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## Focus groups with culturally and linguistically diverse carers in NSW

Summary of findings

## ABOUT CARERS NSW

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

[www.carersnsw.org.au](http://www.carersnsw.org.au)

<https://twitter.com/CarersNSW>

<https://www.facebook.com/carersnewsouthwales/>

## ABOUT CARERS

A carer is any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

Across NSW, there are approximately 904,400 carers<sup>i</sup> and to replace the care they provide the NSW Government would have to spend more than \$17 billion each year.<sup>ii</sup> Carers come from all walks of life, cultural backgrounds and age groups. For many, caring is a 24 hour-a-day job with emotional, physical and financial impacts that can also affect their participation in employment, education and community activities.

For information contact:

Carers NSW

Level 10, 213 Miller Street

North Sydney NSW 2060

Telephone: 02 9280 4744

Facsimile: 02 9280 4755

Email: [contact@carersnsw.org.au](mailto:contact@carersnsw.org.au)

Website: [www.carersnsw.org.au](http://www.carersnsw.org.au)

Prepared by the Policy & Research Team

August 2018

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<sup>i</sup> Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers.

<sup>ii</sup> Carers NSW estimate based on Deloitte Access Economics (2015) *The economic value of informal care in Australia in 2015*.

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## 1. INTRODUCTION

The NSW Carers Strategy 2014-2019 outlines a whole of government plan to improve the position of carers in NSW<sup>1</sup>. It outlines five focus areas, including building the evidence base on carers through research to inform the development of future policy and programs. The principles of the Strategy also stipulate the recognition and inclusion of carers from culturally and linguistically diverse (CALD) backgrounds in all projects.<sup>iii</sup>

Carers NSW plays a key role in leading a number of the actions from the Strategy in partnership with other agencies. In support of the Strategy, Carers NSW utilised funding from NSW Department of Family and Community Services, Ageing, Disability and Home Care (ADHC) to conduct this research project with CALD carers from new and emerging and low-literate communities.

### 1.1 Carers NSW Carer Survey

Every two years Carers NSW conducts a statewide survey of carers to provide an evidence base that informs the organisation's direction, support, and systemic advocacy for all carers across NSW. The Carers NSW 2016 Carer Survey found that CALD respondents had below average wellbeing and high/very high levels of psychological distress compared to non-CALD carers.

However, the number of CALD respondents and the diversity of CALD backgrounds represented in the 2016 sample were limited. Only 17% of respondents reported having a CALD background, and the CALD backgrounds identified by respondents were predominantly those of established migrant communities with relatively high levels of English proficiency<sup>2</sup>. This has generally been the case with the Carer Survey, as in order to collect rigorous and comprehensive data, the language needs to be relatively complex and formal, making the survey inaccessible for CALD carers who are not confident with reading and writing English.

Translating the survey into other languages was considered in 2018 in order to rectify this access barrier and attract more CALD respondents. However, on the advice of the 2018 Carer Survey Reference Committee, this translation was not undertaken. Translating survey questions and responses was deemed problematic with regard to resourcing and data validity.

Targeted focus groups conducted alongside the 2018 Carer Survey were therefore considered to be the most efficient and effective way to capture data from carers in new and emerging and low-literate CALD communities.

### 1.2 New and emerging communities and languages

The Federation of Ethnic Communities Councils of Australia (FECCA) is the national peak body representing Australians from CALD backgrounds. It defines a 'new or emerging community' as one that is small in number, newly arrived and has experienced a significant increase in numbers in the last five years.

Compared to more established communities, new and emerging communities also have some, or all, of the following:

- Lack of established family networks, support systems, community structures and resources

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<sup>iii</sup> The term culturally and linguistically diverse is used in Australia to refer to a wide range of cultural groups that differ from the dominant Anglo-Australian culture according to religion and spirituality, racial and ethnic backgrounds, as well as language.

- Increased vulnerability as they are often from a refugee background and have experienced displacement due to civil unrest
- Low levels of education and skill due to displacement
- Low or no English language skills
- Are unfamiliar with government services and are less likely to access services to meet their basic needs<sup>3</sup>.

In addition, Legal Aid NSW report that many people who are from new and emerging communities in NSW have arrived as refugees under Australia's refugee and humanitarian program. In 2015-2016, the top five countries of birth for people arriving in NSW under this program were, Iraq, Syria, Afghanistan, Myanmar, and Iran<sup>4</sup>.

Languages spoken by humanitarian entrants are often referred to as 'new and emerging'. The Commonwealth Multicultural Language Services Guidelines describe a new and emerging language as a language which:

- has only recently (although not exclusively) become a spoken language in Australia
- has become a spoken language in Australia through the recent arrival of migrants (usually refugee/humanitarian entrants)
- is not an Australian Aboriginal or Torres Strait Islander language
- is not widely spoken or commonly known in Australia
- has not yet reached the stage where academic education or instruction, or NAATI accreditation in translating and interpreting, is readily or widely available in Australia<sup>5</sup>.

A 2016 FECCA publication identified the top 12 languages (and dialects) spoken by humanitarian entrants from 2000-2014 as<sup>6</sup>: Arabic, Dari, Farsi, Hazaragi, Assyrian, Persian, Nepali, Burmese, Serbian, Chin, Dinka and Karen.

### 1.3 Low-literate communities

The Australian Bureau of Statistics defines literacy as the ability to understand, evaluate, use and engage with written texts to participate in society, to achieve one's goals, and to develop one's knowledge and potential<sup>7</sup>. Literacy encompasses a range of skills from the decoding of written words and sentences to the comprehension, interpretation and evaluation of complex texts.

This definition has been broadened from the traditional meaning of literacy as the ability to read, write, listen, and speak a language<sup>8</sup>. The National Council of Teachers of English reports that historically, literacy has been a collection of cultural and communicative practices shared among members of particular groups. This definition has now been expanded to include using and understanding computers and technology to communicate and understand information<sup>9</sup>.

Literacy proficiency levels range from below level 1 to level 5. Low-literacy skills are generally estimated to be level 1 and 2<sup>10</sup>. Tasks demonstrated by a level 2 literacy proficiency requires the person to be able to match text and information, paraphrase and make low-level inferences. However, generally Level 2 respondents although they can read, can only deal with simple, clearly laid out material and in real life situations may find tasks such as learning new job skills difficult<sup>11</sup>.

CALD migrants in Australia have been found to have lower levels of literacy proficiency than native born and native language Australians. This is expected, as many migrants have lower literacy proficiency in the official language of the country<sup>12</sup>. By definition, people from new and emerging communities may comprise of individuals with low levels of education and skill due to displacement and individuals who do not have English language skills. FECCA have also reported that one of the barriers to service access have been linked to low literacy levels and that this is common particularly

among women from new and emerging communities for cultural reasons. In addition, the Adult Migrant English Program, which provides tuition for eligible migrants and humanitarian entrants to help them learn foundation English language and settlement skills, has resulted in poor outcomes for learners with low level of formal education or literacy in their own language<sup>3</sup>.

## 2. METHODOLOGY

The aim of this project was to explore the experiences and needs of carers from CALD communities in order to supplement the findings of the Carers NSW 2018 Carer Survey. The expected outcome of this project was to build on the existing evidence base in order to better understand how to support CALD carers across NSW, especially those from new and emerging and low-literate communities.

Drawing from the aims of the Carers NSW 2018 Carer Survey, the following research questions were developed for the project:

1. What are CALD carers' experiences with services?
2. How do CALD carers access information?
3. How is caring recognised within CALD communities?

### 2.1 Research design

This project employed a qualitative research design using semi-structured focus groups to explore the circumstances, experiences and needs of carers from various CALD backgrounds. Semi-structured focus groups were selected on the advice of academics and experts in the CALD sector as they promote an unrestricted form of discussion and have been found to be particularly helpful in identifying relevant issues within CALD communities<sup>13</sup>.

Six focus groups were conducted during May and June 2018 in the Greater Sydney and Wollongong areas. Research design, promotion and analysis were conducted with ongoing input from the Carers NSW Executive and Research teams, the Carers NSW Research and Evaluation Committee, the Carers NSW 2018 Carer Survey Reference Committee and a dedicated Project Advisory Group comprising researchers and CALD sector representatives.

### 2.2 Project Advisory Group

The Project Advisory Group (PAG) was established in order to provide expert advice to the CALD Project Officer regarding research design and CALD engagement. A number of academics with experience working with multicultural communities and CALD sector representatives known to Carers NSW were invited to participate in three meetings throughout the life of the project.

Three participants external to Carers NSW were successfully recruited to join the PAG:

- Selen Akinci, Senior Project Officer, Partners in Culturally Appropriate Care (PICAC), Multicultural Communities Council of Illawarra
- Dave Robinson, NSW Multicultural Access Project Officer, Ethnic Communities Council of NSW (ECC)
- Abner Weng Cheong Poon, Lecturer, School of Social Sciences, University of NSW

Carers NSW staff who participated in the PAG meetings included the Manager, Policy and Research, the Research and Development Officer and a Policy and Development Officer. They provided input from their experience conducting focus groups and working with CALD communities.

The roles and functions of PAG members agreed in the Terms of Reference were:

- To advise on the project plan
- To design focus group questions and format
- To develop, build and maintain engagement with CALD carers, both known and unknown to Carers NSW
- To recruit participants for focus groups with CALD carers

- To facilitate and/or coordinate focus groups with CALD carers
- To provide feedback regarding focus groups
- To provide feedback on findings and reports from focus groups

PAG members teleconferenced once a month for the duration of the project. Meetings were scheduled for an hour and occurred at key times during the research project process – during the research design phase, before the first focus group was conducted, and early on in the data analysis phase.

Overall the PAG provided valuable insight and suggestions regarding the design and delivery of the focus groups and the analysis of the data. They also connected the CALD Project Officer with a range of community organisations who were able to assist with promotion and recruitment.

### 2.3 Participant recruitment

A key principle of CALD engagement is the long term building of trust and rapport with CALD communities<sup>14</sup>. Due to the relatively short term nature of this project, the Carer Survey Reference Committee and PAG advised that recruiting participants in partnership with facilitators of existing groups and networks within the CALD community would be the most effective strategy.

Targeted recruitment was therefore conducted with CALD specific carer support groups that were already familiar with Carers NSW through their participation in the *together* program<sup>iv</sup>, and CALD focused organisations hosting existing language specific carer groups and networks. A promotional flyer (see Appendix A) was developed and distributed to interested parties with further information.

Taking into consideration advice from Carers NSW staff and PAG members regarding the high attrition rates associated with both CALD and carer events, the CALD Project Officer explored as many opportunities and contacts as possible in order to ensure that six focus groups would take place within the allocated timeframe.

Over 20 contacts were engaged not including Carers NSW staff. The groups selected were based on availability, including regular time, location and duration of group; availability and commitment of the facilitator; number of participants; groups recognised as a new and emerging community or language; and groups defined as low literate in native or English language by facilitator. There was also the aim to cover as diverse a range of CALD groups and caring roles as possible.

On the advice of the PAG, a \$30 Coles Myer gift voucher was offered as an incentive to all focus group participants. Translated Easy Read<sup>v</sup> Carers NSW factsheets and membership forms were provided to all participants as well as translated resources on *My Aged Care*, the *National Disability Insurance Scheme* (NDIS) and Centrelink payments. A catered lunch was also made available to each group.

### 2.4 Translated materials

The Easy Read Carers NSW factsheet and membership form, along with a Participant Information Sheet and consent form (see Appendix B), were translated into 18 languages. These languages reflected the range of communities and networks with which the CALD Project Officer was attempting to establish focus groups. The 18 languages were: Arabic, Assyrian, Bengali, Burmese, Chin,

<sup>iv</sup> The *together* program resourced a network of carer support groups by linking them with local organisations across NSW. It was managed by Carers NSW and funded by the NSW Department of Family and Community Services, Ageing, Disability and Home Care (ADHC).

<sup>v</sup> Easy Read (also known as Easy English) is a style of writing developed to provide concepts and key messages in a way that is concise and understandable for people with very low literacy.

Chinese (Simplified), Chinese (Traditional), Dinka, Farsi, Karen, Khmer, Korean, Nepali, Serbian, Tamil, Tibetan, Turkish, Vietnamese.

These languages included a number of the main languages spoken in the top five countries of birth for people arriving in NSW under the humanitarian program in 2015-2016<sup>4</sup>, the top 12 languages spoken by humanitarian entrants from 2000-2014<sup>6</sup> and the top 10 languages other than English spoken in NSW<sup>15</sup>. Translations were conducted by NSW Multicultural Health Communication Service and EthnoLink Language Services.

## 2.5 Procedure

A total of 83 participants were engaged across six focus groups. Each focus group was scheduled to run for 2 hours with half an hour pre- and post- focus group to debrief with the facilitator and interpreter as required. Prior to the focus group, participants were given a brief overview of the purpose of the focus group by their regular bilingual group facilitator or staff members from a known organisation. All logistics were discussed and planned in consultation with the facilitators ahead of the event including the need for professional interpreters, accessible venues and catering requirements.

Professional interpreters were booked for four of the focus groups. One focus group requested a professional interpreter, however due to the timeframe and location, a suitable interpreter was not available. The facilitator offered to provide interpreting support and a bilingual Carers NSW staff member was able to conduct part of the focus group in the community language. One focus group did not request an interpreter and reported the facilitator would be best placed to interpret. All professional interpreters were certified and booked through the Translating and Interpreting Service (TIS) online system.

Before commencing the focus group, participants were provided with the Participant Information Sheet and consent form. These documents were translated and provided in the community language for all but one focus group, as the translations were not completed in time for the focus group. For this focus group, the interpreter explained the Participant Information Sheet and read out the consent form in the community language. Due to varying literacy skills, Carers NSW staff provided a simple explanation of the focus group and request for consent which was interpreted. Participants were then required to sign the consent form or provide verbal consent with a witness.

Five of the six focus groups were audio recorded by the CALD Project Officer, following the completion of consent forms. Consent for audio recording was not given by one participant in one of the focus groups, so detailed notes were taken instead. The CALD Project Officer and an additional Carers NSW staff member attended all focus groups in order to record key demographic information and write notes to support the data analysis.

To allow for free discussion and leave time for interpreting, only three formal questions were posed to each group, reflecting the three research questions for the project. A range of further prompts were prepared for use as needed in order to maximise discussion (see Appendix C). Demographic data was collected during an icebreaker activity at the beginning of each focus group whereby Carers NSW staff disclosed their birthplace, time since migration, languages spoken, education levels and caring situation. Participants were then encouraged but not obliged to do the same. Demographic information was recorded on the reporting template (see Appendix D).

Following each focus group, Carers NSW staff engaged the group facilitator to elicit their feedback on how the focus group was conducted. Facilitators were generally from the same CALD background as the participants and were able to provide both interpreting assistance and further insight into specific CALD related carer issues. Feedback was collected directly after the focus group or via email after the focus group (see Appendix E for feedback form).

Audio recordings were professionally transcribed by an external agency. Only the English was transcribed. Part of the focus group which was conducted in the community language by the Carers NSW staff member was later transcribed by that staff member. Audio recordings, transcriptions, field notes and facilitator feedback were stored on a secured network and only accessed by the Carers NSW Policy and Research Team.

## **2.6 Data analysis**

Transcriptions and field notes were read through several times with an initial code framework developed around the three topics that structured each focus group. The coding process involved extracting and interpreting meaning from blocks of transcribed text. Each focus group was analysed separately. Emerging similarities and differences between the focus groups were noted. Feedback from facilitators was also noted and used to supplement findings.

The preliminary findings from this analysis are detailed in this report. Further analysis will be conducted using the NVivo qualitative data analysis software in conjunction with the analysis of data from the 2018 Carer Survey.

### 3. FINDINGS

This section provides an overview of the characteristics of focus group participants and the overarching themes which emerged. These themes are reported under the three main headings that reflect the research questions: services, information and recognition. Background information on how each focus group was established is also included.

The findings are reported separately for each of the six CALD focus groups conducted. This was recommended by PAG members as there is limited research comparing CALD communities, with many recommendations on generic CALD issues. It was also noted that specific analysis of each group was greater aligned with person centred approaches.

#### 3.1 Overview

In total, six focus groups were conducted with a total of 83 participants (see Figure 1). Five of these focus groups were conducted with established carer support groups. One of the focus groups was conducted with participants who were recruited by a supporting organisation. The participants in this group did not know each other but were familiar with the organisation and staff members present.

Participants predominately spoke Arabic, Mandarin, Farsi, Burmese, Karen, Karenni, and Serbian. Some participants reported speaking a range of other languages and dialects including Cantonese, Dari, Hazaragi and Kurdish. A number of participants spoke English as a second language and took the opportunity to speak to Carers NSW staff in English during the focus group.

Eight of the top 12 languages spoken by humanitarian entrants from 2000-2014 (with Persian being interchangeable with Farsi) were represented as were the top five countries of birth for people arriving in NSW in 2015-2016 under the humanitarian program (i.e. Iraq, Syria, Afghanistan, Myanmar/Burma and Iran)<sup>4</sup>.

Figure 1: Focus group characteristics

Group	Languages / dialects spoken	Location	Number of participants	Cultural backgrounds/ Countries of birth	Age range of participants	Gender	Established group
<b>Arabic</b>	Arabic	Wollongong	7	Lebanese Syrian	65 years +	Women	Yes
<b>Mandarin</b>	Mandarin Cantonese	Northern Beaches	19	Chinese	65 years +	Mixed	Yes
<b>Farsi</b>	Farsi	North Sydney	13	Iranian	Both over and under 65 years	Women	Yes
<b>Burmese</b>	Burmese Karen Karenni	Wollongong	22	Burmese	Under 65 years*	Mixed	Yes
<b>Farsi</b>	Farsi Dari Hazaragi	Western Sydney	3	Afghan Iraqi Iranian	Under 65 years	Women	No
<b>Serbian</b>	Serbian	Northern Beaches	19	Serbian Croatian Bosnian	65 years +	Mixed	Yes
<b>Total</b>			83				

\*The 7 identified carers were under 65 but the group included participants over 65

## 3.2 Arabic focus group

This was an existing Illawarra-Shoalhaven Carers Support Program carer support group. Contact was established by PAG member currently working with the carer group coordinators. The facilitator was bilingual and able to offer interpreting support. The focus group was arranged to take place during a regular group meeting time in order to maximise attendance.

### 3.2.1 Demographics

This focus group consisted of seven females, the majority of whom were over the age of 65. All were born in either Lebanon or Syria and spoke Arabic, with two participants speaking English as a second language. Participants' migration histories were varied; some had arrived in Australia in the 1960s and 1970s and others in the 1990s and 2000s. All women identified as Sunni Muslims, and all either were, or had been married, and had children.

### 3.2.2 Caring situation

Three of the seven participants identified as carers during the focus group. Two participants reported they were currently caring for ageing husbands with health conditions. One participant reported she was a previous carer for her ageing husband who has now passed away. The other four participants reported they are currently being cared for themselves due to injuries, poor health or ageing. One reported receiving care from her husband, while the other three were being cared for by their children.

### 3.2.3 Themes

#### Services

##### *Unfamiliarity with formal services*

Many of the participants reported they were unfamiliar with formal service systems. Some were currently accessing or had previously accessed government subsidised domestic assistance, in particular cleaning services. However, many reported that the availability of these services was limited and that their quality and quantity had reduced in recent years. Participants suggested that services were stretched and that they were happy for those in more immediate need of formal supports to access services ahead of them.

##### *Need for respite services*

Participants identified that they needed help with cleaning, transport and taking a break from caring. None had accessed respite services. One participant expressed the importance of transport and respite:

*“Transport is very important to me too, because as I said, I feel like I’m isolated. I don’t visit anyone and no one comes to me...I need respite.”*

##### *Cultural barriers to accessing formal services*

Participants noted on multiple occasions that personal care services were not needed as they were happy to complete personal care tasks for the people they were caring for, who were also likely to refuse personal care from an external service. The reasons for this appeared to be cultural and religious. For example, it would be inappropriate for a male to receive personal care from a female who wasn't a wife or a close family member. Men may also feel shame accepting support from other males. As a result, several participants reported poor health and wellbeing from providing high levels of physical care.

## Information

### *Modes of receiving information*

Participants reported their carer support group is their main source of information. Information is provided by both the facilitator and other members of the group. Participants particularly noted the value in being provided information to help them maintain their health and wellbeing. The women did not tend to be proficient in sourcing information online. As one noted:

*“I ask Google on my phone but if I don’t speak his dialect he doesn’t answer!”*

### *Repetition of information*

The facilitator noted that members of the group were often provided with information they did not act on. One positive outcome of the focus group was that one carer took the first step to accessing services. She had not received any previous support and did not speak any English. The focus group prompted this carer to invite her daughter to attend and obtain information on *My Aged Care*.

## Recognition

### *Family recognition*

Participants reported that were recognised as carers by their children. This recognition was shown through the physical, social and emotional support they provided. Daughters were identified as providing the most support to their mothers who are carers. While participants expressed not wanting to burden their children, many of them felt they had few other options.

### *Community recognition*

Participants said they were not generally recognised by the rest of the Arabic community and could not rely on the broader community for support. Friends were described as understanding, but not able to fully comprehend the caring role.

## 3.3 Mandarin focus group

This was an existing *together* carer support group run by Northern Beaches Community Connect. Contact was established by Carers NSW staff previously involved in the *together* program. The facilitator was bilingual and was able to provide interpreting support to the large group. The focus group was arranged to take place during a regular group meeting time in order to maximise attendance. A professional interpreter also attended this focus group.

### 3.3.1 Demographics

This focus group consisted of 19 participants, the majority of whom were over the age of 65. There were more females than males. All participants spoke Mandarin except for one Cantonese speaker. Many of the participants had migrated from China between the 1990s and 2000s, with the most recent having arrived in 2016. Birthplace and religion were not discussed.

### 3.3.2 Caring situation

Of the 14 participants who shared information, the majority reported having migrated for the sole purpose of caring for grandchildren while their children and their partners maintained full time employment. While grandparents who provide child minding support for their children are not considered to be carers, focus group participants readily identified themselves as carers if they provided child minding support for children without disability. Four participants identified themselves

as current or former carers of ageing partners with various chronic health conditions and serious illnesses. These four are identified in subsequent sections as 'carer participants'.

### 3.3.3 Themes

#### Services

##### *Limited awareness of available supports*

Carer participants had a basic awareness of some of the supports available to carers and had previously engaged with them, including Centrelink payments, assistive equipment in the home, home modifications and continence pads. These services were received following a hospital stay by the person they cared for, however carer participants were unable to identify the source of this support.

##### *Financial cost and affordability of services*

Many of the carer participants and other participants indicated that they, or the person they cared for, would like to access home care services, however none had taken steps toward this as they were concerned about the potential cost of accessing support. A hotline in China that can be used to access one-on-one services in the home in place of their children was mentioned, but none seemed to have accessed the equivalent service in Australia.

Participants also expressed that the cost of retirement housing, medicines, dental and health care were of concern, with newer migrants citing the waiting period before being able to access a pension as resulting in additional health care costs:

*"[We are in a] situation where we are not able to access some of the [services] and because the only source of income is from our [kids] and we just don't want to give them too much burden and we've been trying to be very independent and do as much as we can."*

##### *Language barrier to accessing services*

Most participants relied on their adult children to act as interpreters or speak on their behalf in order to communicate with services, but they were also conscious that their children were time poor and therefore avoided asking for help:

*"Of course we would love that our kids could come [and help us], but we really care about them, we know that [our children] are busy and have a very challenging life themselves."*

##### *Desire to access services to remain independent*

Remaining independent was a common goal amongst participants. This included living independently, as demonstrated in the quote below from one of the participants:

*"We choose not to give [our children] too much burden so we decided to live separately, which can be very good for us and because we enjoy freedom and also not too much burden."*

##### *Lack of culturally specific services*

Another key issue raised was the lack of culturally specific and culturally sensitive services in the Northern Beaches region. For example, one participant noted that residential care facilities did not accommodate for food and lifestyle differences, making them unappealing, even though participants stressed the appeal of living independently from their children so as not to be a burden.

## Information

### *Children as the key source of information*

Participants reported they either cannot or do not use a computer to access information or apply for services online. Instead they rely on their children to source information on their behalf. Language was the most significant barrier to accessing information, even when interpreting services were engaged. Use of GPs also appeared to be mediated by support from participants' children rather than trained interpreters:

*"Usually our children represent us, even with an interpreter."*

Participants attended their carer support group on a regular basis, and while they did not indicate that the group was a key source of information, the group facilitator reported that regular information sessions took place.

## Recognition

### *Self-recognition and broader definition of carer*

The focus group consisted predominantly of grandparents who provided child minding support to their children and many identified themselves as current and former carers for this reason, even after the definition of a carer was clarified by Carers NSW staff.

### *Recommended increased recognition from the government*

Those who had come to Australia to care for their grandchildren and now needed care themselves recognised that caring for grandchildren is easier than looking after people who are ageing. They reported that greater recognition from the government would be beneficial:

*"We have cared for families and now need care ourselves, there should be some recognition from the government that we have provided care in the past."*

### *No expectation of support from children for ageing parents*

Many of the grandparents who no longer acted as childminders expressed that there was not an expectation that this care would be reciprocated by their children as they aged, even though care by their family members was their preference. Participants acknowledged that they or their partner will need care or will care for each other sometime in the future. This is demonstrated in the quote below from one female participant:

*"...my partner has dementia, so – and I'm really grateful for the government and relevant departments, they've done a few home visits and provided some help for us...my partner sometimes gets a bit confused and would throw some temper tantrums and so it can be quite challenging to deal with, even now he is able to eat his meals and goes to toilets by himself and I will be there to look after him for a bit, but he is 84 years old and also I was born in 1941 so I'm just wondering, because as we're getting older, I don't know what to do about it and just wondering whether there will be any precautions to take for the situation for the future."*

## 3.4 Farsi focus group (Iranian)

This was an existing *together* carer support group run by a Transcultural Mental Health Centre facilitator. Contact was established by Carers NSW staff previously involved in the *together* program. The group facilitator spoke Farsi (Persian) and was able to provide interpreting support. The facilitator recruited suitable participants from the established group to take part in a focus group on a separate

day and time to regular carer support group meetings. Regular meeting had larger numbers and an established agenda. A professional interpreter also attended this focus group.

### 3.4.1 Demographics

This focus group consisted of 13 participants, all female, with an age range from approximately 40 to over 65. All the participants were born in Iran and spoke Farsi. Many migrated to Australia due to war in their birth country but years since arriving in Australia ranged from as long as 32 years to as recent as 7 months. Although many participants did not discuss their own level of education, many reported that their husbands and children have received a higher education. One mentioned running her own business and another stated that she gave up her career in Iran and moved to Australia to care for her parents.

### 3.4.2 Caring Situation

All participants identified as being current or former carers. There were a wide range of caring situations in this focus group. Many participants were caring for adult children and/or husbands living with mental illness. Other caring situations included caring for chronically ill or ageing husbands or parents, and caring for adult children with disability. Many of the participants were living with depression along with other health concerns including cancer.

### 3.4.3 Themes

#### **Services**

##### *Location of services*

Participants in this focus group immediately recognised the carer support group as an important service, consistently stating their appreciation for the carer support group and the facilitator. Many participants came from all around Sydney to access the group. Participants noted that they were aware of more activities and services in Western Sydney. Many found it difficult to get to Western Sydney and reported services should be consistent statewide to allow access to all:

*“Considering we are carers, we cannot leave the person we care for, for long periods of time, usually only 2 hours. Therefore we cannot travel a long distance.”*

##### *Language and cultural barriers to accessing services*

The most recent migrant from Iran reported, in Australia the individual needs to approach the services rather than having services approach the individual needing support. She continued that many people face difficulties doing this considering the language barrier. This comment from one of the participants illustrated both the language and cultural barriers to accessing services:

*“Because of the language barrier, I haven’t been able to express my feelings to the health care provider, although interpreters have been available. But I couldn’t actually get my message across. Also, because of the cultural differences, it hasn’t been easy to connect with them. Really, it’s been hard. I have had very difficult days.”*

##### *Poor carer health and wellbeing*

However, the most pertinent point was that participants in this focus group reported particularly high levels of health problems and concerns. Financial burden was identified as a barrier to accessing a range of services to improve their health and wellbeing including high-priced dental care, unsubsidised health supplements, unaffordable fitness classes such as yoga and swimming and

respite activities such as holidays and group outings. Only one carer noted to have previously used government subsidised support services in the home following the hospitalisation of her father. No other carer reported using home care services although they expressed a need.

#### *Financial cost and affordability of services*

Participants stated that they were restricted by their Centrelink income, with some noting they were not receiving enough money to cover rent or electricity. One participant queried if interest free loans were available to assist with alleviating the financial burden. Another participant requested an increase in the amount of payment received from Centrelink, including rent assistance and pension:

*“Prices go up but our payments stay the same.”*

*“It’s really hard to make ends meet with the Centrelink income.”*

Travelling overseas to countries of birth or for a break was noted to be important but financially very difficult. One carer stated that the Carer Payment should continue for longer than 6 weeks when a carer goes overseas. She explained that she had no time away from her husband in the last 3 years and a break was needed to save the relationship. Trips overseas were short and unenjoyable as the Carer Payment would be stopped, while rent and other living expenses were ongoing.

#### *Need for respite services*

The need for respite was continually emphasised by participants. Many stated they needed a break from the challenging environment they are normally in. They noted that their carer support group was previously funded for regular outings, whereby now they are only able to afford an occasional lunch at a local restaurant.

This highlighted that participants in this focus group were aware of what services they needed to help them continue with their caring role, however, they did not have the finances to pay for these services:

*“We need to take a break but financially restricted. Need to approve more budget for a routine trip. We are still sharing memories from a previous trip we shared together. We need to revive, in order to continue looking after our family.”*

## **Information**

#### *Sources of information*

Participants identified the carer support group as an important source of information. One participant reported that there should be more information available and other service providers should be sharing more information with participants:

*“For example, only two weeks ago I noticed that we can use My Aged Care. If we didn’t have access to this group and this session, I wouldn’t have known about this.”*

#### *Lack of translated information*

Again the language barrier was noted as a barrier to accessing information. Participants were frustrated with the lack of translated information available on the internet and from services. Some participants reported they would use the internet more frequently to access information if the information was in Persian. Others noted that their computer knowledge was limited. However, many of the participants had access to smart phones and the facilitator of the group reported to use

Telegram, an instant messaging service, to provide the carer support group members with information in Persian.

## Recognition

### *Feelings of isolation*

Due to time limitations this focus group was not explicitly asked if they feel recognised for their caring role. Regardless, during discussions many expressed the general sentiment of isolation and unrecognition. One participant stated:

*“In Iran, we really had a beautiful lifestyle. We had to leave everything behind because of lack of freedom back there. We don’t really want people to put down us here. We don’t have any relatives here. In order to obtain this freedom, we had to pay a big price.”*

### *Lack of recognition by the broader community*

Another participant recalled previous events that made her feel unsupported by the broader community. Her family was separated as her husband was unhappy in Australia and decided to return to Iran on his own. This caused feelings of loneliness and the onset of depression. She had been running a child care business but the impact of her mental health resulted in people ceasing to use her service and subsequently closing down her business. Another participant stated she became a carer for an elderly lady to reduce isolation and feelings of loneliness.

### *Cultural differences in caring role*

Participants stated that caring was such a fundamental part of their culture, and the extent to which they support their family members is quite different to the mainstream in Australia:

*“Culturally...even when we have grown up children we still feel responsible for taking care of them.”*

*“I mean the cultural difference was because this is - like according to my culture, I was visiting my daughter every day - even twice a day - in the hospital. They couldn’t understand me - why are you coming? This is not acceptable.”*

The participants of this focus group also stated that they did not want to burden their children as they themselves needed care secondary to their poor health and welling being. One participant stated she had sought independent accommodation and was living on her own.

## 3.5 Burmese focus group

This was an existing Illawarra-Shoalhaven Carers Support Program carer support group. Contact was established by PAG member currently working with the carer group coordinators. The facilitator was multilingual and provided interpreting support along with another participant who had English as a second language. The focus group was conducted on a regular group meeting time and additional participants from the Burmese community were invited by the facilitator.

### 3.5.1 Demographics

This focus group consisted of 22 participants however only seven were identified as carers by the facilitator. Focus group questions were generally targeted at the identified carer participants. Although there were male participants, all carer participants in the focus group were female and under the age of 65. Carer participants were born in Myanmar (Burma) and some were reported to be born in Thai

refugee camps. All carer participants were relatively new to Australia with a range from 9 years to 3 months since arrival. All participants understood various languages including Burmese, Karen and Karenni, with some being able to read Burmese or Karen. The facilitator was fluent in all three languages and was able to support the understanding of all focus group participants. Individual levels of education were not discussed however, the facilitator noted that many have not studied or received a formal education.

### 3.5.2 Caring Situation

Caring situations for the identified carer participants in the focus group varied. Most were caring for ageing parents and grandparents or ageing husbands. One carer participant was caring for a brother-in-law with disability, and another was caring for two children with disability.

### 3.5.3 Themes

#### Services

##### *Challenges accessing mainstream services*

Carer participants were able to identify a number of caring tasks which they regularly perform as part of their caring duties including cleaning, assisting with showering and taking the person they care for to appointments. Many of the challenges faced were with accessing mainstream services like transport, health care and housing. As well as accessing the Carer Payment and the NDIS.

When asked what services they needed, carers stated they didn't need domestic assistance,

*"They love to clean a house but for the cleaner doesn't matter..."*

##### *Concerns with supporting people they care for to access suitable health care*

What they did need was help with accessing doctors and administering medication correctly. This was noted as one of the biggest challenges, secondary to language barriers, and partly, financial difficulties. It was explained by participants that there is an assumption that all Burmese people speak Burmese. Therefore, people are sent to Burmese doctors who do not speak the same language. They are then also required to go to pharmacies to purchase medication for the person they are caring for, while not understanding how to take the medication, at what time and for what purpose. Medication was also noted to be quite expensive and few carers were able to indicate if they had access to Health Care Cards. Carers are unsure if they are providing the correct care due to the language barrier with the doctor.

*"They don't know what to tell the doctor."*

*"Difficult to understand information from the medicine world."*

Many reported to take their children with them to the doctor to assist with communication, making it a large family event to assist with getting the message across,

*"...they bring their children [to the doctor] and the children understand Burmese language a little bit, and carer and [their] children and with grandfather, grandmother going together [to the doctor]."*

They also noted that people from the community will help each other at doctors' appointments if they meet at the clinic.

### *Difficulty communicating with Centrelink*

Another major access issue raised related to income support. Some carers reported having access to Centrelink payments, while others did not have access or had not had applications approved. Another recurring problem was a lack of understanding around why applications for payments are not approved. When attending Centrelink, carers have been offered Burmese interpreters and at times Karen interpreters over the phone. This remains a challenge as many speak Karenni and/or find it difficult to communicate complex information over the phone.

*“We try to apply at the Centrelink, Carer Allowance but we don’t have. What happened we don’t understand. This is a very big problem.”*

The facilitator noted that Centrelink had come to talk to the group but could not access a Karen or Karenni interpreter. The facilitator herself, could not understand or explain to carers why their applications for income support were rejected, suggesting that the process itself was complicated.

### *Accessing the NDIS*

One of the carers had experience accessing the NDIS for one of her children with disability. She stated one of her two children had access to the NDIS but she was unable to understand the NDIS plan or the supports included in the plan. She was reliant on her doctor for information but the doctor does not speak the same language. Her second child also has a disability but she has not applied for NDIS for that child. She noted that she relies a lot on the multilingual facilitator to bridge the gap of understanding between herself and the doctor. However, this support is limited as the facilitator is not always available to provide support.

### *Accessing transport*

Participants also discussed restrictions in movement due to difficulties with using public transport to travel independently. They required support to top up Opal cards and do not understand travel signs and timetables. Therefore, many participants relied on others who could read English or provide free transport in order to get around.

### *Access to appropriate housing*

A few carer participants noted that their housing was inappropriate for ageing people, placing more strain on carers as ageing parents needed more physical assistance in apartments with stairs. There was a need for assistive equipment and aids, such as walking frames and hand rails but many did not know where to access these services.

### *Need for bilingual supports*

One of the participants who had volunteered to assist with translating noted that there were fewer services and supports available to the 300 or so large Burmese community in Wollongong. He noted that he was aware that there were specific support services for Burmese refugees, and in particular the Karen people, in Sydney. There appeared to be a significant reliance on the facilitator to assist many of the Burmese community members, suggesting a need for more trusted people in the community who speak all the languages and can advocate for carers.

## **Information**

### *Multilingual facilitator as key source of information*

Participants in this focus group expressed both a significant need for information and a significant lack of access to information. The facilitator was recognised as the central source of information for the community and the carers within that community. The facilitator herself was a carer for an ageing parent, but was not included as a participant in this focus group. The key reason the facilitator was identified as the key source of information was due to her ability to speak all three languages – Burmese, Karen and Karenni, along with having English as a second language.

The facilitator reported that she is faced with a number of challenges being the central source of information. She stated she does not always have the answers and tries to send people to the right place to access information. She identified Illawarra Multicultural Services (IMS) or Strategic Community Assistance for Refugee Families (SCARF) as two appropriate sources.

The facilitator is also not a qualified interpreter. Therefore, when supporting carers, families or others in the community she is not always provided with the necessary information as she is not a direct relative. This is particularly true during high stress situations, such as communicating with health care providers. The responsibility to interpret information for carers in those situations often then falls on their young children.

### *Barriers to understanding information*

It is often assumed that people from the Burmese community will speak Burmese, however many do not and in particular those born in refugee camps outside of Myanmar (Burma). Reading and writing proficiency is also varied among the Burmese. Some can read Burmese and some can read Karen but many can't understand all the words. A lack of formal education also means they have trouble understanding 'government speak' even when translated or interpreted in the appropriate language.

Participants noted that they cannot read letters sent to them from any department and that they need someone who speaks all the languages to support them to understand the information and to ask for information. At this point in time they have had no access to formal interpreters in Karen or Karenni and rely on people like the facilitator who has some English skills and can communicate with them in Burmese, Karen and Karenni. Therefore, translated written information is not particularly useful.

*“There is no Karen support speaker or interpreter, no Karenni support speaker or interpreter. It means a lot.”*

## **Recognition**

### *Community recognition*

The carer participants in this focus group identified as carers and were recognised by the rest of the participants as carers. It was often mentioned that the Burmese community members in Wollongong strongly supported each other,

*“...we family, look after each other...”*

It was noted that no one outside of the community provided ongoing support to carers and that there was limited support from organisations. This may have been a result of many carers in the focus group not receiving income support and experiencing significant challenges with accessing Centrelink information and services.

### *Caring responsibilities within the community*

Although the community supported each other well, the primary caring responsibility often fell on the eldest daughter in a family, in particular for those caring for ageing parents. It was explained by one of the participants that traditionally the males or the sons in the family are responsible for doing the 'heavy' jobs. Now that these families have moved to Australia the traditional role of the son is less relevant. One carer highlighted the absence of the son from the family caring role, stating,

*"...the son is always gone."*

The prominence of daughters taking on the role of primary carer was also highlighted by the parents who, regardless of whether they had their own accommodation, would often come and sleep at their daughter's house. It was reported to be common for extended family to live together.

### **3.6 Farsi focus group (Afghan, Iraqi and Iranian)**

Participants in this focus group were recruited by Multicultural Disability Advocacy Association (MDAA) of NSW. Contact was established by Carers NSW staff who previously worked with a staff member at MDAA. The participants did not know each other but were familiar with MDAA staff members present. Two MDAA staff members were present, one of whom spoke Farsi and Dari. A professional Dari interpreter was used for this focus group. The interpreter was a male and also able to interpret in Farsi and Hazaragi. One participant did not give consent to audio recording. Field notes were taken by the two Carer NSW staff present.

#### **3.6.1 Demographics**

This focus group consisted of three female participants from Afghanistan, Iraq and Iran. The common language spoken by all was Farsi/Dari. One participant spoke English as a second language and communicated with Carers NSW staff in English on most occasion. All participants were carers aged under 65 years of age. Their time since migration varied from over 30 year to 3 years since arrival in Australia. Education levels were not discussed although two of the participants noted that they were not able to read very well.

#### **3.6.2 Caring Situation**

The three participants in this focus group were caring for children, either young, teenage or adult children with disability. The range of disabilities were both intellectual and acquired. All three participants were also caring for children living with mental illness.

#### **3.6.3 Themes**

##### **Services**

##### *Accessing the NDIS*

The NDIS was particularly relevant to participants in this focus group. All participants were aware of the NDIS, two were currently accessing NDIS packages for their children, and one was being supported to apply on behalf of her daughter.

One participant had two adult sons living with Autism and noted that the NDIS had improved services but it had taken a long time to access and feels that she constantly needs to keep pushing for services. She added that the effort was not proportional to the gains. The other participant who had NDIS supports for her young son living with Autism and Down syndrome, explained that services were insufficient. Her son had speech pathology and physiotherapy services in the plan. She had attempted to access more supports and to use the NDIS plan more flexibly including using funding to

purchase nappies and pay for specialists. However, she was unable to do so as many of these expenses are not included in the NDIS. She noted that the plan was not very flexible and did not cover higher priorities such as unaffordable medical costs and equipment.

#### *Barriers to accessing services*

This participant was aware of various services available, listing respite, domestic assistance, financial support and childcare as various services. However, she also noted difficulties in accessing these services based on her citizenship status but also a lack of CALD support and racism. This carer was a New Zealand citizen and reported this left her under enormous financial stress as she is unable to access any income support payments while caring for her son full time. One participant was unfamiliar with the range of services available.

Financial difficulties were experienced by all, with one carer stating that transport costs were unaffordable. She explained it was very difficult to push her son's wheelchair and she had requested the NDIS plan include taxis for appointments. She noted that she does not have money for food, let alone transport, and only receives limited financial support from one of her adult sons.

Another participant reported that she and her husband were full time carers receiving Carer Payment to look after two adult children with disability. Her biggest concern was the future of her children when she and her husband were no longer able to take care of them. She asked about loans to purchase another house as she did not want her children to live in a group home but rather to be cared for in their own home.

#### *Lack of culturally sensitive services*

One participant was particularly distressed during this focus group and reiterated that she has not received meaningful support over the last 9 years since her daughter had an accident at 3 years of age. She did not discuss in detail the events of the accident. She did however indicate that her daughter had access to a number of psychologists and counsellors without any improvements. This carer expressed great frustrations with services stating that she is often required to tell her story in detail without any results and no improvements to her daughter's situation. She also noted that the values of the counsellors were different and they did not seem to understand the additional cultural pressures. This carer was currently being supported by an MDAA advocate to access services, including the NDIS, Centrelink payments and continence aids.

#### *Poor carer health and wellbeing*

All the participants in this focus group had a high level of stress and anxiety along with significant physical ailments secondary to their caring role. Conditions included back pain, sleep deprivation and digestion problems. One carer reported she was taking medication for depression. They all identified respite as a need, but had little or no access to any respite services.

### **Information**

#### *Access to information*

All participants indicated that they had difficulty accessing information to varying degrees. One participant reported, although she had been in Australia for over ten years she did not have an understanding of government policies in Australia. She felt unsupported and reported that until she was referred to the advocacy service only recently, she did not know where to go for information and often relied on her doctor for information.

### *Barriers to information*

A number of barriers to accessing information were noted. Besides the language barrier for some, stigma associated with both disability and culture were two of the greatest contributors. One participant noted she had experienced many occasions of difficulty accessing information from services due to stigma associated with disability and her cultural background.

## **Recognition**

### *Self recognition*

Participants in this focus group recognised themselves as carers for their children with disability. However, they did not recognise themselves as carers for their adult children living with mental illness. Two of the participants described caring situations for other children in their family who did not have a physical or intellectual disability. One participant did not initially identify as a carer for her son with a vision impairment and living with mental illness, but later shared that she had been in a caring role since the age of 12, looking after an ageing father in law, a husband with cancer and her children.

### *Lack of recognition in the broader community*

One participant stated that she feels unrecognised by the community, both within her culture and in the broader community. In the broader community, she expressed that she has had experiences with racism, people calling her lazy for not working and also comments from service providers and government departments that she should move back to New Zealand in order to access services. She stated that her son's wheelchair is not always recognised as a wheelchair when they are out in the community. On one occasion a bus driver refused to use the access ramp, calling it a pram and insisting she be able to get on the bus without a ramp.

### *Lack of recognition in own community*

Participants shared that they felt unrecognised and unsupported by their communities. One participant reported that people talk about her unfavourably and she is left to take on the caring role without support from her community. Another participant also noted she feels particularly ostracised by her community and she is often torn between the needs of her daughter and the expectations of her community. She reported that she allows her daughter to wear whatever makes her happy but this leads to judgements being passed about her parenting. She stated that the things they say about her and her daughter causes more stress. Her community is not supportive and she feels unappreciated for the caring role she provides.

## **3.7 Serbian focus group**

This was an existing *together* carer support group run by Northern Beaches Community Connect. Contact was established by Carers NSW staff previously involved in the *together* program. The facilitator was bilingual and was able to provide interpreting support to the large group. The focus group was arranged to take place during a regular group meeting time in order to maximise attendance. The facilitator also invited both male and female carer support group members, although the groups, on occasion, met separately. A professional interpreter also attended this focus group.

### **3.7.1 Demographics**

This focus group consisted of 19 participants, six male and 13 female, all estimated to be over the age of 65. Their birthplace ranged from Serbia, Croatia and Bosnia but all identified as Serbian and spoke Serbian. Many participants spoke some level of English. Seven of the participants arrived in Australia in the 1950s, 1960s and 1970s. The other participants arrived in Australia in the 1990s and 2000s and identified as refugees.

### 3.7.2 Caring Situation

The caring situations in this focus group varied. Some participants identified as carers and others reported they were being cared for by others. Those who reported they were carers noted they were caring for partners or parents who have a range of medical conditions including stroke and cancer, ageing, or who are living with mental illness. Carers NSW staff were informed by the facilitator that many participants would not admit to being carers, not to new people or to each other.

### 3.7.3 Themes

#### **Services**

##### *Importance of carer support groups*

Participants in this focus group immediately recognised the carer support group as an important service, consistently stating their appreciation for the carer support group and the facilitator. The men particularly enjoyed the Serbian Men's support group, noting that it provided great emotional support. Many participants also showed appreciation to Australia for giving them the opportunity to work, earn a living and build a family:

*"...and now we help our friends and we meet every Wednesday for a coffee...that is mentally helping each other."*

##### *Importance of learning English*

A number of participants noted that free English lessons were vital to helping them settle in to Australian life, overcome the trauma of the war and assisted them to develop their independence in their new environment:

*"As soon as we came here I started studying English; I always wanted to be independent."*

*"the first they help is giving the opportunity to study English, to have free classes, and that is the way of stopping thinking too much about the past."*

##### *Service awareness and access*

Participants were aware of a number of services and supports available including domestic assistance and personal care. But only a few reported to have accessed these supports. Some had accessed supports on discharge from hospital and others had a few hours of domestic assistance. One participant reported to have accessed a nursing home facility for her ageing parent, however, a lot of care was still provided regardless of the fact that her parent was not living with her. Participants in this focus group reported there was little reliance on children to provide support as they all worked full time and they did not expect them to provide support to their ageing parents.

##### *Service needs*

Participants discussed the need for assistance with gardening as this was a task becoming too difficult to complete independently as they aged. Respite was also recognised as an important service they needed, in particular, the opportunity to travel back to visit their country of birth:

*"I'm all right here but I'd like to go on holiday in Serbia like everybody."*

One participant reported accessing respite on one occasion to go overseas to Serbia, and this involved her mother staying in a nursing home for the duration of the trip. Participants also noted that doctors who provide home visits were very helpful and needed.

## **Information**

### *Sources of information*

Participants identified the facilitator, fellow carer support group members, doctors and a range of other service providers such as physiotherapists and social workers as sources of information. Many participants reported that they did use the internet to access different types of information but not particularly for information related to their caring role.

### *Barriers to accessing information*

One of the barriers to accessing information was language. Participants noted that interpreting services are not always offered, but they are able to manage with limited English skills:

*“...but I manage somehow using hands and arms to somehow exchange information.”*

Participants reported that a good doctor is important to provide the right information and in turn access to the right services.

One participant noted that although she had information about services from a range of sources she did not access any support to help with caring for her mother because her mother requested she do all the caring.

## **Recognition**

### *Self recognition*

Participants in this focus group explicitly stated that they did not consider themselves carers and that they did not identify as carers even after the definition of a carer was clarified by Carers NSW staff. One participant stated:

*“...you help them in many ways but you don't consider that as a carer. Even in the case of friendships you help a lot; you do a lot for your friends but you don't identify that as the role of carer.”*

This was particularly true for those caring for partners. One participant noted that marriage vows stipulate that you will care for each other in sickness and in health. Many noted that caring was part of the culture:

*“And that is the culture as well, to look after the family.”*

*“...it's just human way of helping others.”*

*“...it's just a natural way of just, you know, giving a helping hand.”*

### *Importance of recognition in own community*

One participant demonstrated the importance of culturally specific support and connection in the Serbian community. She had migrated to Australia at a young age with her parents and once they passed away she lost contact with the Serbian community and language until she met one of the group members. Traditionally parents live with their sons rather than their daughters and nursing

homes are rarely accessed. However, differences were noted and one participant stated that her mother chose to live with her daughter because she particularly liked her son-in-law.

*Broader community recognition*

Participants reported they were not asked about their needs by services they accessed on behalf of the people they were caring for.

## 4. DISCUSSION

A number of common themes emerged from all six focus groups, however the nature and impact of the issues identified by participants varied across and between groups. The common issues raised by the different focus groups are summarised below.

### 4.1 Lack of engagement with formal services

It is well known that CALD carers do not access as many formal services as non-CALD carers. This was reflected in all six focus groups, however, the reasons for this varied. Some participants were unfamiliar with the supports and services available to them, others noted they had difficulty accessing services due to financial restrictions and language barriers. Whereas others, especially in groups representing more established CALD communities, were aware of services but chose not to use them due to cultural reasons such as inappropriate physical contact with support workers and preferences to have care provided by family members.

### 4.2 Limited awareness of formal services

Service awareness and needs raised by participants varied based on types of carers, geographical location and time since migration. Notably, however, awareness of specific services was limited amongst most participants across all the groups. For example, although participants in four of the focus groups were identified (either by themselves or by the group facilitator) as being carers of a person with disability, only participants in two groups (Burmese and Farsi-Afghan, Iraqi and Iranian) reported that they were accessing the NDIS. Similarly, five of the six groups included participants who were aged over 65 or caring for someone who was over 65, however, both knowledge and access of *My Aged Care* services was low.

### 4.3 Cultural barriers and expectations

A key barrier identified to accessing services was a lack of culturally appropriate services that were local to the participants. This was raised by groups that were run in Northern Sydney and the Northern Beaches as well as the most new and emerging cohort, the Burmese focus group. To be culturally appropriate was described by various participants as using the correct language or dialect, being aware of dietary differences and demonstrating sensitivity to increased family involvement, particularly when accessing mainstream services.

One surprising finding given common preconceptions about familial expectations in CALD communities was that all of the groups that contained participants over the age of 65 highlighted the importance of maintaining independence and not expecting children to care for parents who are ageing. Further, some participants in the Mandarin and Farsi (Iranian) focus groups reported they had sought independent accommodation in order to maintain their independence.

### 4.4 Carer identification

The concept of carer recognition varied widely amongst the groups, with participants commenting about self-identification as a carer, family recognition, recognition within their own community, and recognition more broadly. It was particularly interesting to note that different definitions of 'carer' were in play. Participants of the Arabic focus group clearly self-identified as carers according to the Carers NSW definition, as did the Mandarin group, however their definition included minding grandchildren without additional care needs.

The Farsi-Iranian focus group identified themselves as carers including carers of people living with mental illness, however the Farsi-Afghan, Iraqi and Iranian group only identified as carers for their

children with disability, not their children living with mental illness. This may be due to various factors including higher physical and personal care needs of people with disability or the lack of a carer support group to confirm their caring role. The Burmese focus group participants clearly recognised carer participants in the group however the Serbian focus group participants, although they knew they were carers, did not identify themselves as such and frequently reported that caring was the natural thing to do.

Recognition within one's own cultural community also varied from complete recognition, demonstrated by active community support (Burmese focus group), to no recognition, demonstrated by criticism and judgement (Farsi-Afghan, Iraqi and Iran focus group).

#### **4.5 Financial hardship**

One of the key service needs which arose across all focus groups was the need for greater financial assistance. This was mentioned by every focus group but was particularly prominent with participants who had more recently migrated to Australia, some of whom could not access welfare payments due to waiting periods, lack of knowledge of the system and language barriers. Other participants did not always explicitly identify a need for greater financial assistance, but noted that they were unable to access services or supports as they were unable to afford them.

#### **4.6 High demand for carer support**

The carer service in highest demand was respite. This was mentioned by four of the six groups, predominately in the context of maintaining carer health and wellbeing, both physical and emotional. All focus groups touched on the low levels of health and wellbeing of carers, but this was more pronounced in focus groups who contained participants caring for someone living with mental illness (both Farsi groups). No services were directly identified, although the participants from most of the established carer support groups reported great appreciation for the emotional support and respite-like effects those support groups provided. Farsi-Iranian and Serbian groups in particular mentioned that their established carer support groups provided a great deal of emotional support.

Other benefits of the carer support groups noted were feelings of inclusion or belonging, which were clearly lacking in one focus group (Farsi – Afghan, Iraqi, Iranian). These participants noted an exceptionally high level of emotional distress and feelings of isolation. This may be attributed to the lack of a regularly meeting carer support group. None of the participants in this group had access to a carer support group, nor had they had a previous platform to discuss their issues in a group setting.

The two groups that did not discuss respite were the Mandarin focus group, as it did not contain many current carers, and the Burmese focus group, which contained younger carers who were focused on the challenges they were experiencing with migration. These challenges included accessing health care, finding appropriate accommodation, acquiring English skills, balancing constrained budgets, using public transport, obtaining social support and meeting members of the community.

#### **4.7 Reliance on word of mouth**

As mentioned earlier, participants from most of the established carer support groups reported great appreciation for support provided by those groups. These same focus groups (Arabic, Farsi-Iranian, Burmese and Serbian) also recognised that these established carer support groups were their key source of information, whether derived from the facilitator, their peers or a combination.

The Mandarin group, while regularly provided with information through their carer support group, still identified their children as their key sources of information. They also noted that even when interpreters were used, they needed the support of their children to completely understand the

message. This was similar for many other participants, who reported they often needed another person such as the facilitator, or their children, to re-interpret information. This suggests that comprehension of information is more than just a language barrier and that levels of education, skills of interpreters or perhaps complexity of the information, were all contributing to challenges with accessing information.

Doctors were also noted to be a source of information, particularly for those who were not part of an established carer support group. However, these participants also experienced the most difficulty accessing information due to additional stigma related to disability in their own community and the broader community, as well as experiences of racism in the broader community. Conversely, the Burmese community, although more isolated due to location, language and recent arrival, felt more supported and recognised by their facilitator and own community members. Their challenges arose more from a lack of knowledge regarding their culture and languages from the broader community.

#### **4.7 Low digital literacy**

Digital literacy was relatively low across all the groups. Although many were observed to use a smart phone, no one indicated that they used the internet to access services or information. Some participants attributed this to not knowing how to use technology while others reported that there was a lack of translated material online. The latter, more notable in the Farsi-Iranian and Serbian groups, both of which appeared to have a larger number of potential professionals amongst them, suggesting they had a degree of digital literacy but did not use technology for carer specific information.

## 5. CONCLUSION

This research project examined CALD carers' experiences and needs across six focus groups, representing a range of CALD communities across Sydney and Wollongong. It achieved its aim in building on the existing evidence base to better understand how to support CALD carers and resulted in new and strengthened relationships with CALD sector representatives, providing opportunities for further collaboration into the future.

The project also linked CALD carer participants with Carers NSW and information about carer support, disability and aged care services. Several translated membership forms have been returned by the time of writing and a number of participants were directly referred to needed services. The focus groups also provided the opportunity to promote the 2018 Carer Survey. A number of hard copies were distributed to participants on request and flyers promoting the online version of the survey were passed onto English speaking family members. Future analysis of survey responses, membership applications and Carer Line calls and referrals may reflect these outcomes.

The diverse backgrounds of participants and the variation in findings within and across focus groups resulted in rich, indicative data, however the findings from these focus groups cannot be considered generalisable in relation to all CALD carers or even all carers within the CALD communities represented. Further analysis comparing these findings to data from the 2018 Carer Survey, broader population level data and findings from the literature may indicate the extent to which these findings are representative of CALD carers' experiences more broadly. Further analysis and discussion with stakeholders will also be required in order to pinpoint key recommendations in response to these findings.

The project's success in planning and delivering six focus groups with diverse carer groups within a relatively short time period can be attributed to the cooperation and support of the PAG members, carer support group facilitators and other CALD sector representatives involved. The use of existing carer support groups and networks enabled focus groups to be organised quickly and efficiently, and the involvement of known facilitators resulted in open and productive conversation.

Most of challenges experienced in delivering the focus groups were anticipated in the planning phase. These included: difficulty sourcing translated materials on time, participants not consenting to audio recording, and complex logistical issues arising on the day of the focus group. Strategies were anticipated and put in place to alleviate the impact of these limitations. Overall, the groups ran to time and the material was covered, with detailed qualitative data being produced as a result.

## 6. APPENDICIES

### Appendix A. Promotional flyer

**CARERS NSW POLICY AND RESEARCH**



# SHARE YOUR EXPERIENCES



**Are you a carer who was born overseas and speak a language other than English at home?**

A carer is a family member or friend who provides support to someone who has a disability, mental illness or health condition.

Carers NSW wants to find out more about your caring experience.

Come and share your experiences in a focus group with other carers. This will help us in the work that we do to support carers.

We are looking for groups of carers to meet with. We are happy to come along to your regular meeting time and location.

Each group will be about 2 hours.

If you are interested in joining one of these discussions, please contact:

Carol Ismail  
02 9280 4744  
caroli@carersnsw.org.au

by 25 May 2018.

Each participant will receive:

- \$30 gift voucher
- Lunch
- Information about services
- Interpreters and translated material if needed

We will organise a date, time and location with you or your group facilitator.

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[www.carersnsw.org.au](http://www.carersnsw.org.au)   [contact@carersnsw.org.au](mailto:contact@carersnsw.org.au)   CARER LINE 1800 242 636   PO Box 785 North Sydney NSW 2059



This is easy to read information about Carers NSW and what we do.

## Who we are

Carers NSW is an organisation for carers in NSW.



A **carer** is someone who supports a person with a disability or an older person.

Some carers support people who are very sick or have problems with drugs or alcohol.

Carers are often family members and friends.

## What we do

We have a Carer Line you can call for support.



The **Carer Line** can

- Give you information
- Find services for you
- Find carer support groups for you

If you need counselling you can call the Carer Line.

You can call the Carer Line from Monday to Friday from 9am till 5pm.

Call **1800 242 636**



## Membership

This is easy to read information about becoming a member of Carers NSW.

### Membership is free for carers and carer support groups



Membership means we will send you

- Carer information and our newsletter called Carer News
- Invites to events

You can also have your say about things that are important to you

### How to be a member

If you want to be a member fill out the Become a Member form.



Give the form to a Carers NSW staff member

Or

Post the form to Carers NSW

PO Box 785

North Sydney NSW 2059

You **do not** need to put a stamp on the envelope.

## Participant Information Sheet



Level 10, 213 Miller Street, North Sydney NSW 2060  
PO Box 785, North Sydney NSW 2059  
P 02 9280 4744 F 02 9280 4755 **Carer Line** 1800 242 636  
contact@carersnsw.org.au  
**Carers NSW** ABN 45 461 578 851 ACN 606 277 552  
[www.carersnsw.org.au](http://www.carersnsw.org.au)

### Participant Information Sheet

#### Purpose of the focus group

The purpose of this focus group is to explore the experiences of people in your community who care for a family member or friend who has a disability, mental illness or health condition.

Carers NSW is interested in hearing from you about:

- Your experiences of accessing services (e.g. aged care services, disability services, health services)
- How you access information (e.g. online, community radio)
- Whether you feel the care you provide is recognised by your family and community

The information you share will help Carers NSW understand the experiences of carers in your community and may help to improve services for carers.

#### What will I be asked to do?

If you choose to participate, you will be asked to attend a 2 hour focus group. The focus group will be run by Carers NSW staff who may be assisted by another person or organisation known to you. The group may contain other people from your community.

Participating in the focus group is completely voluntary and if you choose not to participate this will not affect your relationship with Carers NSW or any of the other organisations involved.

If you require an interpreter, one will be provided. Lunch will also be provided and you will receive a \$30 gift voucher to thank you for participating.

#### How will the information be used?

The discussion will be recorded, however the recording will be saved in a secured folder that can only be accessed by the Carers NSW Research Team. It will not be shared with any external agencies or government departments. If you do not consent to recording, the recording will not proceed.

A summary of the findings will be published in a report, and may be referred to in other Carers NSW publications, presentations and journal articles. No participants will be personally identified in any published material related to this project.

#### What if I need support?

We do not expect that you will experience any distress or discomfort as a result of participating in this focus group. However, if you become concerned or distressed as a result of participating in the focus group, we will put you in contact with the Carers NSW Carer Line on 1800 242 636 (open Monday to Friday, 9am to 5pm) or you can contact Lifeline on 13 11 14 (open 24 hours, 7 days). If you need an interpreter, call Translating and Interpreting Service (TIS) on 131 450.

#### Questions, concerns or complaints

This project has been reviewed by the Carers NSW Research and Evaluation Committee. If you have any questions, please contact Sarah Judd-Lam, Manager Policy and Research, on (02) 9280 4744 or [sarahj@carersnsw.org.au](mailto:sarahj@carersnsw.org.au). If you have a complaint, please complete the Complaints Form at [www.carersnsw.org.au/about-us/contact-us/complaint](http://www.carersnsw.org.au/about-us/contact-us/complaint) or call 1800 242 636 to register your complaint. If you need an interpreter, please call the Translating and Interpreting Service (TIS) on 13 14 50.

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## Consent Form



Level 10, 213 Miller Street, North Sydney NSW 2060  
PO Box 785, North Sydney NSW 2059  
P 02 9280 4744 F 02 9280 4755 **Carer Line** 1800 242 636  
contact@carersnsw.org.au  
**Carers NSW** ABN 45 461 578 851 ACN 606 277 532  
[www.carersnsw.org.au](http://www.carersnsw.org.au)

### Consent to participate

Please read the information below before you participate in the focus group.

Tick the boxes to show you agree. Then sign the document.

- I have read and received a copy of the Participant Information Sheet or had it explained to me
- I consent to participating in the Carers NSW focus group
- I understand that I may withdraw from the focus group at any time
- I understand that refusal to take part in the focus group will not affect me or my relationship with Carers NSW in any way
- I consent to the recording of this discussion and I understand that I will not be personally identified in any publications

Name of Participant:

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Name of witness (for verbal consent):

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Signature of participant:

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Signature of witness (for verbal consent):

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Date:

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Date:

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## Appendix C. Interview schedule

### 1) Services

First we want to talk about services that you use to help you care. By services we mean any organised group or support you receive to help you care for the person. For example, someone to help you clean the house, or do the gardening.

- What services have you used and what services do you need?
- Do you use respite? i.e. are you able to take a break from caring? How often?
- Do you use counselling? i.e. do you have anyone you talk to about your caring situation? How often?
- Do you use a carer support group? How often?
- Do you use an online group? How often?
- Can you tell me more about this

### 2) Information

Next we would like to find out about how you access information. If you need any information about caring for the person, how would you get that information?

- What information do you look for?
- Do you use the internet?
- Is there someone that you ask for help? (GP/family members/other group members/TV/radio/neighbour/online)
- Where would you go?

### 3) Recognition

Lastly, we are interested in whether you feel that the people in your life recognise the importance of what you do?

- Do you feel that you are valued by your family/community?
- Are you offered help by family/community/workplace?
- How do you decide who provides the most care?
- Are you asked about your needs?
- What do you need?
- Do you feel part of your community?
- What do you see happening in the future?



## Appendix E. Feedback form

### Feedback on process:

1. How did you think the focus group went? *What worked well? What didn't work so well?*

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2. Do you think the group understood the topic / questions?

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3. Do you think the group felt comfortable sharing their thoughts?

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4. What do you think we could do differently next time?

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