THE DOUBLE BIND

CARE TRANSITION EXPERIENCES OF AGEING
INFORMAL CARERS AND PEOPLE WITH DISABILITY
IN MINORITY MIGRANT COMMUNITIES

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Western Sydney University acknowledges the peoples of the Darug, Tharawal, Eora and Wiradjuri nations.

We acknowledge that the teaching, learning and research undertaken across our campuses continues the teaching, learning and research that has occurred on these lands for tens of thousands of years.

MDAA

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A FEATURE STORY

Frank is a 27-year-old male with a disability from a multicultural community. He is committed to making a difference. He dreams of living independently when his parents can no longer support him due to old age. He is trained in Accounting and Business Administration but cannot find welcoming employment because of his disability. His parents, in their mid-60s, are concerned about what the future holds for their son in a complex and uncertain disability care system.

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EXECUTIVE SUMMARY

BACKGROUND AND AIM

An important milestone in social care and social policy since the late 1990s is the continued opportunity for people with disability and, their parents and/or family caregivers, to have longer, enjoyable quality of life. However, as family carers, informal supporters and people with disability age, their needs and expectations also change. Ageing family carers, usually parents, increasingly can no longer provide the quality and intensity of support and care required for their family member with disability. This puts additional pressure on informal long-term care and support relationships. It also threatens the future of care, especially for ageing carers from multicultural communities – who historically and still find access to disability services and other support challenging in Australia.

The intersection of migration and ageing in Australia presents a multifaceted challenge. The phenomenon of migration has led to a growing number of older Australians from multicultural backgrounds. The combination of the demographic shift, the trend of people living longer, as well as the evolving dynamics of informal caregiving for people with disability resulting from the ageing process means it is now imperative to gain insights into the experiences of ageing informal disability carers (hereinafter referred to as 'AIDC') from multicultural backgrounds, and their family members with disability. Understanding their perspectives on, and preparations for, this significant transition into the latter years of life is of the utmost importance. This project, therefore, aimed to work with multicultural communities in collaboration with the New South Wales (NSW) peak multicultural disabled people's organisation, the Multicultural Disability Advocacy Association (MDAA), which advocates for people with disability, their families and carers in order to understand the care transition planning experiences of AIDC and their adult family members with disability. The overall goal is to use the findings of this pilot study to inform the design of an innovative multicultural care transition toolkit to support the care transition planning processes of multicultural families who provide informal disability care.

METHOD

This collaborative qualitative study involved nine families comprising a parent (≥58 years) and an adult family member with a life-long disability (≥19 years) from each family. The total sample was 16 participants (n=16). The families were involved in in-depth interviews (either together or independently) and a follow-up data validation workshop (all together). The WSU research team and MDAA staff worked together through the project's conception, data collection, and organisation of the validation workshop to co-produce this research. After the data was transcribed, the research team initially undertook a group coding process to build consensus around the emerging themes. A research team member subsequently coded the data based on the agreed common codes, and any other emerging codes were noted during the transcription.

RESULTS

The findings showed growing despondence among AIDC over the future care of their family member (mostly an adult child) with disability. The despondence arose from concerns over their own age-related health concerns, and the unreliable support from other family members to take up care and support responsibilities for the family member with disability whom they provided care for. Findings also showed that care transition planning was mostly one-sided, with Informal carers thinking more about their family member's long-term disability care and support than their own end-of-life care needs. Our research found that working towards the independence of the family member with disability through capacity-building initiatives was the most cited planning strategy when considering the complex requirements for a safe and secure future for them. Uncertainties for the future arise due to a lack of information about service options available in the requested language and the ability to access opportunities to support the transition process. Most families seeking independence as a transition strategy reported discrimination and limited employment opportunities for their family member with disability, despite their efforts to build skills to improve employability. Participating families did not report engagement with, or knowledge of, any specific care transition planning service or activities that supported them to think about or plan for the future care for their family member with disability. For some, this study prompted them to think more intentionally about the future without knowing where to start.

CONCLUSIONS AND POLICY RECOMMENDATIONS

There are profound uncertainties for the future of care and support for ADIC and their family member with a disability in multicultural communities. The long-held assumption that these communities rely on an informal family support system is no longer tenable in the face of weakening intergenerational solidarity and the effect of second and third generation migrant acculturation into the Australian way of life. It is, therefore, imperative that stakeholders in multicultural disability support and care, and aged care acknowledge the role of AIDC and the evolving context in which they provide care. Designing tailored household interventions that support the care transition planning process will benefit all concerned – the care and support providers within the family, and the person with disability who relies upon them. More importantly, there is the need for a deliberate multicultural policy response that recognises the voices, concerns, aspirations, and expectations of disability and aged caregiving in multicultural communities when designing tailored care transition services. The research recommends that disability advocacy and carer support organisations work towards strengthening and empowering ADIC and people with disability to negotiate the care transition process, considering their personal cultural values, beliefs, gender, ethno-religious, and family norms.

1.0 **BACKGROUND**

Informal carers and people with disability now live longer due to advances in care systems [1]. Although this is positive news for disabled people, families and the care economy, the combined ageing process also presents an uncertain future for both population groups – disabled people and ageing informal disability carers (AIDC) and supporters [2]. In fact, it may compromise care quality if not properly managed. For instance, as they age, AIDC can no longer provide the quality and intensity of care and support required for a family member with a disability due to their own growing care needs and health concerns, even with additional in-home support. The limited capacity of AIDC places additional pressure on long-term care and support relationships for all involved. As a result, families are seeking new formal arrangements that enable supportive, active ageing end-of-life transition for AIDC, as well as support to ensure the quality of care for their adult family member with disability. For most of these families, searching for opportunities for long-term care for themselves and for their adult family member with disability is not just daunting but a new experience;[3] one that requires information, planning, preparation, allocating family resources, and navigating complex formal care systems across divergent policy domains and systems – ageing, and disability.

In Australia, disability and aged care are separate systems running as parallel policy, funding, and service provision regimes, increasing the complexity of the care transition process for most families. For AIDC and their family member with disability, it is necessary to transition between these two systems in order to receive the appropriate care that meets the changing needs of both population groups. Navigating such complex and distinct systems is considerably more challenging for families from multicultural backgrounds who have historically had, and continue to have limited access to formal disability care and support systems due to long standing structural and socio-cultural factors that have excluded non-white disabled people and their families from disability systems of support [4].

While ageing has challenges with varied needs, these challenges are further exacerbated for older adults from multicultural backgrounds[5]. The adoption of multiculturalism as official policy in the 1970s led to increased diversity in migration sources. As a result of diverse immigration there are now over two million people from multicultural backgrounds residing in Australia[5-7]. Approximately one third of older adults (65+) living in Australia were born in non-English speaking countries. Australia's migration levels are anticipated to continue to rise, as the current Albanese Labour Government aims to expand the intake. In 2022-23, the number of permanent migration visas

has been increased from 160,000 to 195,000 places. As migration continues, the population of older Australian migrants is expected to rise, coinciding with a general trend of increased longevity among Australian adults. By 2057 it is estimated that Australia will have 8.8 million older adults (one in five people), and by 2097 this increases to one in four (12.8 million people) [7].

This study focuses on AIDC from multicultural backgrounds due to the growing need for care and support for both population groups in these communities. Among the general Australian population, 1 in 6 people (18%) live with a disability [8]. The data show similar prevalence rates of disability for people from non-English speaking backgrounds and English-speaking Australians in 2016 [9]. In 2018, the Australian Bureau of Statistics estimated that 5.7 per cent (1.46 million) of the Australian population have a profound or severe disability. Subsequently, Settlement Services International (SSI) estimated that 29 per cent of people with profound or severe disability in Australia come from a multicultural background [9]. By this calculation almost half a million people (about 442,892) with profound or severe disability come from multicultural backgrounds. When mild to moderate disability support needs are considered, this number increases to over 1 million Australians of multicultural background living with disability [10].

Multicultural communities have historically faced challenges accessing disability services [9, 11]. People with disability from multicultural and diverse backgrounds face barriers to obtaining culturally appropriate, safe and responsive services and support due to disability-related cultural stigma, language barriers[12], a lack of information and interpreters, a lack of culturally acceptable services and racism within the disability service sector[9]. Additionally, there are, in some communities, issues associated with ingrained cultural attitudes in relation to disability and impairment and, the socio-cultural expectations that come with being a community member of a multicultural group [11]. Moreover, due to how Australian disability services developed historically, there has been, and remains limited cultural competency and understanding of their own practices of racialisation and racial bias and discrimination within most service providers (disability and mainstream) in providing culturally responsive and safe services to individuals with disability and their support network from multicultural communities [13]. As a result, there is a dearth of culturally appropriate disability services in areas specific to the intersection of cultural specificity and disability services within the National Disability Insurance Scheme (NDIS) [14]. In addition, the availability of specialist expertise for multicultural people with disability in the areas of health[4], education[15], housing[16], employment[17], and justice[18] is limited. It is widely acknowledged that, despite national innovations such as the NDIS, people with disability from multicultural backgrounds continue to face significant barriers and impediments to accessing appropriate, safe, and responsive services across the life course.

Overall, there is very little understanding in the literature and in professional service practice on how AIDC and people with disability, particularly parents and their adult child/children with disability from multicultural backgrounds, navigate the care transition process in the latter years of life. The aim of this project is therefore, two-fold: It aims to understand the care transition experiences of families with ageing carers and adult children with disability,; and to explore what formal arrangements (and how they should be approached and delivered), enable supportive care transition for AIDC, and ongoing quality support for their adult child with disability. The goal is to use the findings from the study to inform the development of a care transition tool kit. Therefore, this pilot study focuses on answering the following two specific questions:

1.1 RESEARCH QUESTIONS

1 How do AIDC and their adult children/family members with disability from multicultural communities in Western Sydney navigate the care transition process to ensure that their support needs are appropriately met in the next stage of life?

2 What formal and/or informal care transition arrangements are necessary and critical to support AIDC and their adult children/family members with disability?

2.0 **METHOD**

This study was designed as collaborative qualitative research [19] utilising the narrative approach [20] [21]. The collaboration involved Western Sydney researchers and MDAA working together to conceptualise and implement the project. The study was conducted in Western Sydney, New South Wales. Western Sydney is particularly unique due to its high rates of disability alongside the large population of diverse multicultural communities that have settled in the region. In South Western Sydney, fewer than half of residents (46.3%) spoke only English at home (this figure was far less than the NSW state average (68.5%)). In some Local Government Areas non-English languages were dominant at home: Fairfield (75.5%), Canterbury-Bankstown (63.7%), and Liverpool (57.2%)[22].

The study sample included nine families comprising a parent (≥58 years) and a family member (mostly an adult child) with a disability (≥19 years). The total sample was 16 participants (n=16) comprising 9 AIDC and 7 family members with disability who directly participated. Two family members with disability did not directly participate but their carers responded to questions about them. The selected families participated in in-depth interviews (either together or independently) and a follow-up workshop (all together). The workshop was intended to validate the findings from the in-depth interviews and to collectively explore emerging common and community issues. As collaborative qualitative research, the Western research team and MDAA co-produced the project's conception, data collection, as well as the organisation of the validation workshop. After the data was transcribed, the research team initially undertook a group coding process to build consensus around the emerging themes. A research team member subsequently coded the data based on the agreed common codes and any other emerging codes that were identified.

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3.0 **KEY FINDINGS**

3.1 **DIFFERENT PEOPLE, SIMILAR PROBLEMS, DIFFERENT EXPERIENCES**

Each study participant was unique. Participants came from different socio-cultural, gender, ethno-religious and linguistic backgrounds, and family circumstances, although they all found themselves caught within a complex disability support sector. The AIDC participants in this study had an average age of 68, ranging from 58 to 78 years old. The average age indicates that a significant number of the participants may require aged care services as they approach the next phase of life. Many participants said that accessing aged care was crucial for their personal well-being during this transition. Consistent with previous research in the informal care economy sector [23, 24], it was observed that all participating ADIC, except one, were females. Notably these ADIC were mostly single parents. This finding, to some extent, is consistent with studies indicating

that individuals with disability often resided in single-parent households[25], leading to lower socio-economic status reflected in the national household earnings' lowest quintile.

The average age of the family member with disability (primarily male) was 34. Eight (8) of the nine (9) family members with disability were sons and there was no consistent impairment type across the participating families. All except two cases, had siblings living within the same household or outside. While the presence of siblings suggests that there should be implications for how we understand the care arrangement within the family [26], as reported further down in this report, siblings could not be relied upon to take up care and support responsibilities as they were busy with their own lives, i.e. were married with their

own families or, were living far away. AIDCs' narratives on their capacity to access additional informal family support indicated that informal family support networks were weakening and were unreliable [27]. This finding highlights the critical need to explore alternative care arrangements to augment current informal care and support within the family household. Table 1 below provides detailed information on the key characteristics of the study participants.

TABLE 1: Characteristics of study participants

PARENT/FAMILY MEMBER CHARACTERISTICS					CHARACTERISTICS OF CHILD/FAMILY MEMBER WITH DISABILITY					
ID	AGE	GENDER	MARRIED	ETHNICITY	ID	AGE	GENDER	DISABILITY	SIBLINGS	HOBBIES
P1	61	F	YES	Vietnamese	C1	19	M	Non-verbal	2 Bro 1 Sis	Bowling, park walk
P2	64	M	YES	Vietnamese	C2	27	M	Autism	1 Bro	Computer games
P3	78	F	NO	Anglo Indian	C3	48	M	Asperger's	2 Bro	Not stated
P4	73	F	NO	Indian	C4	35	M	Autism - L3	None	Writing, going to park
P5	64	F	NO	Pakistani	C5	33	M	Cerebral Palsy	2 Bro 3 Sis	Watching cricket on TV, driving
P6*	74	F	YES	Indonesian Chinese	C6	49	M	Down Syndrome	11 Siblings	Taking photos, painting & music
P7	63	F	NO	Vietnamese	C7	22	M	Autism	3 Sis	Watching movies, going to Comic con
P8	75	F	NO	South African	C8	51	M	Asperger's	None	Greek mythology, archeology, films, filmmaking
P9	58	F	YES	Vietnamese	C9	21	F	Autism	Not stated	Not stated

*P6 is an older sister taking care of a younger brother

3.2 IN THE WORLD OF THE AGEING CARER AND FAMILY MEMBER WITH DISABILITY: NO END IN SIGHT

> 66 I am getting old, so, someday, I cannot continue caring for my son. If he lives by himself my concern is who will really care for him 99

(P7, Female – single mother, with 3 siblings)

> 66 We have looked after him all his life. We are concerned one day me and my wife are getting old, and we cannot continue to help him or assist him with something, and maybe one day we die. I am bit worried about his future because I don't know if he can stand up on his own feet and do something 99

(P2 – Male with a partner)

> 66 The fact that I'm 71 and he's only 35, so he's got another good 35 years to go and he's going to be alone in the world 99

 (P4 – Female, single mother, no siblings)

The three quotes (left) reflect the typical everyday concerns of ADIC of a family member (typically an adult child) with disability. Their lived experiences were clouded with anxiety, uncertainties, grief, and the increasing need for resources and support. This is consistent with other studies on the impact of informal care giving [28]. Among the six emerging themes identified in the informal care and support experiences of AIDC (See Figure 1 below), the most significant was the anxiety surrounding future care arrangements, particularly in terms of safety and long-term security. AIDC expressed a growing sense of despair when contemplating the future care of their adult child with disability. This despondence stemmed from concerns about their own age-related health issues, which emerged as the second most frequently discussed everyday experience.

While participants in the study received some intermittent family support, there were increasing concerns about the reliability of support from other family members. P7, cited above, and similar cases highlight the uncertainties surrounding future family support, despite the presence of social networks. Figure

1 below presents additional experiences of ADIC from multicultural communities.

The stories shared by people with disability reflect a comparable level of concern regarding their future care, particularly in light of the awareness that their primary carers (usually their parents) are ageing. People with disability mainly reported employment-related discrimination, rejection, and sometimes feeling short-changed by those who provide formal services. However, people with disability receiving care from their parents demonstrated satisfaction with the care. For example, participant C2 recounts:

> 66 Well, I would say, I really enjoy being at home with Mum and Dad and my little brother when he's here. I'm not sure if I could actually survive on my own... 99

(C2, 27-year-old male, person with disability)

FIGURE 1: The lived experiences of care
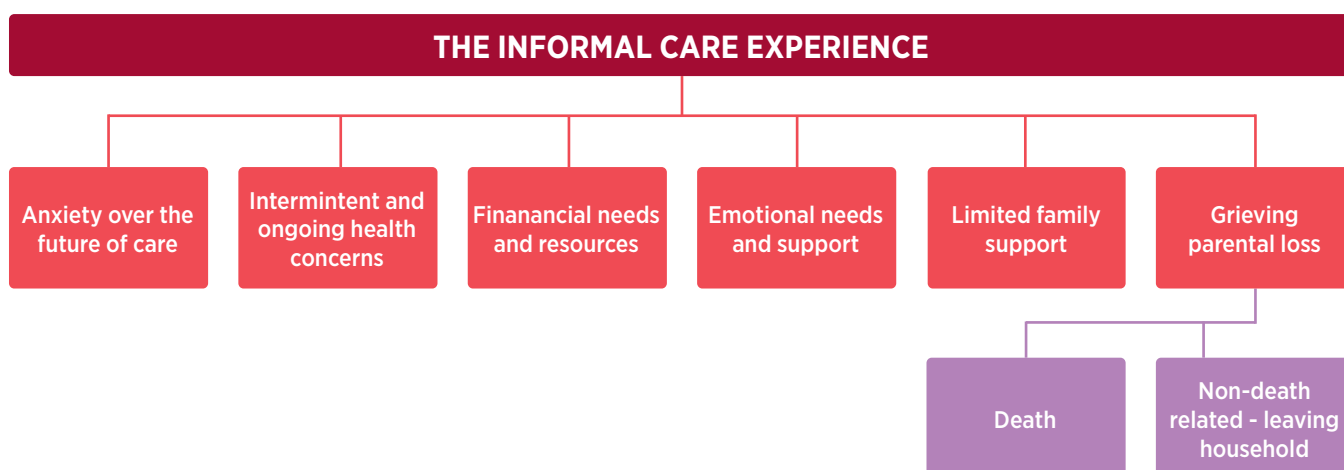
3.3 PLANNING FOR FUTURE CARE: THE MAZE AND THE WIT

Although there was no evidence of a formal or guided care transition planning process; all participants in this study demonstrated agency, strategy, and wit amidst limited resources and opportunities. Overall, the evidence showed that care transition planning was mainly one-sided, with carers thinking more about their family member's care than about their own care needs. The dominant theme for transition planning was working towards the independence of the member with disability (See Figure 2). Most AICDs expressed a desire for their family member with disability to become independent in performing essential life skills such as cooking, bathing etc. once they were no longer able to provide care. Families sought life skills development opportunities to help their child (or family member) with disability. AICDs also focused on supporting them to develop skills that could help them find employment and earn an income. The comments below demonstrate how AIDC think about and plan for the future.

❝ I just want him to be independent... He can do at least cooking for himself... do something independent, not rely on the parent anymore. That is why we try to let him know that he should stand up on his own feet. Don't rely on parent because parent are getting old. That is why we try to get him job, learn to cook, something like that, washing and others ❞

(P2, Male married, brother)

❝ He should get married... He's talking to a girl... She was in during the war [...], and he's all money going— giving to her to support her. Even I gave whichever I was able to give [to support him to find a wife. A wife will support him in the future] ❞

(P5, Female, single mother, with siblings]

Family members with disability who participated in this study, and who were able to engage in interviews, expressed similar concerns for independence as a strategy for their future long-term care.

❝ I always think about it [mothers ageing and health] because obviously, being a mama's boy she always makes food, and I expect things like my clothes washed. I can do it myself, but because mum already does it, so I don't. I'm thinking she's getting old and sicker, so I have to, probably be more responsible and not be as lazy. Because you just kind of get used to it sometime... I want to be independent myself. Having a job would be a good start. If you work, it's not even about the money. It's never about the money. It's just for the fact to keep your mental state active. Because if you're not working, you got nothing to do, you start to think negative. You start to feel depressed. The brain always needs to be active and moving forward. I feel like I've been stuck in one spot mentally for a while because of work and stuff. It's okay ❞

(C5, Male, Cerebral Palsy).

Another family member with a disability noted:

❝ I need to stop spoiling myself and be more independent. ... "Maybe I need to make more friends, especially friends I can depend on ❞

(C2, Male, Autism).

The comments of people with disability above clearly demonstrate their agency and preparedness to work towards independence in preparation for long-term care for when their parents can no longer support them. Figure 2 presents additional transition planning strategies that were discussed. These strategies encompass leveraging continuous NDIS support services such as Supported Independent Living (SIL), respite care, and other core supports. Another strategy mentioned was relying on other family members for intermittent support, although there were concerns about its long-term viability and reliability. Some Participants suggested using the Public Guardian and Trustee system, as well as building other social support networks for future support needs, while others had joined community groups and focus group discussions to support information sharing. Some AIDCs shared that they had considered marriage for their adult child with disability as a means of ensuring companionship and as a way to safeguard their future care. Notably, all of these transition strategies are shrouded in deeply rooted gendered, religious, and cultural considerations.

Despite active efforts of AIDC to support their adult child with disability in attaining independence as part of their transition strategy, they disclosed that there had been instances of discrimination and limited employment opportunities. Additionally, participants also reported a lack of information regarding available service options, as well as their ability to access opportunities to support the transition process (See Table 2). They also expressed apprehension regarding the impact of location and physical space when planning for future care. For those participants who did not own their own home, their adult child with disability expressed a sense of uncertainty about navigating the property landscape and what their future living arrangements might entail. Further details about the complex journey participants must navigate are outlined in Table 2.

Overall, it is concerning to note that participants did not report any specific care transition planning service or activities to support them to think about or plan for the future of care. For some, this study was a trigger to start thinking more intentionally about the future without knowing where to start and where to end.

FIGURE 2: Future planning strategies
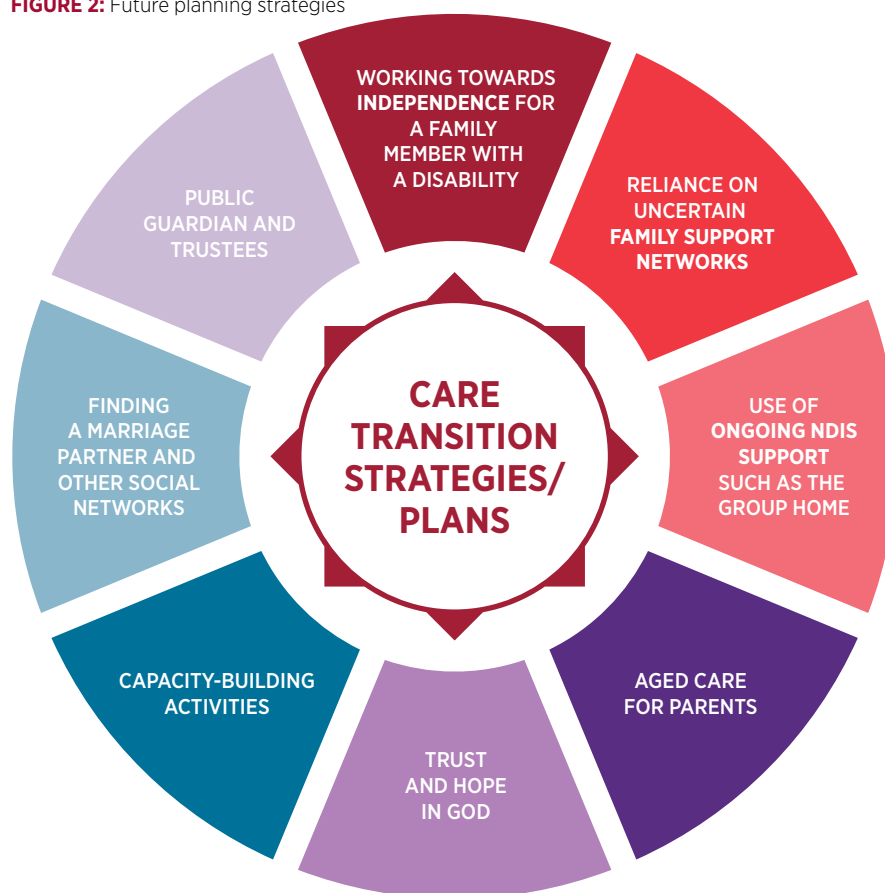
TABLE 2: Factors impacting care transition planning

CENTRAL CHALLENGES (THEMES)	THE SPECIFIC DIMENSIONS
The role of place and space	→ Navigating property ownership and transition plans → Changing from mainstream to special schools → Separation from family/Living alone
Family and community support: The societal myths of family care	→ Lack of supportive social networks → Lack of siblings' support and friendships → Disability-related stigma with the community
Barriers to accessibility - institutional, medical and government services/support	→ Lack of knowledge of the service systems and help-seeking skills → Lack of culturally appropriate/personalised services → Lack of social and emotional connections → Need for more job opportunities, placements, and appropriate training → Increasing numbers of health practitioners who display lack of empathy → Gender and disability disparity at workplaces → Support workers lacking expertise/training to provide support → Poor accessibility to specialist services → Lack of information on accessing services and information

3.4 FORMAL CARE TRANSITION ARRANGEMENTS NECESSARY TO SUPPORT AGEING CARERS AND FAMILY MEMBERS WITH DISABILITY

Due to potential discrimination and difficulty accessing support due to lack of knowledge on how systems operate and where to get accurate information, AIDC expressed a need for more advocacy and awareness about disability issues in their communities. They also discussed the need for more public education about disability rights and how to navigate services. Most participants suggested that arrangements and services promoting independence for individuals with disability align with their expectations for the future. They emphasised the importance of employment opportunities and skills training to facilitate the development of essential life skills. Other suggestions included ongoing NDIS core support services, access to specialist medical care and speech pathologists, assistance from Centrelink services, and accommodation support.

Nonetheless, participants expressed concerns about potential discrimination and difficulties in accessing available support services due to the need for knowledge on how systems operate and where to obtain accurate information.

4.0 CONCLUSION
AND POLICY RECOMMENDATIONS

Multicultural AIDC and their family member with disability are facing a critical crisis when it comes to contemplating and planning for their future of care. There is a growing sense of despair regarding the prospects for both the carers and their family member with disability. The traditional social support systems within this community are weakening, primarily due to differences between first-generation and second-generation siblings in their contributions to caregiving. While cultural expectations exist, the notion of a large and supportive migrant family does not always translate into adequate care provision, or reality.

Therefore, it is crucial for stakeholders in multicultural services, disability care, and aged care sectors to prioritise the needs of AIDC within Western Sydney. Tailored interventions should be designed to support the care transition planning process. Furthermore, it is imperative to implement deliberate multicultural policy actions that incorporate the diverse voices, aspirations, and expectations of AIDC and their family member with disability into the development of tailored care transition services. We argue that advocacy and carer support organisations play a vital role in strengthening and empowering AIDC as they navigate the care transition process for themselves and their family member with disability. Such interventions must consider the cultural and familial norms associated with migrant communities, as well as the evolving nature of informal care.

5.0 **LIMITATIONS**

This pilot study involved 16 direct participants mainly associated with a single advocacy organisation. Although the findings reported here are unique to this group, it is highly likely that the findings have implications for the wider multicultural community, but we do not claim this.

A follow-up mixed-method study is necessary to encompass a broader sample size and more comprehensive representation of multicultural communities.

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