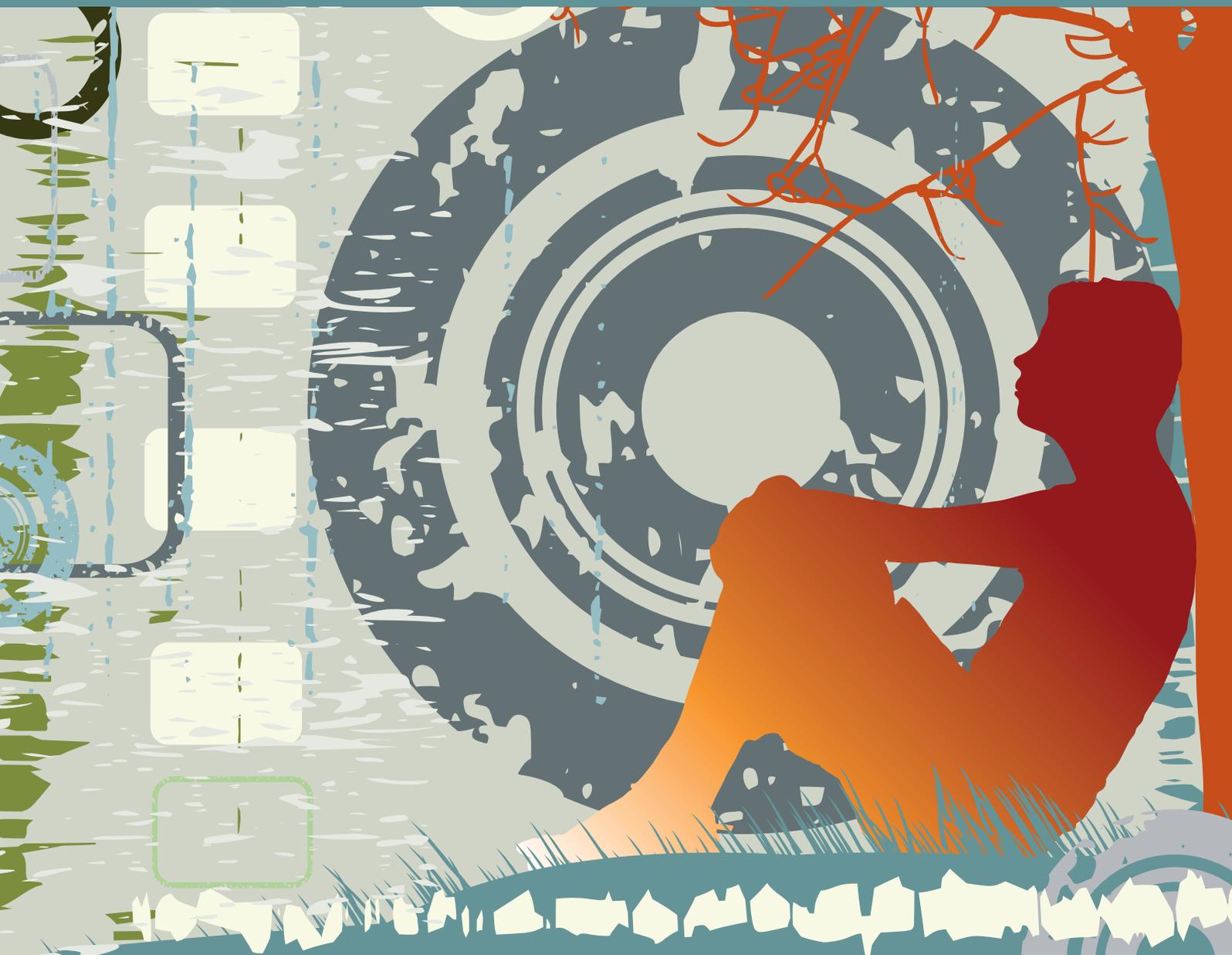


hopping off the roundabout



SUPPORTING YOUNG CARERS IN WESTERN AUSTRALIA

A report of the findings from the Young Carers Roundtable 2007
by Tim Moore and Ros Morrow for Carers WA

Facilitation and Authorship



The Young Carers Roundtable was facilitated by Tim Moore from the Institute of Child Protection Studies at the Australian Catholic University. For ten years, Tim has worked with young carers across Australia and has developed case management, social and recreational, community development and support programs to assist young carers and their families. In 2005 he helped develop the national Supporting Young Carers program and has engaged in research focusing on young carer's educational, respite and broader support needs.

At the Roundtable, Tim worked with young carer champions who shared their experiences and provided feedback on suggested strategies. Carers WA would like to acknowledge these young carers who provided invaluable insights into the needs and experiences of children and young people with care responsibilities:

- Aleria (aged 16, who cares for her mother who suffers with Depression)
- Tammy (aged 18, who cares for her brother who has Down Syndrome and her grandmother with terminal Cancer)
- Raynar (aged 21, who cares for her brother who has suffered multiple strokes)
- Andrew (aged 17, who cares for his father with Parkinson's Disease)
- Rebecca (aged 14, who cares for her mother who has Bipolar Disorder)
- Sven (aged 14, who cares for his cousin who has Down Syndrome and Autism)
- Daniel (aged 13, who cares for his mother who has Multiple Sclerosis)
- William (aged 16, who cares for his brother with Muscular Dystrophy)



This report was written by Tim Moore and Dr Ros Morrow. Dr Ros Morrow is a registered psychologist and is a senior lecturer in the School of Psychology at the Curtin University of Technology. Over the past three years, Ros has conducted and supervised research projects focusing on young carer issues, particularly in regard to their psychological health and wellbeing. In 2005, Ros conducted a state-wide research project to explore the experiences of hidden carers and has developed a tool to assist teachers and services providers better identify young people with care responsibilities.

Foreword

With over 40,000 young carers in Western Australia, the Young Carer Roundtable aimed to build on the recommendations from the National Young Carer Summit 2006 so that we can develop ways to better support this group of young people in our state.

The Roundtable participants have come up with range of recommendations for the key areas of identification; education; respite and whole of government. These will now need to be prioritised within a strategy which we can recommend to government. Carers WA will work with key stakeholders to this end.

Our community can do better in supporting these young people who are caring for parents, grandparents, brothers and sisters. Carers WA is committed to seeing that this happens. We thank all those who took part and look forward to working together to on the next stages.



Carol Franklin,
Vice Chair, Carers WA

The Young Carers Roundtable and Report is proudly funded by the Department for Communities, Office for Youth.



Recommendation Snapshot

Area	Issues	Recommendation
Identification	Promoting young carers and their positive contributions	<ul style="list-style-type: none"> • That existing young carer awards be further developed to promote caring positively and to recognise the significant contribution that young carers make to the community. • That a community awareness plan be developed to promote the fact that many young people have care responsibilities, that caring can be a positive experience and that support is available. This would include resources culturally appropriate to indigenous and CALD communities. • That a group of older young carers be supported to share their stories publicly – to services, schools and at community events – through presentations, drama or audiovisual means.
	Recognising indicators of young caring	<ul style="list-style-type: none"> • That a module focusing on how to best identify and support young carers be produced as a professional development tool for teachers. The module would include information about the lived experience of young carers, indicators of young caring, tips for appropriately responding and how to make contact with available supports. • That a question be placed on school enrolment forms for students inquiring about whether they assume care responsibilities in the home. • That the existing Young Carers Identification Checklist be further developed and distributed with training on how to identify young carers and assess their needs.
	Promoting supports and services	<ul style="list-style-type: none"> • That a resource manual which lists available young carer services and supports, contact details and information on how to access be developed and distributed widely and be made available on the internet. This manual should be disseminated to counselling staff and chaplains within schools, child, youth and family support services, health, disability, aged care and community organisations and peak bodies.
	Supporting participation in decision-making	<ul style="list-style-type: none"> • That existing carer and consumer participation models be assessed to ensure that they meet the specific needs of children and young people and that, if lacking, tools be developed to assist service providers provide young carers with appropriate information about their cared-for relative's condition.
Education	Lack of awareness in schools	<ul style="list-style-type: none"> • That the Education Department appoint a Young Carers Officer to support schools to better identify and support young carers. This worker, who could be located at Carers WA, would also assist young carers directly and help co-ordinate their educational supports as required. • That Carers WA develop, in collaboration with the Education Department, a module on young caring to be included in core training for teaching students in WA universities. This module would include information about how young carers experience their caring, the challenges they face in accessing, achieving and participating in school and strategies to support them. Strategies for dealing with discrimination relating to illness and disability might also be included. This module could be piloted by the Centre for Excellence at the Curtin University of Technology.

Recommendation

Issues

Area

- That teachers, principals and support staff (ie chaplains, school psychologists and youth workers) be provided training on how to create young carer-friendly schools and strategies to support them within their schools. Such training may be incorporated into existing professional development including (but not limited to) anti-bullying, resilience, mental health and classroom management.

Lack of awareness in schools
contd.

- That models of Recognition of Prior Learning be explored and be incorporated in Department of Education guidelines.

Flexibility in assessment
and delivery

- That on-line and distance education models be identified and offered to young carers to reduce the number of hours they are required to physically be at school.
- That Carers WA work with the Curriculum Council to develop young carer specific units (similar to those being developed in SA) that recognise prior learning units (such as disability support, household management, self care etc). These units should be accredited and respond to the individual needs of students.

- That a toolkit be developed for schools and community organisations on how to best develop and maintain partnerships for young carers. This might include examples of good practice, templates for developing memorandums of understanding and joint case planning.

School-community linkages

- That existing supports for students experiencing financial difficulty be identified and promoted to young carers and their families (ie Smith Family's Learning for Life etc).
- That a brokerage fund for young carers unable to access education due to financial difficulty be established and funded by the Education Department and through corporate sponsorship. This fund should allow families to purchase educational supplies, pay for excursions and co-curricular activities and purchase respite when necessary.

Need for additional resources

- That respite providers work with young carers to identify what activities / programs are effective in reducing their levels of stress and anxiety and physical fatigue.
- That program guidelines be reoriented towards achieving 'the respite effect' for both young carers and their cared-for relative and that programs be given the flexibility to broker additional services and to pay for activities such as movie trips, camping holidays and sports that help the young carer relax and reduce social isolation.

Definitions of respite

- That the Australian Government Department of Family, Community Services and Indigenous Affairs and Health and Ageing expand the eligibility criteria for respite.
- That an assessment be developed for respite programs to identify level of need based on both the number of hours provided but also the impact that assuming care has on the young person's life.

Eligibility

Education

Respite



Area

Issues

Recommendation

Respite

Family-responsive approaches

- That research be conducted to identify best practice family centred support models that address the needs of individual members and the family as a whole and that such models be piloted within Western Australia.

Peer-based models

- That the Carers WA young carers camp program be funded recurrently and that the program be expanded so that it can meet the needs of young carers in rural, remote and metropolitan areas.
- That Carers WA be provided with brokerage funds to allow young carers opportunities to participate in school, social and community activities (such as sports, camps, and leadership development programs) with their non-caring peers.
- That the young carers manual be distributed to mainstream child and youth organisations to equip them to better support young carers who seek assistance from their organisations.

Co-ordinated approaches

- That respite services work with mainstream youth programs to develop a respite program for children and young people for periods when a sole parent is in hospital or in centre-based respite. This might include formal fostering arrangements, short-term centre-based support or resourced kinship care.

Collaborative and Whole of Government Approaches

Identifying family-centred approaches

- That research be conducted to identify best practice family-centred support models that address the needs of individual members and the family as a whole and that such models be piloted within Western Australia.

Challenges to interagency collaboration

- That contract managers in WA government departments negotiate outputs that enabled organisations to resource collaboration activities.
- That the young carer program at Carers WA be funded recurrently to ensure that it can meet the ongoing needs of young carers in the state.

The need for effective communication and networking

- That Carers WA be resourced to establish a Young Carers Network (YCN) for government and non-government support organisations and agencies. The YCN would offer a number of benefits:
 - Sharing of information
 - Communication between agencies which will guide evidence-based practice (e.g., sharing of models)
 - Research Seminars and Discussion Groups
- This Network would host an annual forum to progress state-wide responses to young carers and their families.
- That Education, Health, Disability, Community and Youth departments ensure representation by appointing staff to this network.

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1. Introduction

Young carers are children and young people who care or help care for a family member with an illness, disability, mental health issue or chronic condition.

Young caring is an experience shared by up to 40 000 children and young people in Western Australia (Morrow, 2005). Although they provide thousands of hours of support to their families and save their communities millions of dollars each year (Access Economics, 2005), little is known about their lives, their experiences or their needs.

On the 8th August 2007, Carers WA worked with a number of community and government organisations to continue to raise community awareness on young caring and to develop strategies for future responses by holding a State Young Carers Roundtable in Perth. The forum was attended by 66 delegates, representing government agencies and departments, non government organisations (including youth, family, disability and respite programs), and local councils.

The roundtable presented an opportunity for delegates to share ideas and also to discuss programs which are currently being implemented in the community. It was hoped that delegates would develop their understanding of young carer issues while identifying ways that they, their organisations and the broader community might better respond to them.

This report captures the outcome of discussions held over the one day forum. In particular it gives a snapshot of the issues and strategies identified within the 4 key areas – Identification, Education, Respite and Whole of Government Approaches. It also presents recommendations for policy and decision-makers and for practitioners to enhance the response to young carers and their families.

1.1 What we know about young carers:

It has been estimated that approximately 10% of children and young people in Australia assume care responsibilities for a family member or friend. Relatives may be affected by an illness, a disability, a mental health or drug or alcohol health issue, a chronic condition or be frail aged. In some cases, young carers may care for a number of relatives or for one relative with a number of conditions. Most often, young carers care for a single parent who is most likely to be their mother (Carers Australia, 2002).

As the conditions that affect their relatives differ, so too may the tasks that young carers assume in their families. Often young carers will assume household tasks, provide personal care and emotional support while supervising younger siblings and co-ordinating services and programs. Often they will do so with little or no supervision and for extended periods (Moore, 2005b).

“I don’t think there was
a time or year. I believe
I was born to care.
For my brother I do it as
a job and a career.
I feel it was God’s plan.”

Some young carers report that they began their caring from as young as five years old, although most young carers under 18 are aged between 10 and 13 years. Both boys and girls care and may do so with other relatives as part of a ‘care team’. Care responsibilities take an average of 6 hours per day and young carers may care for up to 14 years (Carers Australia, 2002; Moore, 2005b; Moore & McArthur, 2007).

1.2 How young caring affects children and young people

Young carers report that caring can have many positive affects on their lives. Providing them an opportunity to care for those they care about, young carers feel valued, report having strong relationships with their family members and identify a range of skills that they have developed which they will use in other aspects of their lives (Moore, 2005b).

However, young carers also suggest that when their families are not adequately supported, they may assume responsibilities that can have a negative affect on their lives. Many report physical fatigue and injury; feelings of worry, anxiety and distress; social isolation; limited opportunities in education, employment and in connecting with their communities. These affects may be short-lived but will often continue into adulthood when children and young people are not provided supports to overcome challenges and issues (Carers Australia, 2002; Moore, 2005b).

1.3 Progress to date

Since the mid 1990s there has been a growing awareness of the existence and specific life experiences of young carers in Australia. Prior to this, young carers were relatively hidden and were not afforded specific program or policy responses (Becker, 2005). In 2001, Carers Australia released a national report that drew together, for the first time, research from across the country and from the United Kingdom and recommended that a range of services and policies be developed to assist children and young people with caring responsibilities (Carers Australia, 2002).

In 2003, Carers WA hosted a forum where young carers and service providers highlighted key issues and a set of state-based strategies were identified. This forum was followed by two national young carer summits hosted by Carers Australia and a series of research projects that further identified their needs. In response to these forums, Carers WA developed its young carer’s program offering greatly needed support, respite and counselling – with funding from both State and Federal governments.



Although considerable progress has been made, international commentators suggest that Australia has not yet an adequate response to young carers or created policy to address existing gaps. In Table 1, Becker (2007) explores how Australia is situated within the international context.

Table 1 Comparison of current trends in the UK and Australia

Level	Characteristics	Country/Region example
Advanced	<ul style="list-style-type: none"> • Widespread awareness and recognition of young carers among public, policy makers and professionals • Extensive and reliable research base • Specific legal rights (national) • Extensive codes and guidance for welfare professionals and national and local strategies • Multiple dedicated services and interventions nationwide 	UK
Intermediate	<ul style="list-style-type: none"> • Some awareness and recognition of young carers among public, policy makers and professionals • Small research base • Partial rights in some regions • Small but developing body of professional guidance • Some dedicated services and interventions nationwide 	Australia
Preliminary	<ul style="list-style-type: none"> • Little public or specialist awareness and recognition of young carers • Limited research base • No specific legal rights • Few, if any, dedicated services or interventions at national or local levels 	USA
Emerging	<ul style="list-style-type: none"> • Embryonic awareness of young carers as a distinct social group within the 'vulnerable children' population 	Sub-Saharan Africa

Carers WA recognises that as a state, Western Australia sits somewhere between the "Preliminary" and "Intermediate" levels but is committed to engaging community and government to further its progress.

“I didn’t want my brother
to know what was
happening at home
(extent of caring
responsibilities) because
I wanted one of us to
have a childhood”

2. The Roundtable

2.1 Aims of the Young Carers Roundtable

The Young Carers Roundtable was developed to build upon the outcomes of the 2003 young carer forum and to:

- Continue to raise awareness of the existence, needs and issues of children and young people with caring responsibilities
- Develop strategies to respond to need and the negative impacts of caring
- Encourage and facilitate interagency and cross-sectoral networking and collaboration

2.2 The Participants

The roundtable was attended by 66 delegates, representing government agencies and departments, non government organisations (including youth, family, disability and respite programs), and local councils.

2.3 Young Carer Champions

Eight young carers aged between 13 and 21 years attended the forum each of whom has caring responsibilities for one or more family members with a disability, mental illness or chronic condition.

Young carers were actively involved in planning and participating in the forum. This reflected Carer WA’s commitment to youth participation and the view that young carers have a valuable and important part to play in understanding their experiences.

Young carers worked with Carers WA staff and the facilitator, Tim Moore, in designing the day’s format and shared their experiences as part of a panel during three of the four sessions. They also participated in small group discussions and helped participants identify responsive approaches to the issues raised. This proved to be an invaluable part of the process.





2.4 The Process

The roundtable was officially opened by the Hon Sue Ellery who discussed her own experiences as a carer for her mother. The Minister then outlined the WA government's commitment to carers, families, children and young people.

Young carers were then invited to join a panel where they talked about their own experiences of caring and highlighted the key issues that affected their lives. Their stories provided the roundtable with a personal and confronting insight that laid the foundations for the day.

This presentation was followed by four workshops where the topics of Identification, Education, Whole of Government responses and Respite were presented by researchers Tim Moore and Dr Ros Morrow and Carers WA staff Noreen Fynn, Richard Newman and Britta Meyer. Groups of professionals and young carers then met to identify existing programs and service gaps; and to develop a list of strategies to meet unmet need.

3. Identification

Background

Although there are at least 40 000 young carers in WA, only a small number of young carers have been identified by formal services (Morrow, 2005). This is because many young carers have not, or choose not, to identify themselves for fear of:

- being taken away from the family;
- being bullied at school;
- not feeling they are in a safe environment to disclose that they are a young carer;
- losing their anonymity and privacy; and
- consequences experienced by their parents and cared-for relatives (Moore, 2005a).

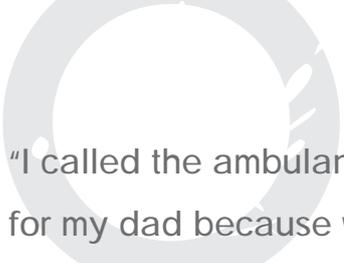
For some simply not realising they are a young carer or not having heard about young carers stops them from formally identifying. Others report being discouraged to do so by parents and families who see caring as a private matter or who are concerned about being judged or scrutinised. Some share experiences of times when they have identified but have not believed or supported – making them reluctant to do so again (Moore, 2005a).

Although many young carers are concerned about the implications of identifying as a young carer, others argue that it was only when they were identified that:

- they were able to get the support that they and their family needed;
- they were able to get assistance in keeping up with education, friends and the community; and
- they were given understanding, recognition, encouragement and support.(Moore et al, 2006)

In particular, young carers valued the opportunity to be connected to other young carers and participate in social, recreational and supportive activities where they felt safe and connected.





“I called the ambulance for my dad because when he gets sick he falls and hurts himself. He gets dizzy and falls, he has something in his head that affects him and has LOTS of medicine”.

Issues Identified in Workshops:

3.1 Promoting young carers and their positive contributions

Participants stressed the importance of raising community awareness in regards to young carers and their needs. They believed that unless services, schools and staff were aware of the issues they could not identify or respond effectively. They called for a broad community awareness campaign that promoted young caring and ways of effectively supporting children and young people with caring responsibilities.

Participants believed that caring and disability and illness were often presented negatively in the media and within the community more broadly. Young carers felt that this often acted to keep some children and young people from identifying and led to bullying and harassment for many who did. It was felt that positive images of caring needed to be presented and that young carers needed to be portrayed not as ‘victims’ or as ‘heroes’ but as young people who were positively contributing to the community and those they deserved recognition and support.



recommendations

Recommendations included:

- That existing young carer awards be further developed to promote caring positively and to recognise the significant contribution that young carers make to the community
- That a community awareness plan be developed to promote the fact that many young people have care responsibilities, that caring can be a positive experience and that support is available. This would include resources culturally appropriate to indigenous and CALD communities.
- That a group of older young carers be supported to share their stories publicly – to services, schools and at community events – through presentations, drama or audiovisual means.

“It’s not so much about the identification as lots of my friends know they are carers – it is more about acknowledging and letting young carers know that you are there to support them when you need it.”

3.2 Recognising indicators of young caring

The importance of effectively identifying young carers and of accurately assessing their needs was highlighted. This would ensure that children and young people could be provided with assistance that was responsive to their needs. Participants argued that professionals needed training on how to approach children and young people who they thought may have care responsibilities and be provided with tools to support them. Young carers believed that this was vital, as many would not tell people about their family situation if they believed that they could not support them.

Children and young people spend a considerable amount of time at school. While young carers may have difficulty in attending school regularly writers such as Morrow (2005) argue that it is the venue most appropriate for identification. To date this seems not to have been the case and to assist with this process a Young Carer Identification Checklist (YICC) has been developed (see attachment page 23). The YICC can help identify young carers who may be at risk and who could be referred to services or organisations such as Carers WA.

Recommendations included:

- That a module focusing on how to best identify and support young carers be produced as a professional development tool for teachers. The module would include information about the lived experience of young carers, indicators of young caring, tips for appropriately responding and how to make contact with available supports.
- That a question be placed on school enrolment forms for students inquiring about whether they assume care responsibilities in the home
- That the existing Young Carers Identification Checklist be further developed and distributed with training on how to identify young carers and assess their needs.

recommendations



“When my cousin goes to a respite centre for a week, that’s when I start to worry about what she’s doing there because of the extent of her autism. It’s taken us years to train her to feed herself and say ‘please’ and do other stuff. The Respite Centres, they have so many other people to look after and they don’t consult with the family about what they need to do . . . whenever Jenna comes back from respite, it’s like back to square one.”

3.3 Promoting supports and services

Service providers stressed the importance of promoting programs available to young carers and their families so that children and young people could self-refer or be supported to access available supports. Participants felt that programs needed to be promoted to schools, community services and disability services and also in youth-friendly venues such as youth centres, libraries and young carer programs.

recommendations

Recommendations included:

- That a resource manual which lists available young carer services and supports, contact details and information on how to access be developed and distributed widely and be made available on the internet. This manual should be disseminated to counselling staff and chaplains within schools, child, youth and family support services, health, disability, aged care and community organisations and peak bodies.

3.4 Supporting participation in decision-making

In recognising that young carers assume care responsibilities for their relatives, participants believed that services needed to appropriately involve children and young people in decision-making. They felt that young carers’ needs in regards to information and involvement be assessed and integrated into support plans and that they be considered part of their cared-for relative’s care team. This was seen as being important as young carers reported feeling anxious and afraid when they did not know what was happening for their relative and, as importantly, what part they themselves needed to play in providing assistance.

recommendations

Recommendations included:

- That existing carer and consumer participation models be assessed to ensure that they meet the specific needs of children and young people and that, if lacking, tools be developed to assist service providers provide young carers with appropriate information about their cared-for relative’s condition.

“Even though the teachers I did confront were supportive and the school counselor understood, but it was my friends who were my support at school.”

4. Education

Background

Schools play an invaluable role in the lives of young carers. As well as providing them with an education which they will need in navigating employment pathways, young carers value school because it: offers them respite from their home lives; provides them opportunities to connect with other young people (particularly those in a similar situation to themselves) and to develop a sense of belonging; and is a place where they can receive support and information from people who were understanding and caring (Moore et al, 2006)

However, research suggests that due to their care responsibilities and issues surrounding families affected by illness, disability and mental illness, young carers access to and achievement in education is limited as is their capacity to fully participate and connect. In a recent Australian study, 50% of young carers reported difficulties in accessing school, 75% in participating in school activities and 80% in achieving their potential. These findings are consistent with previous studies that argued “If young carers left school early it did not seem to reflect their ideals about the importance of education... It was just their only option”(Carers Australia, 2002).

Some of the barriers that young carers face when attempting to access, participate and achieve in school include:

- A lack of services available to ensure that cared-for relatives needs are being met and that young carers can attend school
- Difficulties attending due to limited transport options (particularly when school services are missed)
- Financial difficulties
- Physical and emotional strain, including stress, anxiety and a lack of sleep affecting concentration
- Bullying and harassment
- Behavioural problems resulting from stress
- Social isolation (Moore, 2005c; Moore et al, 2006)

Although only 4% of primary young carers aged over 15 are engaged in education (compared with 23% of the general population), many young carers return to education after relinquishing their care responsibilities (Carers Australia, 2002).



"I had an experience where my teacher was my Year Coordinator and I went to her for help and she helped me. I've now got an extension for an assignment because I'm a carer . . . Another teacher kept asking me questions about why I was late in front of all the class. I told her I was a carer, but she didn't really understand."

Issues Identified in Workshops:

4.1 Lack of awareness in schools

There continues to be a lack of awareness of the existence, experiences and needs of young carers in Western Australian schools. As a result, participants believed that schools were not able to identify, support or provide a responsive program to young carers. Similarly, young carers reported a lack of understanding from their peers and from the broader school community. They believed that if people were aware that young carers existed and were more accepting, young people would be more likely to identify.

However, a number of the young carers agreed with the national research that suggests that only when schools have the capacity to appropriately respond to issues for young carers, many would not identify for fear of being bullied, of being reported to Care and Protection or of unwanted stigma. They argued that schools need to have clear strategies in place so that young carers were safe in sharing their experiences.

recommendations

Recommendations included:

- That the Education Department appoint a Young Carers Officer to support schools to better identify and support young carers. This worker, who could be located at Carers WA, would also assist young carers directly and help co-ordinate their educational supports as required.
- That Carers WA develop, in collaboration with the Education Department, a module on young caring to be included in core training for teaching students in WA universities. This module would include information about how young carers experience their caring, the challenges they face in accessing, achieving and participating in school and strategies to support them. Strategies for dealing with discrimination relating to illness and disability might also be included. This module could be piloted by the Centre for Excellence at the Curtin University of Technology.
- That teachers, principals and support staff (ie chaplains, school psychologists and youth workers) be provided training on how to create young carer-friendly schools and strategies to support them within their schools. Such training may be incorporated into existing professional development including (but not limited to) anti-bullying, resilience, mental health and classroom management.

“I had to drop out of school three times - I’ve had to postpone my life and my career to look after my mum.”

4.2 Flexibility in assessment and delivery

Young carers report that the rigid structure of education often excludes them from participating. As the level and type of care their relative needs is often variable and unpredictable, many young carers find it difficult to meet deadlines and to work to a particular schedule and report failing assignments because they are unable to submit them on time. Participants called for more flexibility in the way that units are assessed.

Young carers reported that it was sometimes difficult to attend classes and to catch up on missed work. Participants felt that young carers might take advantage of a range of on-line and distance education modules, particularly those that could meet their specific needs. Recognising the part that schools play in socialising and supporting young carers, it was strongly felt that young carers should be allowed to develop an educational program that was delivered both on and off campus so that these important social connections might be maintained.

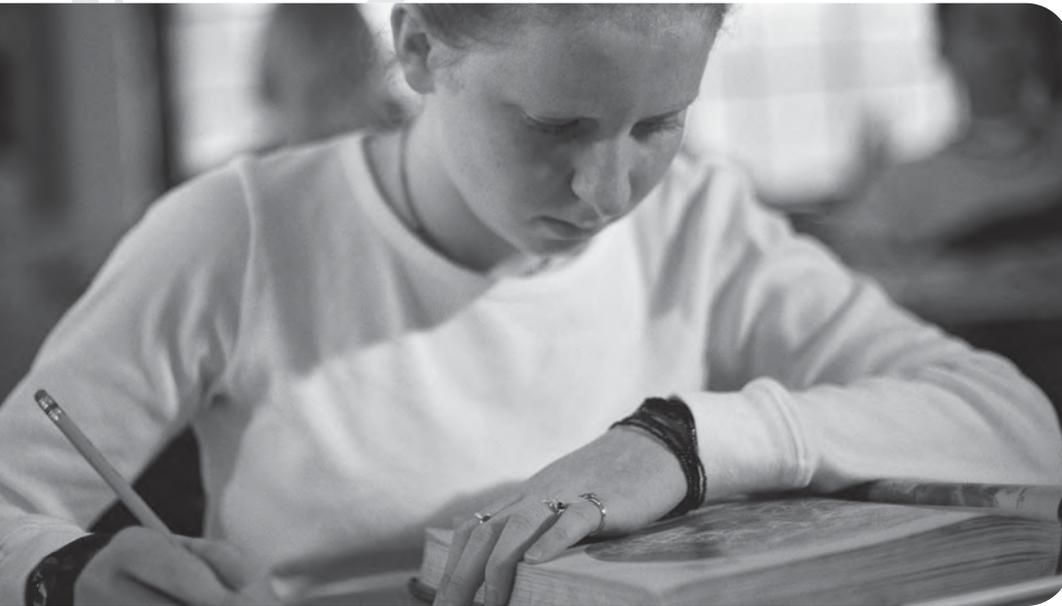
Participants also believed that young carers may be eligible for recognition of prior learning for skills they had developed in their caring role and that accrediting young people for these skills would not only be a positive acknowledgement but could also allow young people to drop lines thus reducing the amount of work they would need to complete.

Recommendations included:

- That models of Recognition of Prior Learning be explored and be incorporated in Department of Education guidelines
- That on-line and distance education models be identified and offered to young carers to reduce the number of hours they are required to physically be at school
- That Carers WA work with the Curriculum Council to develop young carer specific units (similar to those being developed in SA) that recognise prior learning units (such as disability support, household management, self care etc). These units should be accredited and respond to the individual needs of students.

recommendations





4.3 School-community linkages

Participants identified a number of successful programs and partnerships that were addressing educational issues for other 'at risk' young people. Community programs that provided transport, tutoring and financial support were identified as being particularly successful in assisting young people attend and achieve at school. Participants felt that these services could also assist young carers if they were given information on their specific needs and if schools and young carer programs supported young carers to be referred to these programs.

The importance of developing linkages was highlighted by teachers and education staff who felt that schools would find it difficult supporting young carers without external expertise and assistance. They reported that schools were often keen to support young carers but had a limited capacity to do so.

Recommendations included:

- That a toolkit be developed for schools and community organisations on how to best develop and maintain partnerships for young carers. This might include examples of good practice, templates for developing memorandums of understanding and joint case planning.

recommendations



4.4 Need for additional resources

Young carers reported that their access to education was limited due to the poverty that their families were experiencing. Not being able to afford school uniforms, text books or stationery kept them from achieving while not having the money to pay for school excursions, camps or club events further isolated them from their peers. Additionally, young carers felt that it might be helpful to have internet access at home to keep in touch with their schools and to do on-line research when unable to access their school or public library. They felt that currently, many young carers could not afford such IT access and this limited their ability to achieve.

Recommendations included:

- That existing supports for students experiencing financial difficulty be identified and promoted to young carers and their families (ie Smith Family's Learning for Life etc)
- That a brokerage fund for young carers unable to access education due to financial difficulty be established and funded by the Education Department and through corporate sponsorship. This fund should allow families to purchase educational supplies, pay for excursions and co-curricular activities and purchase respite when necessary.

recommendations





5. Respite

Background

The need for responsive and adequate respite has been consistently identified as a key need for young carers and their families providing the young person an opportunity to have time away from their caring responsibilities, to connect with their communities and to combat some of the negative affects of care (such as physical fatigue, emotional distress, poor educational outcomes and social isolation). However, most young carers do not currently access respite and report that traditional models do not adequately meet their needs (Moore & McArthur, 2007)

In particular, many young carers do not access respite because:

- they believe that available programs are not of high enough standard to inspire family confidence, do not meet their cared-for relative's needs or because they had had negative experiences in the past;
- services often do not provide transport, are too far away are too expensive; and
- they are unaware of what programs are available or how to access them.



Research has also suggested that although traditional forms of respite are usually effective in meeting the needs of cared-for relatives they are often unhelpful and, at times, harmful for carers who may feel guilty about having time off, who are anxious or concerned about the treatment of their cared-for relative or are not given the opportunity to relax or rejuvenate during periods of 'respite' (Zilber, 2002). As such, models that achieve the 'respite effect' should be seen as best practice rather than those that see 'respite' as primarily being about giving cared-for relatives time away from the home.

The added complexity of needing to provide supervision to young carers of sole parents during periods of non-home based respite was also highlighted as was the benefits of respite services developing partnership with out of home care providers to ensure seamless service delivery for the whole family.

In Australia, respite for families affected by illness or disability is primarily provided through the Australian Government Department of Health and Ageing but has recently been extended by the provision of the Young Carers at Risk respite program through the Australian Government Department of Families and Community Services and Indigenous Affairs. This new program aims to assist young carers achieve in education and provides short-term respite throughout the school year.

Issues Identified in Workshops:

5.1 Definitions of respite

Traditionally, respite has been understood more as a process or a service than an outcome. This has limited services' abilities to respond flexibly to family need or to meet real need (Zilber, 2002). Participants in the workshop strongly believed that respite organisations should be supported to provide services that achieve 'the respite effect' and be re-oriented to achieve these outcomes. This is significant, as much of the research literature has found that although traditional forms of respite may have positive outcomes for cared-for relatives, carers (including young carers) often report that respite has little or no positive outcomes for them. In fact, some studies suggest that traditional respite might negatively affect some carers who experience feelings of guilt and loss when placing a relative in care, who 'catch up' on other household tasks or who worry about the health and safety of their cared-for relative whilst in care.

Recommendations included:

- That respite providers work with young carers to identify what activities / programs are effective in reducing their levels of stress and anxiety and physical fatigue
- That program guidelines be reoriented towards achieving 'the respite effect' for both young carers and their cared-for relative and that programs be given the flexibility to broker additional services and to pay for activities such as movie trips, camping holidays and sports that help the young carer relax and reduce social isolation

recommendations

5.2 Eligibility

Participants reported frustration in accessing (and providing) services within a service context that targeted 'sole' and 'primary' carers rather than those with the greatest need.

They argued that respite needs to be available to those whose caring has negative impacts on their health, well-being and participation and to others to reduce the likelihood of future stress. Young people's level of support, access to services, age and developmental needs should be taken into consideration rather than just the number of hours they spend caring or whether or not someone else in the family is also assisting.

"I really want to go for the day to have time with my own friends and to get a break, but not overnight..."

I worry when I'm away"

Tim (10years)



Recommendations included:

- That the Australian Government Department of Family, Community Services and Indigenous Affairs and the Australian Government Department of Health and Ageing expand the eligibility criteria for respite
- That an assessment tool be developed for respite programs to identify level of need based on both the number of hours provided but also the impact that assuming care has on the young person's life.

5.3 Family-responsive approaches

Young carers reported that respite was not always satisfactory because the services provided did not meet their real needs. Participants felt that this could be resolved if more time was spent assessing families, working with them to design a responsive program and for this program to be evaluated regularly. Young carers also thought that it would be invaluable for staff to spend time meeting family members so that levels of trust could be increased.

Participants also stressed the importance of providing family-based models of respite to allow families to spend positive time together. This was of importance to a number of the young carers who reflected that they had never had 'a normal family holiday' and that they believed having an opportunity to share positive time with both their cared-for and caring relatives would be good for all family members. Family camps and family holidays where a support worker was available to assume the bulk of the care responsibilities were highlighted as good practice models. Family outings (ie to the movies, bowling or to the park) were also sought by young carers.

Recommendations included:

- That research be conducted to identify best practice family centred support models that address the needs of individual members and the family as a whole and that such models be piloted within Western Australia.

5.4 Peer-based models

Young carers valued respite models that allowed them to connect with other young people. In some cases, this included activities (such as camps and social events) with other young carers but also in meeting and spending time with other young people. This was important, as young carers reported feeling some isolation and sought opportunities to feel included and as though they belonged. Young carers felt that a mentoring program could also support them to develop relationships and to learn from others who had lived through similar challenges as themselves.

Recommendations included:

- That the Carers WA young carers camp program be funded recurrently and that the program be expanded so that it can meet the needs of young carers in rural, remote and metropolitan areas.
- That Carers WA be provided with brokerage funds to allow young carers opportunities to participate in school, social and community activities (such as sports, camps, and leadership development programs) with their non-caring peers.
- That the young carers manual be distributed to mainstream child and youth organisations to equip them to better support young carers who seek assistance from their organisations.

recommendations

5.5 Co-ordinated approaches

Young carers caring for a sole parent must be provided with their own respite during periods in which their parent is in hospital or in centre-based programs. This requires a co-ordinated approach and may require respite services to develop partnerships with child and youth programs to ensure that the young carers' needs are being met during such periods.

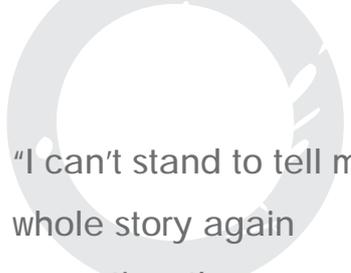
Recommendations included:

- That respite services work with mainstream youth programs to develop a respite program for children and young people for periods when a sole parent is in hospital or in centre-based respite. This might include formal fostering arrangements, short-term centre-based support or resourced kinship care.

recommendations

“My favourite thing to do is to relax with friends and just be part of a normal crowd. The only time I have that is at school at lunch. Never thought of that as respite, just novel stuff, and I just do what I have to do. Usually I have to do my jobs before I can go off and do the things I want to like go to the movies and not have to think about stuff at home.”





"I can't stand to tell my whole story again every time there's someone new and have to redevelop relationships.

Encourage services to retain staff for at least 6 months to allow for trust and relationships to develop enough for the young carer to benefit from the engagement."



6. Collaborative and Whole of Government Approaches

Background

One of the key barriers to effectively responding to the needs of young carers is the uncertainty about who is ultimately responsible for meeting their needs within a siloed service system. Traditionally, health providers have viewed young caring to be an issue for the family support sector and vice versa, while the carer, education and child protection systems have grappled to understand how they might effectively respond and have often argued that the cared-for relative should be the target of support rather than the child or the broader family (Moore & McArthur, 2007).

This situation has been further complicated in Australia where different levels of government are responsible for different aspects of the service system. For example, health services are generally managed locally, while respite programs are managed using federal guidelines. This has meant organisations have often felt unable to respond holistically because their programs only target particular individuals and allow specific service responses.

At a practical level, this has meant that young carers have received limited and ineffective service, if any service at all.

In addition, young carers reported that it was difficult to identify services that would work with their families holistically and felt that the limited services that were provided by individual services were not worth the time and energy required to access them. Young carers also reported their frustration in having to tell their stories time and time again, particularly when their enquiries for support were fruitless.

In other parts of the service system, writers have argued for what is known as 'family-centred, inter-organisational collaboration' which asserts the centrality of the family and encourages a broad, multi-disciplinary response to the needs of both individuals and the family unit. It encourages multiple agencies from a variety of sectors to work together, to share resources and to enable seamless service delivery. It is based on the recognition that when provided with adequate resources, families can deal with challenges and can ensure that children's needs are being met.

Issues Identified in Workshops:

6.1 Identifying family-centred approaches

Young carers and service providers both highlighted the strengths of family-centred approaches that recognised each family member as both individuals but also as members of the family unit. Young carers argued that the best way of supporting them was to support their families, believing that if their care responsibilities were reduced and family mediation, counselling and recreational supports were provided their own levels of stress and fatigue would reduce. Service providers reported the difficulties of providing supports to the whole of family because of limited service targeting and called for greater flexibility in funding guidelines.



Recommendations included:

- That research be conducted to identify best practice family centred support models that address the needs of individual members and the family as a whole and that such models be piloted within Western Australia.

Recommendations

6.2 Challenges to interagency collaboration

Participants felt that the capacity of organisations to work collaboratively was limited by current funding models which were often short-term or non-recurrent and did not allow organisations to adopt a holistic approach to program development, implementation, or evaluation. Services highlighted the difficulty in allocating time and resources into developing partnerships as they had a limited resource base.

Recommendations included:

- That contract managers in WA government departments negotiate outputs that enabled organisations to resource collaboration activities.
- That the young carer program at Carers WA be funded recurrently to ensure that it can meet the ongoing needs of young carers in the state.

Recommendations





6.3 The need for effective communication and networking

Participants greatly valued the opportunity to meet and develop working relationships with other workers and organisations. They believed that to maintain the day's momentum and to provide integrated supports to young carers and their families that a broader communication and networking strategy needed to be developed and for opportunities for interested parties to continue discussions to be facilitated.

recommendations

Recommendations included:

- That Carers WA be resourced to establish a Young Carers Network (YCN) for government and non-government support organisations and agencies. The YCN would offer a number of benefits:
 - Sharing of information
 - Communication between agencies which will guide evidence-based practice (e.g., sharing of models)
 - Research Seminars and Discussion GroupsThis Network would host an annual forum to progress state-wide responses to young carers and their families.
- That Education, Health, Disability, Community and Youth departments ensure representation by appointing staff to this network.

7. Attachment

Young Carer Identification Checklist (YCIC)

Young carer: _____ DOB: _____

Assessed by: _____ Date: _____

Referred: Yes No Referred to: _____

Age Range of Young Carer: 5 to 10 years 11 to 15 years 16 to 18 years 19 to 26 years

Instrumental Activities of Daily Living (IADLs):	✓
Taking out rubbish	
Shopping	
Dusting	
Cooking food	
Preparing ingredients	
Vacuuming	
Washing	
Making telephone calls	
Household repairs and gardening	

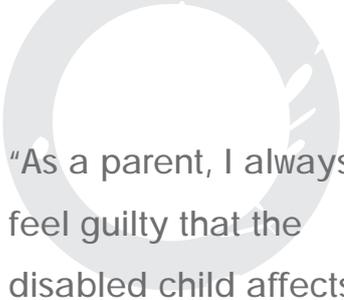
Activities of Daily Living (ADLs):	✓
Dressing	
Bending and picking up things for them	
Walking with them	
Getting them into or out of bed	
Showering and bathing	
Eating / feeding	
Getting them around a place away from the house	
Moving them about the house	
Toileting	
Arranging / attending doctor's appointments	
Helping them to use public transport / transport	
Writing letters / completing forms	
Bladder or bowel control	
Speak with doctors, pharmacists and other health care professionals	
Checking bills or bank statements / paying bills	

Educational Psychological Implications of Caring Checklist (EPICC):	
<i>Educational Subscale</i>	✓
Missing school	
Contacting home while at school	
Report being bullied	
Homework doesn't get done	
Aren't able to concentrate	
Late for school	
Don't participate in after school activities	
Report to sickbay / visit nurse	
Report not sleeping well	
Tired and lack energy	
<i>Psychological Subscale</i>	✓
Don't interact with other children / young persons	
Seem to be depressed	
Demonstrate anger and / or frustration	
Unhealthy behaviours (smoking and / or drug use)	
Quiet and withdrawn	
They worry	
Emotionally upset (e.g. crying)	
Suffer from eating disorders	

Identification:

For screening purposes, it is suggested that a threshold of 50% of the ADLs and EPICC is adopted to identify a young carer. If identified, a young carer should be provided the Carers WA - Young Carers Program telephone number - 1300 CARERS (1300 227 377).





"As a parent, I always feel guilty that the disabled child affects every aspect of the other child's life. That they had to mature beyond their age pretty fast, they did not get to be children themselves. They are like a third parent."

Parent of a Young Carer



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- Marie Taylor and the Nyoongar people on whose land the roundtable was held.
- Members of the Young Carers Roundtable Working Group for their assistance in shaping the day and for their ongoing support



hopping
off
the
roundabout




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