacy. He gave examples of his patients reporting experiences with health practitioners where they have not understood the consultation or felt uncomfortable revealing all that concerns them.

"People agree to things they wouldn't otherwise because they didn't understand well, or didn't have the full picture or just thought to be quick and brush things off."
Community Leader

It was also explained by the community leader representing the Syrian community that a support worker from a CALD background may better understand the emotional dimensions of the effect of the disability on the family. He stated that "if the worker is not trained in that area [cultural awareness] they will not comprehend. They may also not comprehend the emotions associated with an illness as such. Culturally, the family would be very impacted and emotional on behalf of another family member if they were not well." For this community leader, emotionality regarding illness reflected the more communal connectedness of his cultural background, which he contrasted with the more individualised and matter-of-fact Western approach to illness and disability.

61

Similarly, one of the African representatives explained that a carer from an African background would understand the stigma associated with disability in the culture and so be aware of how to discuss and offer assistance, without causing offence. An African carer, he explained, "would know how to go about things that are sensitive to the disabled person and try to avoid the 'grey area' and actually come up with a positive image of the services they receive." For other community leaders, though, it was not seen as essential for a carer to share the *same* cultural background as a client but still preferable that they have a CALD background. It was suggested that coming from a CALD background would equip a carer with an intimate understanding of cultural and language barriers. And it may even offer the added benefit of assuring the client that their privacy will be preserved as their information will be kept confidential from their immediate community.

Other participants in the interviews expressed no specific preference but emphasised the need for carers to be aware and respectful of cultural beliefs and practices, such as religious observations. Two of the individuals with disabilities who are not existing clients (sub-group A2) indicated they had no preference. However, one of these assertions was qualified by the urgency of their need for support and willingness to accept any carer offered. The family of an individual explained that while he had an initial preference, now "he just wants anyone." This was confirmed by the individual with disabilities himself who said: "It doesn't matter, I just need some help."

For existing clients of AnglicareSA, who have lived longer in Australia, the impact of cultural background on service provision and preferences was reported as being less relevant. One adult client with disabilities (sub-group A1) minimised any impact of his culture and emphasised his integration into Australian society. He stated that he did not prefer a support worker from a CALD background, and that it would be important to him that his carer spoke English. What was very important to this client, though, was the experience and attitudes of staff toward disability and provision of care. He explained that: "The most important thing is to know a bit about blind people ... unfortunately, a lot of people mix blind people together with down syndrome and other disabilities and put them in one basket." In addition, he regarded the general attitude of the carer to be as important as cultural background, with enthusiasm, warmth and readiness to assist, essential qualities.

The need for diversity in cultural background of support staff was also raised repeatedly in the staff focus groups (group C). The benefits of CALD clients being matched with staff from similar cultural backgrounds or with volunteers from a CALD background was considered by staff to be beneficial. However, participants largely agreed that in order to build cultural competence and support diversity it would be beneficial at times for carers to be from different cultural backgrounds to the client. The need for there to be choice for the client and for an early determination to be made about who the client may feel more comfortable with was seen to be of upmost importance by staff. They also emphasised the need for diversity in the pool of customer advocates.

A common theme shared by all participants in the primary research was that respectful, considerate and compassionate care is most important for CALD people with disabilities. As one community representative said: "Being looked after by someone from a different background wouldn't be an issue if the service is 100% correct. What they need is to be looked after properly."

Gender Preference. There was also a strong preference, evidenced in the primary research for carers to be of the same gender as the client with disabilities from community leaders group (group B) and the individual client interviews (group A). Each of the three main cultural communities consulted, in group B emphasised that different cultural beliefs and values to Western cultures regarding gender expectations and boundaries meant that having a same-gendered carer would make the provision of care "easier" and more comfortable. While this was regarded to be a more pressing concern for older generations, there was an emphasis on the importance of a carer's gender that was shared across cultural groups, regardless of age. As one community leader explained: "If someone is male, if a female member from another culture comes in to look after the man that would be culturally inappropriate."

It was also noted that there may be situations where the client's preference needs to be considered in the context of broader cultural beliefs and family values. For example, one individual with disabilities (sub-group A2) said that while he would prefer a male carer for his personal care, it may be more comfortable for female family members if the carer was female. To balance the interests of the client and family, he expressed that greater care for privacy and respectfulness of space would be required by a male carer in a family home with female members. Another male individual with disabilities (sub-group A2) also preferred a male carer, but was willing to forgo any specification if it would hasten the provision of services.

Individual Goals versus collective care approaches. Staff participants in the primary research echoed the literature by noting that within the NDIS there is a move away from a more holistic focus on the family and support networks toward the individual and his/her journey toward independence. As Hasnain, Sotnik, and Ghiloni (2003) suggest, the Western view regarding the significance of independence is not shared by a number of cultural groups. As a result, the disjuncture between Western and non-Western ideals can be a barrier to participation for CALD people and communities (Pooja Sawrikar & Katz, 2008, Soldatic et al: 2014).

Staff perceived that this could be problematic for some CALD families whose culturally reinforced role is seen to be as primary carer responsible for the family member with disabilities. Staff indicated that the emphasis on inter-dependence within CALD communities and the role of family and wider community in the care of people with disabilities needs to be accommodated in the service approaches of support agencies and in the planning processes for the NDIS.

"The whole family is the focus of support for CALD communities, not just the individual. CALD families need to be targeted as a unit for support." Staff Member

Staff focus group participants talked about the need to balance family involvement in a client's care with what is needed by the client and carers. This is especially important in determining what supports are included in an NDIS service plan, and the goals that are set for clients. It was noted by a staff member that a family's perspective on what a client may need can involve 'doing for' the client, rather than enabling independence. Within CALD families, 'doing for' the client is more pronounced when the care of a child, even an adult child, is an intrinsic part of the culture and central to the family's values and sense of purpose. The importance placed by the NDIS scheme on gaining independence sharpens the focus on the individual and longer-term goals, which may include self-management and less reliance on family. This focus on the individual can potentially cause tension between CALD client's and their family.

It is important to note from the research, though, that there was not a complete rejection of the individual goal-driven framework of the NDIS. In fact, there was still general support in the primary research for the underlying principle of individual goal setting and the pursuit of greater independence for CALD people with disabilities. It was noted by community representatives that the general campaign in Australia challenging the perception of disability as being an inability, could usefully be transferred to CALD communities. One leader said that this approach to disability "was a positive message" and "would be something that every family member would want to have" for their family member with disabilities. Having individual goals for education and greater participation in society was also seen as positive within the CALD communities interviewed (subgroup B). A community leader said: "If there is a way to lead an independent life, I think that would be something that everyone would want to go for."

Parents of a child with disability (sub-group A2) indicated they are very supportive of their son having independence in later life, and concerned that his disability would not inhibit his education or prospects. They expressed a desire for him to "grow up normally ... to study and be healthy." An adult individual with disability (sub-group A2), who lived at home with her family and was primarily cared for by her mother, was also very focused on regaining the independence she had prior to an accident, causing a brain injury. Her main concern with her current support, funded through the Motor Accident Commission, is a lack of transport options, enabling her to socialise with friends and participate in community activities, independently. She said: "I want to get out from home, but I can't."

"Independent but still part of the family unit. Give me more independence but don't break the unit." Community Leader

The dominant message from CALD communities from the primary research is that while there is no conflict about supporting greater independence through disability support services in the NDIS scheme, the understanding of independence is framed by cultural beliefs about the ongoing role of the family. The mother of the woman with an acquired brain injury explained that her daughter is independent because she can make her own

decisions. However, when her daughter is not at home and out doing activities, she worries about her safety and whether she has had a fall or unable to get home. Unless the daughter was to marry, her mother stated that if her daughter chose to live alone independently it "would hurt me." She explained that culturally: "The parents in the house do the caring. We are not going to live separately or alone …. we live together." This emphasis of family life was reinforced by a community leader from a different CALD background (Group B). He also emphasised that the "general attitude is that when someone is grown up they still live at home, unless he or she [gets] married or unless there are some clashes with the family … but when that happens it is devastating."

Staff focus group sessions offered strategies to mitigate this tension for CALD families. They suggested that those assisting with NDIS planning sessions "need to go in to listen, not with a mind-set of solving their problem only, as you can overlook what they are actually asking for." Setting positive, incremental steps for clients that include 'active' forms of support, which gradually introduces independent action and encourages acceptance by the family, is also recommended.

Community leaders reinforced this message, noting that CALD families needed a slow transition from family-led models of care to formal care outside the family. Key to this transition was developing trust in providers. As one leader stated: "To remove worries there needs to be more confidence in using the services." For other leaders, however, there is also a need to support families to build this capacity, particularly carers who may not be able to relinquish this role. These leaders expressed the concern that without enough information or training, family carers may not be able to provide adequate care. As one leader said: "They may have their own perception of how to help this person that may not be helpful."

The primary research therefore suggests the need for a program to be developed to support CALD families of people with disabilities through mentorship, capacity building and referral to appropriate training for carers of family members or others in the community with disability. It recommends that funded ILC programs should be considered for potential gaps in provision of support to CALD people with disability and their families. It also recommends investigating possibilities for additional funding for CALD specific programs within the ILC. Currently, only one program is funded in South Australia through the MRC that directly targets engagement with CALD communities and people with disability, signalling a potential funding gap opportunity. In addition, contact should be made with other ILC programs operating interstate to encourage possible collaborations or joint advocacy initiatives.[3]

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[3]Research is also being undertaken by Advance Diversity Services and the Social Policy Research Centre at the University of NSW into CALD communities and access to the NDIS. Initial contact was made, and early indications are that there is great alignment between the research findings of the UNSW project and the research findings in this report. This may present an opportunity for joint-advocacy work in future between Advance Diversity Services and AnglicareSA.

Delivering culturally appropriate services

Staff participants in the focus groups all found language to be a barrier to service delivery but had several strategies to assist understanding clients from a CALD background, who speak English as a second language. Staff noted that they focus on using basic terms, minimise the use of technical words, read body language and rely on family members who may have greater fluency with English. All these strategies are supported by the literature, which suggests that delivering information in a way that can be understood (e.g. jargon free) is an effective approach to communication necessary for CALD people with disability (Hasnain et al., 2003; Pooja Sawrikar & Katz, 2008). Staff also cited the importance of documents being in Easyread format and clients having ready access to resource materials that are in a variety of languages.

In terms of providing care for CALD people with disabilities, staff participants noted that the cultural backgrounds of CALD clients may have a strong influence on body language, which can be very important when providing care for people with disability. It was particularly noted that the types of contact individuals may want varies across cultures, and that this might because that different cultures may have very different senses of personal 'space.'

Staff providing CALD client services, in supported accommodation, repeatedly raised the need to be aware of food preferences informed by cultural background. Cultural cuisine and familiar foods are especially important in supported accommodation because food is a central focus; it is pivotal to the routine of a home and any social engagement, with staff changes often occurring around meal times. Ensuring that clients have familiar food choices is considered of significant importance to recognising and supporting cultural diversity. Staff suggested that family members of CALD clients could be involved in providing information or advice on cuisine. Where necessary, alternative food options could be sought from restaurants or specific food suppliers contacted to provide familiar options to clients.

As part of understanding cultural backgrounds, staff emphasised the need to become aware of individual client likes and dislikes. Participants spoke about current strategies for ensuring services are individualised, reflect the preferences of clients, and which of these services could be incorporated into NDIS planning to ensure cultural relevance. Staff highlighted the document "Nothing About Me Without Me", a personal account of clients' routines, behaviours, social nature and character, as essential to be retained or encompassed in the NDIS approach service policy. Individual Lifestyle Plans (ILP) and Behavioural Support Plans (BSP) were also regarded by staff to be important. However, they noted their reliance on "Nothing About Me Without Me" to be the pivotal document, assisting them with tailored care and understanding individual clients. The strength of this personal account from the client's perspective is that it is not too technical and involves the client directly. Participants noted that the addition of the NDIS's longer-term goal-setting would add longevity to this individualised approach, which would be advantageous.

"The main thing with CALD communities is to develop a solid relationship of trust. You begin with the trust, not with the service …. From there, they will actually respond." Staff Member

The building of respectful relationships was identified in the research as being a vital element in the care of all clients, but especially those from a CALD background. One staff member from an African background emphasised that it is important for staff to be aware of the impact of stereotypes on the client/carer relationship. The example he provided is the assumption that a client from a CALD background doesn't understand anything that is being said because they can't speak the language well. This misapprehension can damage the carer/client relationship and developing sense of trust as well as the pride of the client, whose "dignity will also be countered here".

Best Practice support for CALD staff and Clients in AnglicareSA. Some excellent best practice examples worth highlighting as models in the report came from one staff focus group session particularly, which reinforced the importance of leadership at the managerial level (and above) and exposure to more extensive cultural competency training.

This staff focus group, comprising members of the supported accommodation and children's services teams, had systems in place if a CALD client is admitted to their service to ensure that cultural considerations were at the forefront of procedures. One of the teams in this group had also implemented supportive workplace practices for CALD staff. As part of engagement with CALD people, this staff focus group emphasised that priority needs to be given to building relationships with clients, and cited the strategy of using CALD staff and volunteers to assist with establishing rapport with CALD clients. The knowledge about how to build rapport with CALD clients is then shared knowledge with other supported accommodation and children's services team members. In a children's services setting, staff noted that with CALD families it is important to get to know the parents first in a general conversational manner before seeking specific information on their child's needs. Where possible, a slow transition period is usually required, making sure that information and any cultural preferences are shared amongst the team. Sharing clients' information and cultural preferences with other team members is important as one staff participant stated, "so they aren't expected to repeat it to every single worker." In emergency admission, where slow transition of clients is obviously not possible, staff members reported that it is having a culturally diverse team available or on call to seek advice.

The teams involved in this staff focus group aim to make CALD clients and culturally appropriate service practices a focus of regular discussion at team meetings to embed cultural competency training and build a knowledge base within the team. Staff often undertake their own research on what might be acceptable 'welcome gifts' for CALD clients, invite CALD families into the service to provide guidance on food preparation or contribute to cross-cultural events, enabling the sharing of food and cultural traditions. In addition, one of the staff teams actively celebrate the diversity of their staff with a map in

the workplace for each staff member to indicate their country of origin. Each of these strategies enhance a sense of cultural belonging for CALD clients and staff and, it was noted, "make such a huge difference."

Organisational Support. Staff in the focus groups were also asked what system changes or assistance could be provided by the organisation to better support them to provide culturally appropriate services and supportive work environments for CALD staff. Several groups raised the possibility of having CALD champions or contact points identified in the organisation, across all portfolios and service streams, to provide advice, support and mentoring to staff. One staff participant said it would be beneficial to all staff, even those with extensive experience with CALD clients: "If there was a pool of people we could ring and say we have this person coming in from this CALD background. We could then have a general conversation on what are some key things that we need to consider that may help make that person feel more welcome."

It is a recommendation arising from the suggestions of staff in the focus groups, that the development of specialist CALD support services within AnglicareSA could be enhanced through more formalised use of CALD volunteers who want to give back to their community, as well as existing CALD staff members who can assist with rapport building and provision of possible interpreting services for clients. According to the research inputs, the benefits here would extend beyond the client to include AnglicareSA in terms of increasing cultural diversity, as well as CALD communities by opening potential opportunities for increasing employment of CALD people from the volunteer pool. The potential for developing CALD staff from volunteers within CALD communities was raised several times by community leaders as the best means of building capacity within communities and creating greater options for CALD people to be cared for by members within their communities. As one community leader said: "If there is someone from the community who can do the care for someone that would be best." This research notes that some staff teams already use CALD staff member or volunteers to assist with rapport building with CALD clients and as a source of guidance on cultural etiquette. These already existing complementary staffing strategies could be developed to further enhance culturally appropriate delivery across the organisation.

In terms of improvement to service practices, staff raised the need for protocols to be established across all service streams within AnglicareSA to set clear guidelines for CALD service provision. Staff suggested that these protocols should include some of the engagement considerations discussed. However, they also highlighted that guidance should also be given on: rostering of staff to better support CALD clients; formalising admission practices and processes for CALD clients when accessing accommodation and services; and further procedural matters such as clients in supported accommodation being able to access cash, rather than cheques or supermarket cards, to enable purchasing of culturally appropriate food items from a diverse range of stores.

Staff also suggested that the AnglicareSA internal staff system, MATRIX, requires an upgrade and could include additional information, highlighting the diversity of the workforce, various languages spoken by staff, as well as research articles and information on cultural awareness sessions and events. To ensure that cultural capacity is developed across the organisation, staff also suggested that it would also be beneficial to ensure that examples of best practice CALD service provision and staff support in AnglicareSA are shared across the organisation, via the staff intranet, or the website.

Finally, this report recommends that where referrals to other agencies or providers is deemed necessary for CALD clients who cannot be supported through the organisation, before a referral to another organisation is made it should be ensured that the same the high standards set for AnglicareSA in culturally appropriate delivery will be met. As part of developing a CALD service policy, then, it would be ideal to have a formalised assessment of other appropriate providers, to develop strong referral relationships and the possibility for knowledge exchange and staff development opportunities.

Accommodation preferences and respite services

The cultural context of familial responsibility for care and communal living was most pronounced in discussions with CALD individuals and their families surrounding accommodation preferences and respite care. There were varying degrees of willingness to accept formal disability services externally amongst CALD participants in the primary research, but the clear preference expressed by individual clients and non-clients with disability (group A 1, 2) is for care in the family home. As one individual (sub-group A2) said: "Families are the ones to take care of them ... or people [who] come to the home."

It was particularly found that the prospect of supported accommodation for family members with disability is not an option that is generally accepted. Several participants indicated that this would not be considered culturally appropriate and would be refused by the individual and family. However, one community leader thought that the care of a child away from the home may be acceptable if it was a large family with too many responsibilities for the parents. Another acknowledged that a need for hospitalisation or rehabilitation for a short period would be acceptable. Apart from these qualifications, most CALD participants in the research indicated a strong resistance to this form of support. A community leader (group B) said that in his culture: "We would have barriers going to facilities like this. If there is someone to look after them it would be culturally inappropriate to send someone away from home. That is not accepted in the culture. We don't do that to our parents and we don't want our children or grandchildren to do that to us." Similarly, an individual with disabilities (sub-group A2) stated emphatically that: "People want to stay and take their last breathes in the laps of their family."

"Home services as opposed to institutionalised services ... that is very clear cut for them ... they don't want to." Community Representative

This refusal of forms of supported accommodation is recognised by community leaders as a significant barrier for some members of CALD communities who may need more intensive support. However, CALD research participants indicated that the notion of familial support and inter-dependence is intrinsic to, and highly valued by, CALD communities. As one community leader stated: "This is the problem, or maybe it is a good thing."

Questions posed in the primary research regarding respite care evinced a similar response from CALD participants. 'Respite' was predominantly interpreted as being care provided outside of the family home and away from family, and rejected by most participants in the research. This form of respite was not seen as necessary by both parents of children with autism (Sub-group A1), both insisting that the care of their child was the family's responsibility. One of these parents explained that he is aware of respite care but is not looking for that form of support. He said: "My wife doesn't like it at this stage and I'm also not going to do that." An individual with disabilities from a recently arrived refugee background (sub-group A2) also emphasised that he did not want to be separated from his family for any length of time. Despite the clear need facing his family because his wife is unable to care for him for any length of time due to being hospitalised herself, he refused to leave his home or children. The influence of his recent experience as a newly arrived refugee, particularly the process of seeking asylum during which he was separated from his family, reinforced the cultural preference for being cared for at home, *even when* his wife was absent, and no care was available.

The Productivity Commission has recently recommended that provisions for respite care in the NDIS and individual plans need to be more clearly articulated. Recommendation 9.6 of their report is particularly relevant to CALD families. It states that there is a need for participants and their informal carers to be better informed that core supports provided in plans can be used to fund "additional in-home care or support in shared facilities to provide respite" (2017: 58). However, this research recommends that further to the report, it is also important that there is more explicit explanation given to CALD people with disability on the broad range of possible respite and accommodations services, including in-home care and support within the family. As one community leader made clear: "Families need to know that there is support out there for them also."

Housing Needs. While this research did not specifically focus on housing or accommodation needs, the impact of CALD people and their families' strong preference for in-home care may influence housing demand and have ramifications for accommodation services and broader policy on housing provision. Individuals and their families who participated in the research were predominantly living in private rental, their own homes, or as residents in housing provided by AnglicareSA through the Refugee and Transitional Housing services program. (All the individuals' homes were in the northern or north-eastern suburbs of Adelaide.) However, one individual with disability, who has lived in Australia most of his life, and an existing AnglicareSA client, lives in a supported accommodation facility.

The literature contends that the impact of inadequate or transient accommodation on CALD communities is significant, noting that there is a relationship between lack of social services provision and unsatisfactory accommodation (Australian Human Rights Commission, 2010; Pooja Sawrikar & Katz, 2008; Stone, 2005). One participant in the research who resides in AnglicareSA accommodation was concerned about the suitability and longevity of his housing. He asserted that he required additional home modifications and a longer lease to enable home-care for his extensive primary health issues and physical disabilities. He explained that he requires in-home access to a dialysis machine, but can only do so, in more permanent accommodation.

This individual's situation raised a systemic issue of the need for cross-portfolio service connections and referrals, focusing on CALD communities. For example, a review of AnglicareSA's accommodation services database for CALD families may reveal those who live with disabilities (identified through the requirement for housing modifications) who can then be targeted for outreach intervention or advocacy work in relation to the NDIS. In addition, opportunities for more holistic support to CALD people with disabilities can be undertaken that include consideration of housing provision, its longevity and suitability for people with disabilities, as well as other forms of community service support. It is therefore recommended that current work on the creation of a disability accommodation strategy, and any other relevant organisational strategies, incorporate initiatives specifically targeting CALD clients with disabilities and aims for cross-portfolio interventions.

Recommendation 4 Co-design a CALD service policy with CALD people, ensuring that services provided to CALD clients are culturally appropriate and relevant.
• Co-design a CALD service policy with CALD volunteers, AnglicareSA staff, clients and community leaders.
• Assess funded programs through ILC for any coverage gaps of CALD communities, with consideration given to a program supporting CALD families of people with disabilities.
• Incorporate CALD service considerations into mainstream services by establishing a network of CALD champions in each portfolio area to support the Principal, Multicultural Services and provide advice on culturally appropriate service delivery.
• Promote best-practice examples of AnglicareSA culturally appropriate service delivery and workplace practices on the organisational website and amongst staff, with links to research, articles and information on cultural awareness sessions.
• Identify preferred CALD service providers to enable referrals where appropriate or collaborations when required.
• Foster cross-portfolio service connections and referrals for CALD clients as part of developing organisational strategies, such as the disability accommodation strategy.
• Provide tailored information to CALD clients and potential clients about AnglicareSA services provided in the home, including explanation of the range of respite and accommodation services available which focus on 'in-family' support.

Topic 5: Building Organisational Capacity

Cultural diversity of AnglicareSA support staff and clients

The Joint Standing Committee on the National Disability Insurance Scheme reported that data is not available to "report on the number of participants who re culturally and linguistically diverse" (Commonwealth Government 2017, p.16). Because CALD clients are not currently well served by the NDIS, better data collation about them is needed nationally, so they can specifically targeted. It is also necessary to collate better data on CALD staff within the disability support workforce.

On an organisational level, the collation of data on CALD clients and CALD staff also needs to improve. Areas requiring attention for both are in terms of consistency in collection, centralisation of information which is held across each service stream and portfolio in the organisation and the need for regular updating and analysis.

The following data was collated from direct contact with each of the Managers from the Mental Health and Disability Portfolio on CALD clients and CALD staff, including the

areas in which they are located as of 17 November 2017. General staff numbers were provided on 20 October 2017.

Program	CALD Clients	CALD staff*	% of Staff
ASELCC	19	5	20.8%
OATS	33	0	0
NCA	16	0	0
Case Coordination	11	1	25%
Disability	22	47	54.7%
Exceptional Needs	0	19	28.8%
Children's Disability	10	8	33.3%
Mental Health Services	51	5	11.9%
CALD	162	85	
TOTAL	939	242	

*This includes Part-time and Casual staff (not FTE total)

This data shows that there are 17.3% CALD clients across the disability and mental health services and 35.1% CALD staff. The data also provides a high-level view of the alignment between CALD clients and CALD staff. This alignment data, broadly indicates where there are gaps in workforce diversity (NDA team), or need for increased diversity to meet CALD client needs (Mental Health Services team). It is notable that in the disability services stream, over half of the staff are CALD, which is extremely positive.

A finer-tuned analysis of cultural groups in staff and client categories, including languages spoken by CALD staff within each service stream and across portfolios, would enable: targeted workforce planning for CALD clients; greater specificity to inform a CALD client service policy; and assessment of the need for translation services and preparation of an 'in-house' translator database.

In the staff focus groups for this research, of the thirty participants, ten identified as CALD (reflecting the overall percentage of CALD staff across the disability and mental health service streams in the organisation). Information was sought on languages spoken amongst existing Anglicare staff who attended the sessions to form the basis for a database for future use. Staff who participated in the focus group sessions reported fluency in and the following languages: Mandarin; Manclingo; Dinka; Swahili; Khmer; German; Tamil; Fante (Fantse, Mfantse, Fanti). It is recommended that the collation of information on the languages spoken by CALD staff across the organisation should be completed as soon as possible to enable creation of a Translator Database. It may be necessary for this to be done in a manually with Managers directly approaching staff in each service stream to ensure consent is gained and privacy provisions, surrounding collation of personal data are upheld.

"What is going to help going forward is that we are becoming a more culturally diverse workforce. When I look back to when I first started we had very limited diversity. Once we get that diverse workforce, that will also help bring people along and improve our knowledge." Staff Member

Participants in the staff focus groups raised the issue of having diversity and availability of carers from various CALD backgrounds so that clients have access to staff from relatable cultures. The necessity to have culturally diverse support staff for CALD clients was strongly reinforced through the preferences stated by CALD participants in the research, particularly from new and emerging communities.

To meet the demands of the NDIS it is widely recognised that the disability workforce will need to expand to around 6,000 employees in South Australia alone. It is also acknowledged that within the fee-for-service framework of the NDIS, and under the current 'bare-bones' costing of the Reasonable Cost Methodology, that delivering the necessary expansion of the disability workforce is an enormous challenge, particularly within the current timeframes (Anglicare Australia, 2017). In addition, the cost methodology does not adequately accommodate costs for training or professional development and creation of strategies to better support the transition of the workforce to a new delivery model. Within the context of these challenges, and unless the NDIA build funding into packages or separately fund workforce development initiatives, it will be necessary to consider alternative funding opportunities.

Within the state government, there are currently several programs underway focused on skill development and meeting the challenge of the demand for an increased workforce to meet projected service growth under the NDIS. The Jobs First Employment Program (JFEP) in the Department of State Development offers funding for specific, tailored programs to organisations seeking to develop their workforce, with attention being given to employment, supporting the NDIS scheme. Advice has been that there are currently no programs underway that target employment of CALD staff within the NDIS but the potential is there for a funded pilot program to create employment outcomes within AnglicareSA. For example, a program could focus on re-skilling in the Aged Care service stream to enable cross-portfolio staffing and development of adaptive capacity amongst the workforce. Alternatively, a training program could be undertaken with targeted participants in the Newly Arrived Youth Service (NAYS) or other CALD volunteers across the organisation. From the preliminary staff data, it may be that employment outcomes could be targeted to the mental health services stream or NCA team. To meet funding requirements, it would be necessary for there to be collaboration with a training provider, ideally one that specialises in training for CALD service delivery. The possible creation of opportunities for CALD individuals to become workers in this sector was raised repeatedly by community representatives, both to improve service delivery to CALD clients and enhance the prosperity of CALD communities through employment, particularly in newly arrived and emerging communities.

74

Cultural competency of staff

The research highlighted a need to build capacity across the organisation to deliver specialist CALD services, underpinned by centralised data collation, and through an extension of cultural competency training.

Across the four staff focus groups that were held, there was a good balance amongst participants between longevity of experience and those who were newer to mental health and disability support. Several staff who participated have more than thirty years of experience in the disability or mental health sector, while others have less than five years.

Due to this breadth of experience, participants in the staff focus groups all demonstrated capacity in delivering individualised service support to people with psychosocial disability and disabilities in general. Several participants noted that service delivery to clients with disability requires staff to be highly attuned to individual preferences and need, with care often modified to suit individuals based on the development of relationships and gradual building of rapport with the client. One participant commented that: "Disability is a language in-itself."

This experience in service delivery to clients with disability enabled participants in the primary research – even those staff who had minimal experience with CALD clients – to understand the need to accommodate cultural differences and to suggest possible strategies they could use when working with CALD clients. There is a high level of receptiveness amongst staff to learning about cultural differences and a strong commitment to values of respect, careful listening, and the importance of involving families in the care of family members with disability. This inclination toward receptiveness to cultural appropriateness may also reflect the characters of those who are attracted to the human services. As the Anglicare Australia Submission to the Productivity Commission's *Issues Paper on the NDIS Costs* noted: "People are typically attracted to the disability and care sector through a strong set of internal values that motivate them to want to work with those less advantaged, and to do meaningful work that services their community" (2017: 15).

In addition, twenty-five of the thirty staff (83%) who participated in the focus groups, had direct experience caring for clients from a CALD background. Staff in the larger focus group of fifteen participants, all of whom had experience with CALD clients, were asked directly whether they felt confident, meeting the needs of clients from diverse cultural backgrounds. Of the thirteen who submitted responses, eight said that they were confident without any hesitation. The remaining six were equivocal, indicating that they were confident but had some hesitations, with one participant explaining that she "would need to speak to someone first to make sure I was fully aware of cultural needs" before feeling confident. One participant who had undertaken the extended cultural competency training offered through AnglicareSA, reported that the sessions had increased her confidence. She said that the training was "one of the most powerful training (sessions) that we have done ...

it comes up from time to time with the team and has definitely been embedded with us. It was very worthwhile and meant a lot."

The staff focus groups highlighted that while there is broad awareness of issues of cultural competency evident amongst AnglicareSA disability and mental health support workers and coordinators, a *low* level of staff have undertaken intensive or more formal cultural competency training. Most staff in the focus groups had not participated in any training beyond what they had received as part of their Certificate III, with some participants describing this as too general and not overly helpful. This reported experience is reflected more broadly in the literature which indicates that there is not adequately trained culturally competent staff in the NDIS/disability services space (AMPARA, 2016). This lack of trained staff is further confirmed by the NILS evaluation of the NDIS (Mavromaras, 2015). The evaluation highlights that staff believe they are ill equipped to work with CALD clients or clients from diverse backgrounds, mentioning that cultural training is often too short and too generic.

All thirty staff participants in the focus groups indicated they would be eager to learn more about CALD communities and to undertake further training as appropriate. It is recognised, however, that there would be a financial and logistical challenge to ensuring all support staff can access the five-hour cultural competency training. Staff participants in the research suggested that one team leader in every group could undertake extensive training and then act as a CALD leader for their team. It was suggested that embedding this expertise could then occur in team meetings even in an informal manner to create awareness about the impact of cultural background on service provision preferences.

Interpreter services

Staff focus group participants were asked if they would know how to seek interpreting services. Most indicated that they have some awareness of where they could seek assistance, citing the free National TIS service and Relationships Australia. The two focus groups with experience delivering services to CALD clients had greater awareness of where to access translation services. However, most acknowledged that they have little experience with using these services (two out of ten, in one group had regular experience working with a translator and ten out of thirteen in the other group indicated that they had referred clients to interpretation services and were comfortable doing so). Staff participants from the children's services stream reported that their greatest difficulty, using translation services is finding an available interpreter and, then, ascertaining whether the NDIS will fund it.

"The issue of interpreters has not been solved at all." Staff Member

Staff who haven't used translation services gave various reasons for why they hadn't. One said that it: "can be costly and hard to arrange". Another said that she was "not sure what options are available". Many others also cited uncertainty regarding costs and lack of knowledge about what was included within the NDIS funding parameters. As has been mentioned in this report, recent announcements from the NDIA regarding translation does

not provide enough clarity for staff or CALD clients. As explained it is suggested that free services can be used to "implement funded supports in their NDIS when engaging a provider". However, it is not clear whether they can be used while personal care or service support is being delivered and there are restrictions on use when a client wants to review their plan or add further services, if this review doesn't relate to an already funded support.

The level of complexity of this current funding and provisions policy for translation services is likely to create additional confusion and may lead to limited utilisation. Clients and staff will need very specific guidance on what they can and cannot claim within the NDIS scheme. It is suggested that this issue is directly addressed with the NDIA to develop a clear schedule of which services will attract funding, and many exclusions. This schedule should them be disseminated to all staff and provided to CALD clients.

Beyond the issue with funding constraints, additional limitations with translation services were also reported by staff. Staff from the mental health team felt that using translation services can make connecting with the client more difficult as it requires talking through a third party, resulting in is less eye contact and direct interaction. Participants explained that they felt the emotion and sincerity of engaging through a translator can be difficult to maintain as the exchange becomes about reaching an outcome, not developing or building a relationship. The imbalance in power between carer and client can also be reinforced through this process. Staff suggested that they would like further information and training about how best to utilise translation services, as well as guidance on other apps or visual tools which may be available to assist with delivery of services to CALD clients.

It was also noted by staff that there is a need to be cautious about a general call to TIS, as not all interpreters understand or have the sensitivity to work with mental health or disability clients. Staff focus groups highlighted that some interpreters are better than others in this regard. In response to this feedback, it is suggested that a preferred provider database of providers with proven experience in mental health or disability and demonstrable understanding of the challenges facing clients be developed. It was suggested that translators who have received training through Relationships Australia were generally superior and could serve as the starting point for developing the preferred list. Utilisation of existing CALD staff as 'in-house' interpreters was also suggested and the need for a database of languages reiterated. It is recognised that a process of collating language background of staff will need to be undertaken on a voluntary basis, which will also ensuring that staff are prepared to provide translation services. FECCA supports the use of bilingual staff and in-house interpreters and suggests that this approach should be reinforced by sound data collation on clients' language and interpreting needs, as well as enhancing staff capacity through training (2016: Exec Summary, 3).

Recommendation 5
Embed commitments to cultural inclusivity throughout the organisation, in strategic documents and initiatives to enhance cultural competency and workforce capability.
• Set a clear strategic objective on the role of CALD clients in AnglicareSA business development planning and client growth opportunities within the NDIS framework.
• Up-date and centralise data on CALD clients and staff to underpin strategic decisions on translation of materials, engagement approaches and the development of a CALD service policy.
• Establish relevant CALD workforce and client representation targets in the organisational goals of each service arm and the KPIs of relevant Senior Managers.
• Pursue a pilot CALD workforce project with the Department of State Development to increase the number of CALD disability support staff in targeted service streams of AnglicareSA (involving the Newly Arrived Youth Service).
• Implement compulsory cultural competency training for executive staff and members of the NDIS Customer Advocate team. Consider extending this training to an identified CALD leader within each disability, accommodation and community service team.
• Create a 'Translator Database' of bilingual AnglicareSA staff and a 'Preferred Translator' guide to suitably experienced translation services.
• Investigate funding provisions for translation services as part of NDIS pre-planning, plan development and service provision to ensure maximum use of funded supports, and prepare a schedule of funded services for staff and CALD clients.

7. Next Steps: Challenges and Opportunities

This report identifies extensive cultural and systemic barriers facing CALD people and communities that are likely to prevent engagement with, and access to, disability support services.

The research found that cultural views of disability from home country experience, stigma, a lack of familiarity with Australian healthcare and related systems, and established conceptions of familial and community responsibility for the care of people with disabilities, are key factors impacting CALD engagement with formal disability services. Systemic limitations in the NDIS model for delivery have also been shown to pose additional challenges for CALD clients with disabilities: many are not fluent in English, require greater support in planning and purchasing of services, and may not meet scheme expectations of client capacity for self-advocacy. These are significant and complex challenges.

To meet the needs of CALD clients with disability and engage with the strategies suggested in this report – targeted engagement and communication, outreach services in collaboration

with CALD communities, development of specialist CALD services, and increasing capacity across the organisation – considerable organisational effort will be required.

The identified importance of rapport building with CALD clients, particularly with service providers who can establish relationships based on trust and cultural awareness, has been one of the strongest themes to emerge from the research, particularly for new and emerging communities who face the greatest barriers to accessing support services.

It is recognised that within the framework of the NDIS, the capacity to develop these connections and provide extensive support to CALD clients is not specifically funded. Anglicare Australia identifies this challenge in its submission to the Productivity Commission on NDIS costs:

> The result is a cost underestimate in the whole system, and the on-ground reality is that there is substantial unpaid work being done with NDIS participants such as: pre-planning for an NDIS appointment; assisting with plan set-up, including case management; and providing stop-gaps for the lack of Local Area Coordinator (LAC) capacity and processes for LACs to undertake plan set up and service connections (2017, 5).

Relatedly, difficulties with engagement and outreach efforts were raised by CALD community representatives during the research. It was noted that there is not the required level of outreach contact from service providers direct to CALD communities. Each community leader expressed a willingness to engage with and support initiatives to reach their communities, but there was a sense that service providers may not respond. It was noted, for example, that, "We discover that there is someone in organisations who have ethnic liaison but they are busy and they don't contact us." Another community leader said that while CALD communities welcome cultural days and often invite providers, these events "would work if they attend. The main thing would be how to get them there."

Community leaders who are involved with service delivery recognised the financial constraints on providers within the NDIS funding model. However, they still insisted that outreach activities, like community information sessions and home visits, were essential for many CALD communities to "break down barriers". While acknowledging that these efforts were difficult to undertake without additional funding, one leader emphasised that such approaches "would improve things. Rather than wait for people to come because if you wait for people to come to you, it's going to take years." Another argued that it is important to begin to apply these longer-term strategies now to reap efficiencies later.

The Productivity Commission's report on *National Disability Insurance Scheme (NDIS) Costs,* found that without government intervention, the NDIS' market-driven model is likely to produce thin markets, which will have the greatest impact on participants living regionally with complex and significant needs, and participants from CALD backgrounds (Finding 7.1). A corresponding recommendation suggests that a range of approaches, including block

funding, should be considered for these groups and calls for the NDIA to release its policy on a Provider of Last Resort (POLR) and market intervention framework (Recommendation 7.1).

Anglicare Australia has also advocated for a provider of last resort for people with exceptional needs (2017). The Anglicare Australia submission to the Productivity Commission contends that the significant level of case management required and service coordination complexity involved with these clients means that "consideration of a provider of last resort is also merited" (2017:19).

An advocacy argument for a POLR necessarily signals that the provision of service support to these cases of 'exceptional need' are not likely to be able to be accommodated within the existing NDIS pricing model, and hence provider service delivery. POLR is a policy 'white flag', heralding provider incapacity to uphold value-driven missions to assist and support the most vulnerable.

The business imperative of providers cannot be ignored. This research therefore recognises that advocating for a safety net for CALD clients and other exceptional needs groups is one tool to highlight the inadequacy of the existing NDIS costing framework, and the needs of clients at risk of exclusion from the scheme. Yet appeals for a safety net may also implicitly result in the creation of a two-tiered service delivery system, whereby those with the greatest and most complex needs are left with a minimal level of services, while others can freely negotiate and pursue individualised services and a 'choice' of provider – as was the original intent of the NDIS.

It is suggested that, with the more recent Productivity Commission recommendations for block funding for exceptional needs clients, consideration be given to advocacy on this front in addition to scrutiny of any policy which is released on the POLR. The possibility signalled by the Productivity Commission for a range of other approaches, including block funding to better support this cohort, should be carefully considered and viewed as an opportunity to advance alternative possibilities for collaboration between the NDIS and providers to address the needs of the most vulnerable clients. Moreover, the Productivity Commission's recommendation that resources for Information, Linkages and Capacity Building funding should be increased (Finding 6.1) signals that this may provide another opportunity to seek additional funding for CALD people to ensure they are adequately connected with appropriate services. It is hoped that this report will provide some impetus and evidence for these purposes.

In consideration of policies for a POLR, it will also be necessary to take account of the exceptional barriers and needs confronting CALD people with disabilities. The Productivity Commission's recommendation for a separate gateway for participants with psychosocial disabilities may provide a benchmark for assessment of any POLR policy or proposed alternative funding model to address the exceptional needs of CALD communities (Recommendation 4.4, 2017). The provisions made within this recommended gateway need

to be upheld for all exceptional needs clients: specialised staff; face-to-face engagement; models of outreach to engage people who are unlikely to approach the scheme; provision of linkages to both clinical and non-clinical services and supports outside the scheme; and the collection of data on both entrants into the scheme and people linked to services and supports outside the scheme are important for CALD people with disabilities and should inform any policy attempting to redress thin markets and inequity of access for all exceptional needs clients.

The five key recommendations provided in this report strongly reflect the primary research undertaken with respected CALD community leaders, CALD people with disabilities, their parents and families, and AnglicareSA disability and mental health support workers. It is hoped that by voicing their experiences, challenges and insights, each of the 55 people consulted for this research have provided a platform for further advocacy, as well as series of recommendations meriting serious consideration and, where possible, implementation.

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83

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