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victoria



Centre for Multicultural Youth



Refugee and Migrant Young People with Caring Responsibilities:

What do we know?

Background paper and sector consultation report



Ethnic Communities' Council of Victoria (ECCV) Inc. was established in 1974 as a voluntary community based organisation. Over 35 years later, ECCV is a broadly based, statewide, peak advocacy body representing ethnic and multicultural communities in Victoria. ECCV's role includes supporting, consulting, liaising with and providing information to Victoria's ethnic communities. ECCV delivers policy projects for key partners in areas like multicultural policy, aged care programs and skilled migration strategies.

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Foreword

The Ethnic Communities' Council of Victoria (ECCV) feels privileged to have been given the opportunity to work in partnership with the Centre for Multicultural Youth (CMY) and Carers Victoria. This paper represents a close collaboration between these three organisations, motivated by a shared commitment to exploring and illuminating the circumstances of refugee and migrant young people with caring responsibilities.

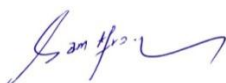
Perhaps one of the most striking features of this topic is the lack of available information and data. In fact, this was a strong motivating factor for the ECCV, CMY and Carers Victoria when they came together to work on this paper. It must be said that our endeavor would have been all the more challenging had it not been for the generous and insightful contributions of all those who attended the statewide sector consultation. We wish to extend our most sincere thanks to this cohort, for their vital knowledge and invaluable support.

It is a matter of great concern that such a significant proportion of Australia's young people are currently attending to the needs of others, while their own important needs are not being adequately met. Also troubling is the fact that the efforts of these young people are not being duly recognised by the wider community. In fact, many young people are themselves unaware of the extraordinary nature of their caring responsibilities. This lack of recognition reflects the broader confusion that surrounds the definition of a 'carer'. This paper suggests that this is a term that needs to be redefined, in order that it may more accurately reflect and recognise the 'hidden' caring work that is undertaken by young people in our communities.

At present, large numbers of young people are performing a variety of caring duties for family members and loved ones. This can include such things as property maintenance, household management, interpreting, intimate care tasks and assisting with the social, emotional, medical and mobility needs of another person. As our paper demonstrates, young people from migrant and refugee backgrounds are over-represented in such caring roles. This is due to many factors, including the increased prevalence of disability in refugee and migrant households and the existence of culturally held values related to disability and to familial responsibilities.

Although we are keen to highlight the valuable skills, experience and personal satisfaction that a young person may gain from caring for another, we are also concerned that this extra responsibility may be overly onerous for those who must also find time for their important educational, employment and social aspirations. Caring responsibilities can reduce a young person's ability to focus on themselves and their own needs during this very important and formative life chapter.

It is imperative to note that the recommendations made herein are not necessarily being put forth by the ECCV, CMY, or Carers Victoria. Rather, they are the result of an in-depth, collaborative consultation. These recommendations emerged during a statewide forum, which was attended by many representatives of the caring and multicultural sectors. The recommendations are insightful and important, but more research will need to be undertaken if they are to be better explored and refined. It is hoped that this report will provide the necessary impetus for such further research and action. It is this that is required if we seek to better support these young people, so that they may strike a balance between caring for others and caring for themselves.



Sam Afra JP, Chairperson, Ethnic Communities' Council of Victoria

Introduction

The Ethnic Communities' Council of Victoria, the Centre for Multicultural Youth and Carers Victoria are committed to informing a debate about issues arising when young people from migrant and refugee backgrounds have caring responsibilities. The following paper was developed throughout 2010 and 2011, as these three organisations came together in order to explore the effects of caring responsibilities upon young people from refugee and migrant backgrounds.

To this end, we have gathered information from two distinct sources. First, we have consulted the available research literature on this topic. Second, in order to supplement and enhance the literature based research, we hosted a statewide forum, bringing together representatives from the carers support and multicultural sectors.

The knowledge and feedback that emerged from these separate sources was both diverse and complementary. It is for this reason that the following paper has been arranged into three separate and distinct sections. These are presented as follows:

- ***Part I – Background Paper***
This section presents the information garnered from our study of the available research literature on this topic.
- ***Part II – Sector Consultation Report***
It is in this section that we report on the outcomes of our 2010 statewide sector consultation and the recommendations that have emerged as a result of this process.
- ***Part III – Where to from here?***
In this section we conclude on our findings and make suggestions regarding future action and research.

This paper provides some valuable insights into the complex circumstances surrounding young people with caring responsibilities, particularly those from refugee and migrant communities, who have been found to be overrepresented in this sizable, yet 'hidden' population of carers.

Also explored are the complexities that arise whenever we try to ascertain who a 'carer' actually is. This speaks to the emerging claim that policy and practice in the caring sector should place greater emphasis on the activity of caring, rather than the definition of a 'carer'.

In *Part II – Sector Consultation*, readers will find a set of recommendations. These recommendations were put forth by forum participants. Recurring issues are to be found in the calls for redefinition, raised awareness, improved recognition, opportunities and services. Given the source of these recommendations they are very 'real' and very insightful, and we ask that they be given their due import by policy makers. With that in mind, we have ultimately found that the key recommendation is a call for more evidence based research on these issues. This is crucial if governments are to fully respond to the broader social and services issues that are raised by this paper, so that young carers from refugee and migrant backgrounds may receive the opportunities they deserve.

Section I

Background Paper

SECTION I – BACKGROUND PAPER

The purpose of this paper is to:

- raise awareness of the concept of informal caring amongst youth in refugee and migrant communities;
- highlight the challenges affecting young people with caring responsibilities when accessing services; and
- engender a discussion with people working with or advocating for young people from refugee and migrant backgrounds on how they, and the sector, might respond to these challenges.

The Commonwealth Government is undertaking an inquiry into the feasibility of a long-term care and support scheme for people with caring needs, and their carers and families. This represents an important opportunity to recognise the needs of young carers from refugee and migrant backgrounds and their families and ensure an equitable and fair system for all carers and their families (Productivity Commission, 2010, 2011).

Studies have shown that a significant proportion of Australian youth are providing care for family members, yet their needs are all too often inadequately met (Moore & McArthur 2007; Enduring Solutions 2003). While some young carers receive insufficient levels of support from the service system, many do not receive any assistance at all. This situation is particularly relevant to young people from refugee and migrant backgrounds as they are more likely than other youth to have caring responsibilities (ABS 2008), and may experience additional barriers to receiving the help they need from service organisations.

This background paper will highlight an absence of data on:

- the characteristics of young carers from refugee and migrant backgrounds;
- their caring responsibilities;
- the services and support required by them; and
- the barriers they face when seeking help.

As a result of this lack of data, much of the content of the paper discusses young carers as a generic group. Without further specific research, the development of evidence based policies and support services for young carers from refugee and migrant backgrounds and their families is constrained.

This paper is to highlight this gap and the importance of addressing it, and propose 'signposts' for further research and subsequent policy development.

1. Who are young carers?

As a first step in providing baseline information about youth from refugee and migrant backgrounds with caring responsibilities, it is important to define, in general terms, who the 'young carers' are in our community, their demographic characteristics and particular needs.

There are a number of different understandings and definitions of what it is to be a 'carer' (see Figure 1). This diversity of definitions is important to the issues raised in this paper about eligibility and access to services by young people from migrant or refugee backgrounds. However, these definitions may not be commonly or uniformly understood within the community (Quantum, 2009).

Figure 1: Definitions of “carer”

Legal understandings. The Victorian *Equal Opportunity Act 1995* defines a carer as “a person on whom another person is wholly or substantially dependent for ongoing care and attention, other than a person who provides that care and attention wholly or substantially on a commercial basis”. Note that this covers someone who is caring for children without special care needs in addition to those people caring for an adult with care needs.

The Australian Bureau of Statistics (ABS) defines a carer as, “[a] person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions or persons who are elderly (i.e. aged 60 years and over). This definition does not apply to persons caring for children who do not have additional care needs.” Many government funded carer support programs use this ABS definition for eligibility purposes, such as Centrelink’s Carer Payment and Carer Allowance and the National Respite for Carers Program.

There is often a distinction made between formal (paid) and informal (unpaid) carers. Personal care or disability support workers, for example, are paid for the care they provide and are often also referred to as ‘carers’ by employer groups, the media and in the community. However, these ‘carers’ are not defined as such according to the above *Equal Opportunity Act 1995* or ABS definitions.

Within the category of informal carers, there are further sub categories and definitions used by representative bodies. For example, in Victoria:

- a) Bodies representing those providing unpaid care to a person with a disability, mental health problem, chronic illness or frail aged are represented by Carers Victoria.
- b) “Kinship carers” (family members who are not parents caring for a child who does not necessarily have a disability) are represented by Kinship Carers Victoria.
- c) Foster carers (people who care for children on a temporary basis, who may or may not have a disability) are represented by Foster Care Victoria.
- d) Grandparent carers are a subset of kinship carers.

Academic social policy discourses about caring are often broader than, and may include, all of the above.

The starting definition used for this background paper is that used by the Australian Bureau of Statistics. This is used to determine eligibility to Commonwealth funded services. Carer Associations also use ABS definitions to guide their work.

The term ‘young carer’ is used in Australia to describe children and young people up to 25 years of age, who provide unpaid help or informal support for a family member who has a disability, mental illness, chronic condition, is aged, or has an alcohol or drug-related problem (Cass et al 2009; Hill et al 2009). We will see later in this paper that the limitations of this definition can provide challenges for young carers themselves, particularly those from diverse cultural backgrounds. ‘Young adult carer’ is sometimes used to refer to 18-25 year olds with caring responsibilities.

2. Prevalence of caring among young people

A number of factors have had an impact on the emergence of young people taking on caring responsibilities within their home (Noble-Carr & DFACS 2002). These include government policy changes towards community care, increased prevalence of disability and changes to family make up.

The 2003 ABS Survey of Disability, Ageing and Carers estimates that the overall number of young carers in Australia is 348,600 (ABS 2004). This figure covers children and teenagers up to 17 years of age and young adults aged 18 to 24 years. Out of the 348,600 young carers, 170,600 are under 17 years of age, comprising 3.6 per cent of all children and young people in this age range; and 178,000 are aged between 18 to 24 years, comprising 9.1 per cent of young people in this age range (ABS 2004). The experiences of caring and corresponding support needs can vary considerably according to the age of the young person (Cass et al 2011).

Studies have noted that this count of carers is likely to be an underestimate due to a number of interrelated factors, detailed below:

1. Recent work research and national surveys because these methods rely on disclosure of suggests that many young people are likely to be 'hidden' from the young person's caring responsibilities, either by the young person themselves or by the family member needing care (Becker 2007; Warren 2007). In order for youth to disclose their caring responsibilities, they are often required to first identify with the term 'carer'. The literature highlights that many young people are unaware that the assistance they provide to a family member is greater than that perceived as a typical level of responsibility in the home by other young people of similar age (Moore & McArthur 2007; Noble-Carr & DFACS 2002). This issue may also reflect a lack of awareness and understanding within the community more generally about the significant role young people play in providing care to family members who need assistance.
2. The fear of unwanted intervention from child protection authorities (as parents fear this would undermine their role as guardians), or the desire of families to keep care needs private due to concern about stigma attached to mental illness, physical ailments and drug and alcohol conditions (Hill et al 2009).
3. A common experience of many young carers is that the stigma associated with the circumstances of their cared-for-relatives transcends beyond their immediate social networks to their local school where incidents of bullying and harassment are reported (Moore & McArthur 2007).
4. While it is not possible to know how many young carers are hidden, work done by the Social Policy Research Centre has shown that it is possible to determine how many 'potential' young carers there are by correlating the number of young people who live in families in which there is at least one person with a disability and/or care needs. Furthermore, not all young carers co-reside with the person they care for, and not all young people living with a person with a disability will be providing care. It is possible to posit that, if all 'potential' young carers were providing assistance, the number of hidden young carers could be equal to or greater than the number of identified carers. Further analysis of this data shows that the proportion of identified to potential carers is higher in the 20-24 age group as compared to the group of 15-19 year olds (Trish Hill et al 2009, using Census 2006).

3. Prevalence of caring among young people from migrant and refugee backgrounds

Significantly, young people from migrant and refugee backgrounds are over represented in both groups, that is, as identified young carers and potential young carers. Young men from migrant or refugee backgrounds in particular are more likely to be hidden carers than identified as such. It is unclear as to whether this is because these young males are less likely to have caring responsibilities, or whether they are equally likely to be caring, but are less likely to identify or be identified as a young carer (Trish Hill et al 2009).

There are a number of possible explanations for the high prevalence of identified or potential caring in these groups. Disability is more prevalent in households of people from migrant or refugee backgrounds. Work done in the UK suggested that there may be a stronger sense of responsibility to care for kin within families of migrant or refugee backgrounds (Becker et al 1998). We do know that families from ethnic backgrounds are less likely in general to access services that support people with a disability or mental health problem (Stolk et al 2008, NEDA). Such a pattern could increase the need for care to be provided within the family which would include, under some circumstances, that provided by young family members.

As for hidden young carers in families from refugee or migrant backgrounds, culturally held attitudes about the shame or stigma associated with having a disability or mental illness and needing care may in turn generate reluctance in young people to disclose their caring status and seek assistance.

Within this complex set of factors, there is debate about the fundamental causes of the higher prevalence of caring by people from migrant or refugee backgrounds. Some see cultural factors as most important, such as those which render support services as inappropriate and can form the basis of attitudes that see caring as primarily a family responsibility (EDAC 2003, Masic 1996). Others, such as Young et al 2006, see the higher prevalence as more determined by socio-economic and demographic factors.

4. Characteristics of Young Carers

The Australian Bureau of Statistics' *Census of Population and Housing 2006* uncovered the following trends regarding (identified) young carers:

- The prevalence of informal caring increases with age.
- Young women were slightly more likely to become carers than young men.
- The prevalence of identified young carers was found in low-income and sole-parent households.
- The majority of identified young carers live with their care recipient and were providing assistance to a parent who was most likely to be their mother.

In view of the above profiles, it is important to stress that the experiences of young carers significantly varies depending on a number of factors including:

- the age of the carer;
- the care recipient's illness/incapacity;
- the number of people being cared for;
- the carer's relationship to the care recipient;
- the availability of and access to formal services and support;
- the assistance received by carers from other family members; and
- the time period and frequency over which caring has been provided.

Significantly, the experiences of young carers are shaped by the interplay of these factors in their lives and the differences in their circumstances to other youth (with no caregiving responsibilities). For instance, young carers compared to non-carers are less likely to complete Year 12, be employed full-time, or participate in both study and paid work simultaneously, and are more likely to be living in low income households (Hill et al 2009). It is unclear from the Australian research literature as to the ways in which the presence of different cultural expectations about caring roles influence the experiences of young carers from refugee and migrant backgrounds. However, the implications of cultural diversity as an additional factor must be considered by policy makers and the formal service system.

What is clear is that young carers are a highly diverse group, a reality that should be reflected in program design, resourcing and practice. The diverse cultural, religious and social expectations and experiences of families from different ethnic and religious communities should be acknowledged and valued.

5. Diversity of caring roles and tasks

Young carers take on a larger share of tasks and responsibilities compared to most people their age, although it is important to note that the circumstances of young carers are very diverse, as is the range of tasks undertaken by them.

The wide range of care tasks performed by young carers and the time spent doing them extend beyond the normal household chores performed by other non-carer youth. These responsibilities, whether domestic, emotional, nursing or intimate, vary according to their age (Hill et al 2009). Likewise, what might be considered to be an 'appropriate' or sustainable level or type of care provided by a young person will also partly depend upon their age. This issue is highly relevant to practitioners determining how best to intervene to support a young person.

Care tasks performed by young carers include:

- Property maintenance, paying bills and banking;
- Attending medical appointments and managing medications;
- Listening, giving advice and providing emotional support;
- Assisting with mobility, securing transport and organising social activities;
- Daily household chores such as cleaning the house, washing and preparing meals;
- Intimate care tasks such as bathing, dressing and feeding particularly for recipients with physical health ailments; and
- Interpreting information for their families.

Taking into account the effort and time involved in performing these tasks, and the low income household circumstances in which they often take place, it is evident that the caring role may affect the young person's current educational, social and economic participation and later opportunities in life (Hill et al 2009).

6. Impacts and effects of caring

For young carers, the care they provide can incur personal costs. Studies have focused on the negative aspects of caring which have an impact on young carers' physical and emotional wellbeing, their relationships, their connectedness to the broader community, their family's financial stability and their future opportunities (Moore & McArthur 2007) These impacts include:

- reduced opportunities to participate in social activities due to having less free time, less energy and money;

- reduced opportunities to form meaningful intimate relationships or friendships due to the value judgement and negative attitudes their peers hold from not understanding their circumstances;
- the inability to fulfil academic requirements due to combining caring responsibilities with schooling. This results in disrupted attendance; not being able to concentrate during class due to concern about their care recipients; the inability of parents to assist in the learning process; and having less time to do homework;
- reduced opportunities to secure full-time employment and adequate income.

There is a risk that the cycles of poverty young carers experience as children due to their caring responsibilities may continue into the future due to limited opportunities and lack of access to paid work. Research points to the financial strain imposed by both care giving and long-term ill health within a family (Cass et al 2009). This is worsened by the difficulty in accessing social security payments.

In spite of the challenges young carers face, many express a desire to continue in their caring role, if they and their families can access services and support. Such commitment to the role is indicative of the positive aspects that are associated with what they do. These benefits include an acquisition by the carer of skills that can be of assistance throughout life, such as their capacity to deal with challenges, empathy, and developing a sense of achievement from forming close and meaningful relationships and contributing to family resilience and integrity (Moore & McArthur 2007). Such connectedness is one determinant of the wellbeing of a young person; however, when considering both the costs and benefits of informal caring, the literature demonstrates that the negative effects of young caring tend to outweigh the positive effects (Becker 2005).

Work done by Francis and Cornfoot found that newly arrived youth from refugee and migrant backgrounds face challenges that are different from those born in Australia. They are more vulnerable to social exclusion, as many are confronted with the difficulties around integration and adjustment to their new homeland. They have to deal with the challenges of settling into a new country, such as: losing the support of extended family and community (many would have had to leave behind other family members); dealing with experiences of trauma and cultural isolation; learning a new language; transitioning into a new educational system; and finding housing and employment. Some of these youth also have to provide emotional support for other family members (e.g. siblings) who themselves may be struggling with their own settlement and acculturation difficulties (Francis & Cornfoot 2007). Thus, the circumstances of newly arrived refugee and migrant young people place this group at extreme risk of remaining in a cycle of entrenched social exclusion and disadvantage.

Existing Australian studies about caring have not targeted the specific experiences and needs of young people from refugee and migrant backgrounds. As a result, the picture from existing research about the impacts of caring upon young people from different ethnic backgrounds is unclear and incomplete (Cass et al 2009). At this stage it is not possible to infer with confidence that negative impacts of caring affect both groups in exactly the same ways. There is little formal research from Australia that examines how these additional risk factors interrelate with those associated with

caring. For example, are negative impacts associated with migrant or refugee experiences compounded by some of the possible negative impacts of caring, or can caring provide protective factors to young people from ethnic backgrounds by providing a role, status within the family, strengthening of family relationships and so on?

Anecdotal evidence and practice wisdom (see *Part II – Sector Consultation*) suggest the possibility that young carers from ethnic backgrounds are at higher risk of social isolation than other young carers in general and are also less likely to be accessing services for their own support.

7. Needs of young carers

Young carers identified that the provision of support services for their cared-for-relatives would alleviate their worries and address some of their needs as well (Moore and McArthur 2007). This reflects that the needs of young carers are interwoven or interdependent with those of the person they care for. Young people often provide care because there is a shortfall in the quality or quantity of formal care available for a family member, or because the family is not accessing formal care. The reasons for this can be multiple and complex and correlate to many of the issues already referred to about hidden carers. Families may not know about the supports that are available, or may choose not to access them because they consider them to be unsuitable and/or associated with anxiety and risk. It is likely that issues will also be affected by an overlay of cultural and linguistic complexities.

Studies (Moore and McArthur 2007, Noble-Carr 2002) have identified a range of support needs (both formal and informal) required by young carers. These include:

- recognition, understanding and respect, especially from the professionals they are in contact with from the health and education sectors, welfare organisations and the wider community;
- formal support and assistance for care recipients with personal and intimate care tasks, domestic activities and especially with transport;
- accessing respite care and having the opportunity to take time out from their carer responsibilities, as this can greatly influence their ability to participate in education, employment and social opportunities;
- financial support for the families to cover the costs of medication, health care and fee-for-service support;
- access to services that are age and culturally appropriate, flexible and affordable;
- raised awareness of their rights and the provision of age and culturally appropriate information on illness, disabilities, caring, flexible educational opportunities and formal respite; and
- flexible and sensitive schooling, TAFE, university and workplace arrangements to allow them to better manage their combinations of education, employment and care.

8. What sort of help is available?

A range of services are provided to young carers at both federal and state government levels and administered through voluntary and community sector organisations. These services include:

- counselling, group work, information referral and advice;
- educational support
- peer support, for example, buddy and mentoring programs, carer camps and daytrips, online forums and communities;
- domestic and personal assistance through the Home and Community Care Program;

- respite support through the Young Carers Respite and Information Services Program and the National Respite for Carers Program;
- financial support through Centrelink in the form of Carer Allowance and Carer Payment (Cass et al 2009; Hill et al 2009); and
- online information and websites.

However, the service system is constrained by funding. The Australian Government's recent commitments provide \$23.8 million over three years (to 2013), for respite and information services to support young carers across Australia. This means that services are severely rationed particularly in rural and remote areas.

Many young carers are unaware of the services provided and how to access them, and only a small number of young carers identify themselves as 'carers', or as being 'at risk' or 'in need'. It is likely that these hidden carers are those who need support the most because they live in families which experience access barriers and so are in turn less likely to be accessing support services for the person with carer needs.

The combination of rationing and identification issues result in a number of system and service issues. Moore and McArthur (2007) interviewed young carers and identified the following problems with accessing support:

- unaffordable services;
- limited resources and programs available for young carers;
- lack of flexibility in the way mainstream services are promoted and provided;
- inflexibility in access arrangements due to location of services and hours of operation;
- inappropriate acknowledgement of young carers by service providers and lack of knowledge of how to deal with their needs;
- inadequate support for young carers due to a lack of a co-ordinated systemic approach between the various service systems including youth services, education system and health services;
- lack of recognition of young carers in program guidelines for mainstream youth services and restrictive formal eligibility criteria; and
- lack of understanding of the close connections between support for young carers and support for the family members for whom they provide care (i.e. interdependency).

9. How can service providers help?

It is important service providers recognise the family issues of their clients, and the impact these issues have on young carers. Understanding a young person's context and their family needs is a necessary step to minimise the care load and to alleviate anxieties about the care responsibilities that are being performed. It has been argued that adopting a family focused and inter-agency collaborative approach, one that assesses the needs of the family, as a whole, and provides assistance accordingly, is an effective way to address the needs of young people with caring responsibilities. Given the challenges that are associated with identifying young carers for support and the cultural barriers that prevent them from seeking assistance, this may be an appropriate response. There is a strong argument to

suggest that adopting a young person centred, but family focused approach within the service system would assist in the identification of young carers and would be more effective in ensuring their needs are appropriately met (Carers Victoria 2009).

Likewise, in relation to the inevitable constraints on funding, there is a need for further debate about which policy approaches should be taken in relation to young carers. There is a strong argument that almost any amount of funding to support young carers will be insufficient and ineffective so long as the care needs of family members are not also adequately addressed.

Bettina Cass of the Social Policy Research Centre (SPRC) has initiated a useful debate based on the distinction between assistance, mitigation and prevention, suggesting that most current programs assist young people to care but are rarely designed to prevent the negative impacts of caring at their source (Cass et al 2011).

Practitioners still encounter and work with these groups of young people. Workers from migrant and refugee services, schools, health and disability services, youth services and so on have a wealth of practical wisdom to offer about the diverse needs of this group. The following sector consultation report documents the discussions and views of representatives from this group, who came together to discuss these matters at a forum hosted by the ECCV, CMY and Carers Victoria.

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Section II

Sector Consultation Report

SECTION II – SECTOR CONSULTATION REPORT

In August 2010, the Centre for Multicultural Youth, in partnership with Carers Victoria and the ECCV, held a statewide forum titled: *Who Cares? Refugee and Migrant Young People with Caring Responsibilities*. The forum aimed to build a clearer picture of the nature and extent of caring responsibilities for young people from refugee and migrant backgrounds and the current responses from the service system.

The forum was designed to:

1. Raise awareness of the concept of informal caring amongst youth in refugee and migrant communities;
2. Highlight the challenges affecting young people with caring responsibilities when accessing services and;
3. Engender a discussion with people working with or advocating for young people from refugee and migrant backgrounds, particularly related to the question of how services should respond to these challenges.

The forum was attended by more than 60 people from a range of services.

This report summarises the key issues that came from the guest speakers' presentations and the small group discussions, as well as the recommendations put forward by the participants.

1. Identification Issues

Identification issues for young people

There is a lack of awareness amongst refugee and migrant young people, who don't often recognise what they see as 'normal' responsibilities are in fact 'caring' responsibilities. At the forum, this was identified as a key barrier to identifying young people with support needs.

Some of this can be attributed to cultural expectations. These expectations impact on the circumstances of young people with caring responsibilities, their understanding of their roles, their needs, expectations and pathways to access support. Cultural values and expectations imposed on young people by their community, particularly around familial responsibilities when providing care, have a considerable impact on their needs and the way they access help. Participants at the forum reported that caring for family members was expected of young people, and that providing care was seen as a 'duty' that could not be questioned by youth.

Young people who are able to identify and express their needs, and become aware of the support services available, may feel shame when asking for help due to stigma from their communities for 'failing' to adequately fulfil their familial duties.

Identification issues for service providers

Forum participants were conscious of the significant lack of representation of refugee and migrant young people seeking support from agencies, particularly if they were from new and emerging communities. Participants reported difficulty in identifying these young people. This, in turn, is an impediment to the provision of support services, despite services being certain that they do, in some capacity, come in contact with youth from refugee and migrant backgrounds.

Some workers felt that the current service system has underlying assumptions/models of care and support that may be counterproductive to the assistance young carers require, as these models do not acknowledge or respect the different cultural responses to 'caring'. Some workers may presume that western values of caring also apply to this group, and put pressure on young people to comply.

2. The experiences of young carers from refugee and migrant backgrounds

The forum heard of a range of issues and needs specific to young people from refugee and migrant backgrounds.

Many young carers (of all backgrounds) experience social isolation, disrupted schooling and difficulties in finding and keeping employment. In addition, young carers from refugee and migrant backgrounds are often required to provide high levels of informal care to their relatives. For instance, they may need to stay home to support ill relatives and are often asked to translate and interpret health messages and act as an intermediary between the cared for person and services. Isolation is an issue for young carers, but also for their families, particularly if they are newly-arrived and mainly networked in their own cultural community.

While young carers are serious about meeting their responsibilities towards their cared for relatives regarding the supporting tasks required of them, they are likely to dismiss their own needs. For instance, they are less likely to keep appointments scheduled for their own support. It was suggested at the forum that more assistance is required to help them to keep their own appointments. They may also ignore their own settlement issues, as they seek to provide care, juggle study, work and domestic responsibilities. Despite this, it was noted that youth from refugee backgrounds demonstrate strength and resilience, but need the service system to provide additional support to facilitate their settlement experiences.

Participants at the forum highlighted that agencies working with this cohort need to be aware of the following complicating factors:

- Newly-arrived youth from refugee backgrounds, with caring responsibilities, often have very complex needs which include torture and trauma issues from experiences of displacement, civil conflicts and uncertainty.
- Some young migrants have limited or no access to finances. This situation is critical to specific groups such as Pacific Islanders and Orphan Visa holders within their first two years of arrival* who are not eligible for Centrelink benefits.
- Some young people, who provide financial support for immediate family members living overseas, yet are waiting to be reunited with them, express frustration and distress, as they carry guilt for not being able to adequately support their families. These youth are likely to experience health (mental and physical) challenges, an erosion of confidence and feelings of inadequacy.

Another point of note is that caring for younger siblings is a common experience amongst young carers. A speaker at the forum (herself a young woman of Sudanese background) highlighted that parents tend to hold expectations of their firstborn to provide for the needs of their younger siblings. This may be the case in an ongoing manner, if the parent works or is ill, or may surface when the parent travels overseas or interstate to attend to family, cultural or other responsibilities.

While this is not recognised as a caring responsibility *per se*, its impact can be similar to that of 'caring responsibilities', e.g. health issues, fatigue and an inability to attend appointments, study or work.

* For more information on Orphan Visa and Last Remaining Relative visas, see CMY's discussion paper on this topic at www.cmy.net.au/publications and resources

3. Systemic barriers

Participants in the forum identified the following barriers in the current service system. These increase the challenges facing young people of refugee and migrant backgrounds who have caring responsibilities:

- The provision of information to newly-arrived youth in their community languages is limited and multilingual staff are needed to facilitate communication and understanding.
- The assumption that young carers will self-identify and the onus placed on young people to seek support.
- The over-reliance on schools to identify and refer newly-arrived young people. This is problematic, even though schools have been, to a certain degree, successful in understanding their students' needs and providing appropriate support. This is because they are often under pressure to respond to many needs and have limited resources.
- The need to extend the service sector's primary focus from raising awareness of the needs of their clients, to addressing those needs more appropriately. While it is important to provide education on the conditions and circumstances of young carers, the primary focus should be on addressing their needs in an age and culturally appropriate manner.
- The limited duration of the service period, which allows access to provider and support workers.
- Currently, respite is a concept that is uncommon in some communities, particularly as it involves interacting with workers who are strangers to the clients requiring assistance. It was noted that utilising these services can be distressing to people receiving care. Current respite services may not be culturally sensitive and age appropriate.
- Finally, participants reported their frustration with having to internally advocate, within their organisations, for better support for young people with caring responsibilities.

4. Successful strategies

The forum included a consultation with participants about what strategies have proved successful in their work with young people from refugee and migrant backgrounds. The following strategies were suggested:

Developing Cultural Awareness

- Encouraging young people's involvement and allowing them to educate workers about their culture. This can help dispel any assumptions made by the workers.
- Providing cultural awareness training to workers.
- Acknowledging the importance of familial relationships in refugee and migrant communities and shifting the focus of the support provided from an individualistic to a collective/family-inclusive approach.
- The use of interpreters is recommended, but there are limitations around their working hours and flexibility. Interpreters need to be more accessible to young people through the provision of after-hours service. However, it is possible some young people resist the use of interpreters out of fear their private life will be exposed to their communities.

Outreach

- Home visits are effective in addressing the remoteness of services and in replacing set, agency-based appointments that young people may struggle to attend.
- Identifying appropriate support contacts in the area where young carers live to increase their access to services.
- Offering a suite of respite at home, or 'on site' services. This can take the form of financial literacy, homework assistance or extra tutoring.

Trust

- Investing time in establishing trust with young carers, displaying genuine concern for their wellbeing and adopting an informal approach has been valuable in developing relationships.
- Providing personal help with referrals and following up referrals on the behalf of young carers.

Other strategies

- Advocacy within schools has had a positive impact on raising awareness amongst school staff about the profile of young 'carers' and identifying their needs.
- Fund programs/policies targeted at young carers from refugee and migrant backgrounds.
- Simplifying the service system to deal with the complexity of services and setting in motion a care plan for young carers, with culturally sensitive education, clear points of access, support mechanisms and tools, is essential. Young people are more likely to engage via informal barbecues or drop-in centres rather than attending appointments.
- Increasing networking opportunities between service providers to share information.

Participants in the forum highlighted the importance of adopting a whole-of-family approach when providing services to young people of refugee and migrant backgrounds. This allows for better consideration of the broader circumstances of the family and improved support for them as a unit (this is valid for all services, not solely in the caring sector). This family-centered model presents challenges around confidentiality, which services need to reflect on.

5. Forum recommendations

Statewide forum participants were asked to offer recommendations on what would make a difference to young carers and to those who support them professionally.

Below are the recommendations that came out of the forum.

5.1 Redefining 'carers'

- Redefining caring responsibilities and concepts of who a 'carer' is, in order to address the social exclusion of some groups. This requires a broader definition of 'caring' to include young people who are not currently eligible to access support – such as those caring for younger siblings.

5.2 Community Awareness

- Raising the profile of refugee and migrant young carers to develop an understanding about the impacts of caring in a social inclusion agenda.

- One of the ways this could be done is by increasing refugee and migrant communities' understanding about the roles, needs and challenges experienced by young carers and by providing education about respite to family members.
- A national publicity campaign could be developed, in partnerships with ethnic organisations and ethnic media.
- Raising awareness is also needed among key contacts such as schools, community elders and health providers to recognise young carers and provide advice on where and how to access support.
- A commitment to building the capacity of community leaders to recognise the caring responsibilities taken on by young people. There is also a need to disseminate information on support services available to young carers and promote carers' programs through ethnic media.

5.3 Improving the Service System

- Increasing flexibility of programs and services with a focus on less structure and more informal approaches. The service system needs to adopt a more holistic and client-focused approach, one in which support workers are encouraged to perform home visits and work flexible hours. This would ensure greater engagement between young people and service providers.
- Ensuring there are more services, more workers and more time allocated for workers to adequately respond to the needs of refugee and migrant young carers. The service system needs to respond and bring in support for young carers, rather than refer them out.
- Encouraging the involvement of young carers by inviting their input in decision-making processes.
- Networking and the creation of a platform for support workers to come together and talk about issues encountered in their work.

5.4 Respite

- Increase in respite hours and availability.

5.5 Employment

- Extend support to carers to secure work as part of long-term care support. This can be facilitated in several ways, including the provision of subsidies and scholarships for young carers, so that they can enter the workforce.
- Employment support services should recognise young carers often have experiences and skills (such as personal care, navigating the service system, translating) that are highly relevant to employers. Recognising and valuing these skills by employment services assists in the empowerment of young carers and in building their confidence.
- Addressing existing barriers to the employment of young carers, such as the lack of alternative suitable care services and lack of flexible paid employment.

5.6 Schools

Encouraging sensitive and flexible schooling arrangements. This can be done through extending academic support to young carers outside of school hours, recruiting more support staff at schools and incorporating the role of the carer in teacher training.

Section III

Where to from here?

6. What is needed?

The research evidence base on young carers from refugee and migrant backgrounds is less developed than it is for young carers in general. This is a significant constraint to advocating for the needs of this group or recommending improvements to service systems to meet their needs. There are indications that more young people from refugee and migrant backgrounds provide care but may be less likely to receive formal support than other young Australians.

An Australian research evidence base is urgently needed that explores the characteristics, roles, experiences and needs of this target group and their families. It is only by truly understanding those experiences that relevant policies can be developed, policies that recognise the assistance that is required by young carers from refugee and migrant backgrounds, as a group, and which enhance and/or develop services to address their needs and those of their families.

7. Possible research questions

There is a need for further research to add detailed knowledge regarding:

- the patterns of caring by young people from migrant or refugee backgrounds;
- the mechanisms through which they come to provide care; and
- the barriers they face in seeking and receiving assistance.

Here are some questions for further investigation. They are in no particular order.

Figure 2: Suggestions for further research

To what extent are the experiences of young carers from refugee or migrant backgrounds similar or different to those of the more general population of young carers?

To what extent do particular migrant or refugee experiences affect the incidence of caring by young people and their experiences of it?

What are the ways in which different settlement patterns impact upon the capacity of young people to cope with their caring responsibilities?

In what ways do different cultural expectations of family caring affect the experiences of young people in families with a person with a disability or chronic health condition?

Do different cultural attitudes and expectations about gender have an impact on the incidence of caring by young people and the likelihood of its disclosure?

How do the service access patterns of individuals and families from migrant and refugee backgrounds impact upon the roles played by young people within these families?

What are the current service access patterns of young carers from migrant and refugee backgrounds themselves? Are these different from the general young carer population?

What is the level of awareness of disability and caring amongst the generic service providers (schools, youth workers, migrant resource centres, language schools etc.) which are accessed by young people from migrant or refugee backgrounds?

Do young carers from migrant or refugee backgrounds receive more or less informal support through family and community networks than other young carers? To what extent does the condition of the person being cared for have an impact here because of differing levels of stigma attached to different conditions?

8. Conclusion

A literature review and sector consultation on the characteristics and needs of young people from refugee and migrant backgrounds who have caring responsibilities drew attention to the complexity and multiple facets of this combination of experiences and roles. In general, academic research about caring has been relatively quiet about how the interaction of refugee and migration experiences might affect young people with caring responsibilities. Conversely, migration and refugee research has had little focus on the provision of unpaid care by young people.

It is possible to speculate that young people from refugee or migrant backgrounds experience the impacts of their role in similar, or even more negative ways, than their counterparts from the general population. However, without further research, it is not possible to triangulate existing findings about caring by young people with those associated with refugees and migration, at least not with the certainty required. Without this confidence, policy formation can only be based on a set of assumptions.

The statewide forum provided an opportunity for the carer support and multicultural sectors to come together and reflect on the issues they face. The inclusion of the sector consultation in this paper is recognition of the value and insight service providers provide.

The forum highlighted, among many issues, the importance of networking and building partnerships. Many participants pressed for more opportunities to come together. While some multicultural agencies explained that they don't have the knowledge or skills to work with young people who have caring responsibilities, other agencies that did provide specialist programs for carers explained they hadn't built connections with multicultural communities.

ECCV, CMY and Carers Victoria are committed to this forum being the first step, not the only step. These organisations will continue to work in partnership to advocate on behalf of young people with caring responsibilities from refugee and migrant backgrounds.

