



## **Who Cares?**

# **Refugee and Migrant Young People with Caring Responsibilities**

### **Background Paper**

The Ethnic Communities' Council of Victoria in collaboration with the Centre for Multicultural Youth and Carers Victoria are committed to informing a debate on caring issues in relation to young people who take significant responsibility in care for family members. Pertinent issues are a hidden prevalence of young people with caring responsibilities from refugee and migrant communities in Victoria, their unacceptably large caring loads and their low representation when seeking help from support associations.

The Commonwealth Government is undertaking an inquiry into a long-term care and support scheme for people with care needs, their carers and families. While the need for a feasibility study at this level is long overdue, greater recognition and support for young carers from refugee and migrant backgrounds and their families should be one of its priorities to ensure an equitable and fair system for all caring families.

Studies have shown that a significant proportion of Australian youth are providing care for family members, yet their needs are being 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. The situation is even more challenging for young people from refugee and migrant backgrounds as they are more likely than other youth to have caring responsibilities, and a significant number of them are hidden from service organisations.

In Victoria, the caring service system is falling behind in understanding the specific challenges and needs of young people from refugee and migrant backgrounds despite indications from census data that this target group are more likely to have caring responsibilities than those who speak only English at home (ABS 2008). Given the vulnerability of youth from refugee and migrant backgrounds to social exclusion, it is vital that the formal service system and schools explicitly recognise and respond to their needs.

## **Why this background paper?**

This background paper is developed to first, raise awareness of the concept of informal caring amongst youth in refugee and migrant communities; second, highlight the challenges affecting young people with caring responsibilities when accessing services and third, engender a discussion with people working with or advocating for young people from refugee and migrant backgrounds on how services should respond to these challenges.

The paper aims to raise awareness of the limitations evident in the development of policies and support services for young carers from refugee and migrant backgrounds and their families. These limitations are a result of 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 their families, and the barriers they face when seeking help. Therefore, the aim of this paper is to highlight the importance of addressing this gap, propose 'signposts' for further research and policy development, and generate discussion in this area.

## **Prevalence of caring among refugee and migrant young people**

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

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).

Over the last two decades, changes around the social expectations of when youth transition into adulthood (from education into employment, moving out of the family home) has extended the age range of young people to 24 years of age. Simultaneously, a number of changes in government policy and the demographic trends of families have had an impact on youth taking on caring responsibilities within their home (Noble-Carr & DFACS 2002).

In view of these changes, the ABS Survey of Disability, Ageing and Carers for 2003 estimates that the overall number of young carers to be 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).

Studies have noted that this count of carers is likely to be an underestimate due to a number of factors. Recent work suggests that many young people particularly those from refugee and migrant backgrounds are likely to be 'hidden' from research and national surveys because these methods rely on self-disclosure (Becker 2007; Warren 2007).

In order for youth to disclose their caring responsibilities, they need 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 more than what they perceive as their responsibilities at home (Moore & McArthur 2007; Noble-Carr & DFACS 2002). This illustrates that there is a lack of awareness and

understanding within our community about the significant role young people play when providing care to family members who need assistance but do not have service system knowledge.

Other reasons for not identifying as a 'carer' may be the fear of unwanted intervention from child protection authorities (as parents fear that their situation would undermine their role as guardians and children fear that uncovering their circumstances would break-up their families) 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 problems (Hill et al. 2009). 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). As for families from refugee or migrant backgrounds, culturally held attitudes about the shame associated with having any of the conditions mentioned above generates reluctance to disclose their status and seek assistance.

These reasons highlight the existence of 'hidden carers', that is, people who undertake caring roles and responsibilities yet do not identify themselves as 'carers' (Cass et al. 2009). It also illustrates the complexities of identifying and supporting young carers from refugee and migrant backgrounds and it brings us to an understanding of why this group remain a hidden one. We can also posit that the number of hidden young carers is substantially greater than the number of young people who identify as 'carers' and those who are in contact with service organisations.

Current research on the profiles of identified young carers confirms findings from the Census of Population and Housing 2006 data that:

- 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 the person they care for and were providing assistance to a parent who was most likely to be their mother.
- The provision of informal caring by young people is more common in Indigenous, refugee and migrant background communities than mainstream groups who spoke only English at home.

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 number of people being cared for
- the carer's relationship to the person needing care
- the nature of the illness/incapacity of the person for whom they care
- the availability of and access to formal services and support
- the assistance received by carers from other family members or friends
- the period of time and frequency over which caring has been provided

The experiences of young carers are shaped by the interplay of these factors in their lives. The differences in their circumstances to other youth (with no care-giving responsibilities) are significant. 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. They are more likely to be living in low income households (Hill et al. 2009).

These differences are magnified for young carers from refugee and migrant backgrounds where strong cultural expectations about caring roles determine in what capacity they have to operate. Such expectations become the norm in families where no one else is available. These roles become even more set when families cannot access nor afford professional alternatives.

The implications of cultural diversity as an additional factor must be considered by policy makers and the formal service system. Considering that young carers are a highly diverse group, a 'one size fits all' approach simply does not work. Thus, the diverse cultural, religious and social expectations and experiences of families from different ethnic and religious communities should be acknowledge and valued.

### **Diversity of caring roles and tasks**

While young carer's circumstances are diverse, the range of tasks undertaken by them is also diverse. These youth take on a larger share of tasks and responsibilities compared to most people their age. Often, their caring role competes with other aspects of their social and economic participation, leading to their exclusion.

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).

Care tasks performed by young carers include:

- Listening, giving advice and providing high levels of emotional support
- Assisting with mobility, securing transport and organising social activities
- Attend medical appointments and manage medications
- Daily households 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
- Property maintenance, paying bills and banking

Taking into account the effort and time involved in performing these tasks, and the low income household circumstances in which they 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).

For newly arrived youth from refugee and migrant backgrounds this already difficult situation is compounded, as youth in this group face challenges that are different from those born in Australia. Young carers who have recently arrived in Australia are more vulnerable to social exclusion as many are confronted with the difficulties around integration and adjustment to their new home. What makes their caring responsibilities even more alienating is having to deal with the challenges of settling into a new country, losing the support of extended family and community (many would have left behind important 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.

## **Impacts and effects of caring**

For young carers, the care they provide incurs costs. Studies have focused on the negative aspects of caring as many of these aspects reinforce young carers' sense of isolation and social exclusion. These aspects have an impact on their physical and emotional wellbeing, their relationships, their connectedness to the broader community, their family's financial stability and their future opportunities (Moore & McArthur 2007).

While these studies canvassed young carers who may or may not be from refugee and migrant backgrounds, we infer that the negative aspects affecting both groups are similar. These aspects include:

- reduced opportunities to participate in social and recreational 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 challenge to fulfil academic requirements due to combining caring responsibilities with their schooling. This may result in disrupted attendance; not being able to concentrate during class due to concern about the family member; the inability of parents to assist in the learning process; and having less time to do homework
- risk of emotional and mental health problems
- reduced opportunities to secure full-time employment and adequate income
- complex transitions from adolescence to adulthood

There is a risk that the cycles of poverty young carers experience as children due to limited household finances 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 young carers have 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 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 which contributes to family resilience and integrity (Moore & McArthur 2007). Such connectedness is one determinant of the wellbeing of a young person, however considering both costs and benefits of informal caring, the literature demonstrates that the negative effects easily outweigh the positive effects in care giving as participation in many instances comes out of necessity (Becker 2005).

## **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. This indicates that the needs of young carers are often inter-dependent with those of the person they care for. Studies have identified a range of support needs (both formal and informal) required by young carers. These needs include:

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

### **What sort of help is available?**

While studies have identified a range of needs required by young carers and their families, it is important to keep in mind that a range of services exist at both federal and state government levels and administered through voluntary and community sector organisations but they are not necessarily available in all regions of Victoria and in some cases Australia wide. These services include:

- 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 - (These services are inconsistent and unreliable and they are focussed to benefit either the care recipient or the young carers but not both)
- financial support through Centrelink in the form of Carer Allowance and Carer Payment - (Payments are inadequate as they only cover basic necessities such as groceries and the application process required for income support payments is complicated) (Cass et al. 2009; Hill et al. 2009)
- counselling
- education support through tutoring
- peer support from buddy and mentoring programmes and when attending carer camps - (These camps only offer short-term respite)

The level of support from the service system is further limited as many 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. Moore and McArthur (2007) identify a range of service design and access issues and these include:

- 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 and lacking the knowledge of how to deal with their needs

- inadequate support for young carers due to a lack of coordinated systemic approach between the various service systems including youth services, education system and health services
- lack of recognition of young carers in programme guidelines for mainstream youth services and stringent formal eligibility criteria indicating that these services are not specifically targeted at them nor designed to meet their needs
- lack of understanding of the close connections between support for young carers and support for the family members to whom they provide care

Given that service providers only identify the needs of people with a disability or mental health problems and do not explore the broader circumstances of their family, it is argued that support options become uninformed and often fail to adequately respond to a young carer's needs (Carers Victoria 2009). It is therefore important that service providers recognise the family issues of their clients. This is clearly illustrated in an Australian study where young carers expressed that the best way services could support them is by supporting their relatives with care needs (Moore & McArthur 2007). An understanding of a young person's context and their family needs is a necessary step to minimise the care load and alleviate anxieties about the care responsibilities that are being performed (Cass et al. 2009).

It has been argued that adopting a family focussed 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 young carers' needs. This becomes particularly clear when one considers the challenges that are associated with identifying carers for support and the cultural barriers that prevent them from seeking assistance. There is a strong argument that suggests that the adoption of both approaches yields better outcomes for young carers. This would also facilitate the identification of young carers within the service system (Carers Victoria 2009).

### **Where to from here?**

Reflecting on the range of services that are being provided and their shortcomings when addressing the needs of young carers, these limitations are further accentuated for young people from refugee and migrant backgrounds due to their complex needs. At this point, the research evidence base on young carers from refugee and migrant backgrounds is less developed than it is for young carers in general. Given the limited information available on this group, we can only infer that dedicated services and/or professional support targeted specifically at them are relatively non-existent. As previously mentioned, 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.

What is needed is an Australian research evidence base 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 to recognise young carers from refugee and migrant backgrounds (as a group requiring assistance) and available services can be expanded so as to address their needs and those of their families.

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