REPORT FROM STATEWIDE MULTICULTURAL YOUTH ISSUES NETWORK MEETING

Who Cares? Refugee and Migrant Young People with Caring Responsibilities
9:30am to 12:30pm, Wednesday 25th August 2010
The Abbotsford Covent, Community Room

The Centre for Multicultural Youth (CMY) in collaboration with the Ethnic Communities’ Council of Victoria (ECCV) and Carers Victoria are committed to informing debate in relation to young people who take significant responsibility in caring for family members. Studies have shown that a significant proportion of Australian youth are providing care for family members, yet their needs are being inadequately met1. 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.

The Commonwealth Government is currently 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.

A background paper has recently published by ECCV in collaboration with CMY and Carers Victoria and can be accessed from the CMY website: www.cmy.net.au/statewideNetwork

Overview

CMY’s second State-wide Forum for 2010 focused on the issue of young people from refugee or migrant backgrounds who have responsibility for providing care for a family member with an illness or disability.

Despite the fact that young people from refugee or migrant backgrounds are more likely to have caring responsibilities, services often struggle to identify these young people as carers and provide appropriate support.

This forum provided an opportunity to bring together the caring and multicultural sectors, to discuss and build a clearer picture of what growing up with caring responsibilities looks like for this cohort of young people within the current service system.

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1 Moore, T & McArthur, M 2007, ‘We’re all in it together: supporting young carers and their families in Australia’, Health and Social Care in the Community, vol. 15, no. 6, pp. 561-568
More than 60 people from a range of services participated in the forum, many of whom had never previously been involved in a CMY event. Guest speakers and discussion groups explored a number of issues including:

- The definition of ‘caring’
- The experience and impacts of caring for young people
- The needs of young carers
- Community and cultural expectations of caring
- The challenges for the service system in responding to the needs of these young people
- Recommendations for the future.

This report summarises the proceedings of the forum including guest speakers’ presentations and the small group discussions, as well as follow-up actions to be explored and developed by CMY, ECCV and Carers Victoria.

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**Speakers**

**Tim Moore**  
Research Scholar,  
Australian Catholic University’s Institute of Child Protection Studies

PhD scholar Tim Moore specialises in research with vulnerable and disadvantaged young people.

With his colleagues at the Institute of Child Protection Studies, Tim Moore recently submitted a report on children acting as carers for parents struggling with drug and alcohol issues and has completed a study on young people transitioning from life in juvenile detention centers.

Tim opened this forum by outlining the experiences of young carers generally before sharing his insights about young carers from culturally and linguistically diverse backgrounds. His presentation was based on his extensive experience working with young carers and included many direct quotes from young people. A copy of his PowerPoint presentation can be accessed at [www.cmy.net.au/statewideNetowork](http://www.cmy.net.au/statewideNetowork)

Key points included:

- Young carers are children and young people who care for, or help care for, a family member (or friend) affected by illness, disability, drug or alcohol and / or mental health issues.

- Internationally, very little research has been conducted with young carers from CALD backgrounds.

- Statistics show that there are around 390 000 young people with caring responsibilities in Australia, however this figure is a gross underestimation as it doesn’t take into account young people caring for parents with drug and alcohol issues.
On average in each classroom, there are two young people who are taking on extra responsibilities at home – there are likely more in classrooms with high numbers of CALD children and young people.

As a result of their caring responsibilities, some young people miss out on the supports that they need.

Young carers often aren’t recognised as a target group or as ‘at risk’ by services or funding bodies.

Young people from CALD backgrounds are more likely to care for family members but less likely to receive support.

Young people from CALD backgrounds are also more anxious about how the community and services will view them than are other young people.

Young people from refugee backgrounds are more likely to be caring for an adult in the family with post traumatic stress syndrome and also much more likely to be translating health information.

Young carers from refugee and migrant backgrounds may be caring for family left behind in their country of origin and sending money back.

Young carers are often positioned as either heroes or victims by the wider community however this is unhelpful as it can add extra pressure.

The caring responsibilities of young people include intimate and personal care, emotional care, looking after younger siblings, cleaning and other household chores, and trying to generate income to support their family.

There are many negative impacts of caring (see Tim’s PowerPoint).

Services are often unsure how to work with young carers from CALD backgrounds. Commonly these young people don’t fit into services’ target groups and are referred on endlessly.

The following steps are required, to improve the lives of young carers from CALD backgrounds:

- Ensuring that these young people are safe
- Assistance needs to be a shared responsibility
- Services need to become more flexible and responsive in the way they provide support
- Health care professionals need to be engaged so that they can start referring the young carers to services - because they are the ones who are in contact with the person requiring care in the family

Young carers need people to advocate and fight for them just as hard as they do for the person they care for.

**Nyadol N**
Young Person

Twenty-two year old Nyadol N is a community development worker and activist and has been instrumental in the Lost Boys Association of Australia since arriving in Victoria in 2005. She lives in a large regional centre. She is currently one of the executive
Nyadol presented her personal story of caring for her family. She spoke of the challenges and sacrifices she has faced and of the cultural and community expectations that surround the concept of caring.

As her mother has had to temporarily return to Africa to care for a family member, Nyadol has been the main carer for her seven brothers and sisters since the beginning of the year. She has also been a key carer (with her mother) for several years. Over this period, there have been times when Nyadol has worked full time or studied full time, and at other times worked and studied part time.

More recently, Nyadol has been unable to further her studies due to her family responsibilities.

Community expectations
As a Sudanese young woman, and one of the oldest in her family, Nyadol said it’s her ‘duty’ to be in charge when her mother has to leave the house. This sense of duty is never questioned. There is no opportunity to talk to the community about the struggles this may present. When talking to community leaders, she felt that (as is the case in Sudan) there is an expectation that girls are not supposed to study and achieve and that their responsibilities are at home.

Services
Nyadol said that she didn’t know what services were available to help her. She is well connected and speaks fluent English, yet still had difficulties finding the appropriate services. She fears that finding these services would be harder for many other young people in her situation who are less connected and educated.

She has also found Centrelink to be not very understanding of her predicament: her inability to work while caring for seven siblings. Anxiety around not being able to pay bills and dealing with services, adds to her existing anxiety about looking after her family.

Keith Hitchen
Manager, Education, Equity & Access Program
Action on Disability in Ethnic Communities (ADEC).

Keith provided a perspective from a service dedicated to empowering people from ethnic backgrounds that have caring responsibilities. Keith highlighted the services that ADEC offer and provided details of the programs and projects that they are delivering.

Keith highlighted some of the barriers that young people face in accessing services such as ADEC and barriers that ethnic communities in general face in accessing information. He also highlighted the difficulties and shortcomings of services, including funding restrictions that dictate whether programs can be offered to young people and a lack of flexibility in terms of catering for clients with a range of circumstances and complex needs (opening hours in particular are not flexible enough for young people).

Barriers for young people accessing carers’ services include:
- Young people’s lack of knowledge of the service system.
- Young people often not recognising themselves as ‘carers’.
- Young people are neglected by service providers (due to their hours of service).
- Young people are discriminated against by service providers due to their age.
- Services make assumptions of young people’s needs because young people often do not adequately express their needs.

Keith Hitchens’s PowerPoint presentation can be accessed at: www.cmy.net.au/statewideNetwork

Consultation

A key focus of the forum was to gather information from participants to paint a more informed picture of what caring looks for young people from refugee and migrant backgrounds within the current service system. This information would be used to develop recommendations.

Ben Ilsley, policy advisor at Carers Victoria, facilitated the consultation. Participants broke into eight small groups to discuss the following three questions:

1. What do you know?
2. How do you work with this group of young people?
3. What needs to change?

This is a summary of what was said:

What do you know?

a) Do you work with refugee and migrant young people who have caring responsibilities?

- Nearly every group reported that they do work with young carers from refugee and migrant backgrounds in some capacity.
- Some groups reported that because they find it hard to identify young carers they were unsure if they were working with them.

b) What have you noticed about them and their needs?

Each group reported seeing a range of different issues and needs that this group of young people faced. These included:

- Most young people don’t identify as young carers. This often means they don’t receive support from any services.
- In order to fulfil their caring responsibilities many young carers are not attending school.
- Some young carers are required to provide high levels of informal care and may be kept home from school for company. This could be reflective of the isolation their families face as well as their regular interpreting responsibilities.
• Young carers are commonly required to translate and interpret important health messages for their families.

• Young people are often required to drive family members to appointments. This presents an increased risk of coming into contact with criminal justice system.

• Many groups reported that young carers from refugee backgrounds were regularly required to care for younger siblings when their parents travelled overseas.

• Many groups also reported that these caring responsibilities were a key barrier to young people finding employment.

• It was reported that young carers had very limited social networks and were often isolated.

• Most groups reported that emotional support is needed for these young people. It was also reported that young carers are facing health, nutrition and fatigue issues.

• Many groups reported that young carers were reluctant to access services and that assistance with appointments is often required.

• Generally, it was reported that there is a lack of awareness and recognition of mental health issues by young carers.

c) How does the cultural background of the young person affect what they need and how they access help?

The most commonly reported impact that a young carer’s cultural background had on their needs was around their communities’ cultural expectations of caring. Many groups reported that caring for family members was completely expected of young people. Participants reported that it was seen as a duty of young people and could not be questioned.

Other cultural impacts (?) reported by the groups included:

• Some young carers felt that there was shame and stigma attached to asking for help.

• Young carers from refugee and migrant backgrounds often have very complex needs. These can include torture and trauma issues.

• They are often caring for family overseas and carry guilt for not being able to provide for them.

• Young people faced difficulty drawing a distinction between the role of a carer and the role of a family member.

• In the context of settlement, finding time to focus on their caring needs was often difficult for young people already juggling study, work and home responsibilities.
• Some young migrants had limited access to finances – especially Pacific Islanders and Visa Number 2 (?) holders who are not eligible for Centrelink benefits.

• Services (workers) putting pressure on young people – imposing Western values on young people, parents and their families

• It was noted by some groups that young people from refugee backgrounds have significant strengths and skills but need extra support to make settling in bearable.

• Lack of information in their language and a lack of multilingual staff

2. How do you work with these young people?

a) What Works?

Four key strategies were consistently highlighted as integral to successful work with young people from refugee and migrant backgrounds with caring responsibilities:

- Family focused support
- Support driven by young people
- Practical assistance
- Flexibility and stability

Family Focused Support

• Participants reported that family focused support was fundamental to providing effective carer support for refugee and migrant communities.
• It was noted that transparency is very important when working in a family focused context.
• Some participants reported that they often have to advocate within their own organisation around the need for family focused support.

Support Driven by Young People

Participants reported that the most effective work was driven by the needs of the young people rather than by the needs of the worker. This required:

• Workers to meet with young people at places they are comfortable and familiar with (outreach).
• Workers to respect the cultural values of young people
• Workers to allow young people to educate them about their own culture.
• Taking an informal and casual approach to working with these young people.
• Investing time in establishing trust.

Practical Assistance

Practical assistance was noted as particularly helpful for young carers and their families. Types of practical assistance mentioned included:

• Providing homework tutoring and computer equipment for young carers.
• Providing child care so that carers or their family members can attend appointments.
• Using translators.
• Offering a suite of respite and financial support.
• Providing respite support to allow for study time.

Flexibility and Stability

Time and again flexibility and stability were brought up as essential components of working with young carers from refugee and migrant backgrounds. Participants noted that:

• Flexibility is regularly required for effective service provision.
• Flexibility may require lateral thinking and an organisational openness to providing outreach and home visits.
• Flexibility may also require extended service periods so that workers are available to young carers after-hours.
• Stability requires investing time in establishing trust.
• Stability requires workers to follow up and offer personal help with any referrals made.

b) What Doesn’t Work?

Participants made it clear that ignoring these strategies (listed above) would mean work with this group would not be effective. Participants singled out the following strategies as clear mistakes:

• A ‘one size fits all’ approach to support.
• A dependence on young carers to self-identify and seek services.
• An over-reliance on schools to identify and provide support to young carers from refugee backgrounds.
• Not focusing on the educational needs of young carers.
• Culturally inappropriate respite
• Services and funding boundaries don’t allow flexibility.
• Not working in a family-focused context.

c) What are the Major Challenges?

Participants from each group discussed the major challenges faced both by young carers and the services trying to support them.

Challenges facing carers

The challenges that young carers face centre on health literacy and terminology and their ability to successfully navigate the service system. Responses included:

Terminology and health literacy

• Low English language levels.
• Low levels of health literacy especially around mental health.
• Distrust of interpreters regarding confidentiality.
• Difficulties around confidentiality with professionals from the same culture.
• The terminology of ‘mental health’ and ‘carer’ carries stigma.
• The terminology used by health professionals often does not exist in other language groups.
• Lack of accreditation of work that young carers do
Navigating the service system

- The complexity of services.
- Lack of education about the services.
- Young carers lack knowledge about the dynamics of purchasing respite services.
- Young carers have difficulty keeping appointments.
- These issues are compounded for young carers from regional or rural areas who also face issues around the lack of services, social isolation and transport.

Challenges facing services

Two of the major challenges that participants noted services face were restrictive funding schemes and a lack of networking opportunities. Participants documented that:

- Restrictive funding and working models that were purely ‘outcome’ focused often interfered with a whole-of-family approach.
- Funding restrictions often meant that not enough time is available for individual clients.
- Working in a family-focused model was very challenging especially in regards to confidentiality.
- Culturally sensitive work was challenging for many agencies.
- Engaging with parents of young carers is very challenging.
- There are very limited opportunities for service providers to network and share information.

3. What Needs to Change?

a. What would make a difference for this group of young people?

Participants noted recommendations that fell broadly into three categories for this question.

More Accessible Support Programs:

- Flexible programs that are less structured and more informal in nature – suggestions included using sports, recreation and barbeques to make programs more accessible for young people.
- Services provision to include outreach so that young people don’t need to seek out services.
- Changes in guidelines that restrict young people who aren’t in school from accessing help.

Community Education

- Community education so that communities better understand the needs of young carers.
- Education about respite to care recipients.
- Information about carers support during the Australian Cultural Orientation (AUSCO) pre-departure program.

More Specialised Services
• More bicultural workers and workers who focus specifically on newly-arrived communities
• Separate funding for carers from CALD backgrounds
• Examine criteria and definition of carer to build CALD voice

b) What would make a difference to your work in this area?

Participants noted numerous recommendations to improve their own work. These included:

**A Better Understanding of Caring in a Cultural Context**

• Redefine ‘caring’ to fit for CALD/ethnic groups
• Considering additional carers as well as primary carers.
• Current service system has underlying Anglo assumptions/models of illness, care and support.
• The need to assess the relevance of care services for different CALD groups.
• The need for cultural competency training.
• More emphasis on raising the profile of young carers from CALD backgrounds.

**Flexibility**

• Flexibility in services is the key – not a ‘one size fits all’ approach.
• Specifically, flexible opening hours and the ability to provide outreach were argued for.
• Many participants felt that the more time they could spend with individuals, the more positive outcomes would eventuate.

**Networking and Training**

• More information sharing
• Importance of raising awareness among key contacts for young carers – schools, elders, health providers, to recognise carers and suggest support.
• Build networks and partnerships before seeking funding
• Find and develop ‘cultural champions’ within communities
• Cross cultural training to workers in sectors like education
• Training to better identify carers from CALD backgrounds

c) What are your recommendations about how we can move forward?

Participants from each group identified key steps that were needed to effectively move forward in this space. This included the opportunity for more networking and training, greater community consultation, a clearer definition of ‘carer’, a more responsive service system and further research.

The following recommendations were made:

**More Networking and Training**

• More information sharing
• Cultural courage to work with these young people
• More organisational networking and collaboration.
• More forums to connect workers, initiating a platform for people to come together and talk about issues

Community Consultation and Awareness Raising

• Communities need to be brought into the conversation around young carers.
• Young carers’ programs can be promoted through ethnic media.
• Build the capacity of community leaders to engage with young people and hold information sessions.
• Involving carers in the decision-making.

Build Definition

• Redefine the concept and role of ‘caring’ to include refugee and migrant young people.
• Identify different types of caring that are common for refugee and migrant young people

‘No Wrong Doors’ approach

• Advocacy is needed to establish the ‘no wrong doors’ approach across the service system.
• This requires services to respond and pull in support rather than refer out.
• This requires the cultural competence to work with these young people.
• Increasing engagement through informal functions with young people and service providers.
• Address the needs of young people who are not permanent residents

More Research

• Research is needed to highlight the needs of young carers and establish effective models to move forward with.
• For regional and rural solutions suggestions were made to look at Internet Communication Technology as a means to address access issues.
• Suggestions were put forward to learn from the Aboriginal service system.
• Tim Moore suggested useful resources and current research could be found at www.acu.edu.au/icps and www.youngcarers.net.au

Evaluations

The evaluation forms provided by participants showed that the guest speakers’ presentations were very well received. Many participants also commented that the small group discussions were particularly useful, however, many also noted that more time needed to be allocated to them.

It was apparent that participants felt that the topic of young carers was very important to their work and that this forum should not be an end-point in the discussion. Many participants wrote in their evaluations that the dialogue must continue. Other suggestions for what should happen after this forum included:

• Report from this forum to be circulated.
• More networking opportunities to be provided.
• Training to be made available.
• Information sheets to be produced.
• A Newsletter/ email updates to be circulated.
• Further consultation.

Where to from here?

CMY, Carers Victoria and ECCV are committed to this forum being the first step, not the only step. Following on from this and taking into account suggestions on the evaluation forms, we have planned a series of follow up actions:

• ECCV will use input from the forum to expand on its background paper (circulated prior to the forum) and develop a policy discussion paper (to be launched early next year)

• A tip sheet on resources and how to support young people of CALD background with caring responsibilities will also be developed and circulated by the end of the year.

• CMY will include information about young carers in its ‘cross cultural training’ material on how to work with newly-arrived young people

• CMY, Carers Victoria and ECCV will continue to work in partnership.

For more information

For more information about this Statewide Forum, visit CMY’s website
www.cmy.net.au/StatewideNetwork

Or contact:

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