



Final Report

Bring It! Young Carers Forum
26-27 November 2008

May 2009 Web Version



Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Acknowledgements

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Foreword

Forums often have a reputation of being quite 'dry' passive events where academics present papers, the audience listens... and nothing further develops from that information. 'Bring it!' 2008 was a very different experience - dynamic, positive, interactive and fun.

The main objectives of the Forum were to:

- provide young carers, key stakeholders, academics and government representatives with the opportunity to have an input into the development of a young carers' policy agenda
- examine research and models of best practice in the key areas of concern previously identified:
 - access to government services
 - identification
 - respite
 - education
- build young carers' capacity in terms of self-confidence and advocacy.

Young carers from each state and territory attended the Forum. These young carers were:

- representative of the broader population of young carers in Australia
- able to demonstrate personal drive, good communication skills, determination, resilience, good humour and a positive focus
- able to demonstrate an awareness and use of services available to carers in Australia.

The Hon Bill Shorten, MP Parliamentary Secretary for Disabilities and Children's Services and the Hon Jenny Macklin, MP Minister for Families, Housing, Community Services and Indigenous Affairs officially opened the Forum, acknowledging the achievements of young carers, their contribution to Australian society and the need as a society, to support them and help them through their education and transition to employment.

A highlight of Bring it! was the young carer meetings with Ministers, other politicians and advisers. This was part of their advocacy and communication skills development. These meetings were highly successful both at the political level and for the young carers and generated considerable interest in young carers and their contribution to Australia. A particular thrill for young carers was attending question time during Parliament and being acknowledged by the House.

We would like to thank Agnes Shea for her welcome to country, all speakers and panel members for their time and very valuable input. We would also like to thank Jenny Macklin and Bill Shorten for taking time out of their busy schedules to be part of the Forum. The participants' input was valued and their knowledge and understanding of issues affecting young carers and their families was an important element in the overall outcomes of the Forum. Additionally, our congratulations to the staff at Carers Australia who worked tirelessly to deliver a positive and dynamic Forum.

But most importantly, we would like to thank the young carers who shared their stories, and made us feel very proud to be part of their lives if only for a short time.

Based on the evaluations, Carers Australia is confident the program elements and structure were sound, functioned well for participants, and gave every opportunity for authentic and valuable input.

Pam Webster
President | Carers Australia

Joan Hughes
CEO | Carers Australia



Acknowledging young carers

The Hon Jenny Macklin, Minister for Families, Housing, Community Services and Indigenous Affairs:

"If I can say to all of you who are here today, you are very, very special young people, extraordinarily special young people, compassionate and committed way, way beyond your years. One of the things that's so wonderful about you is that you really are the voices of so many other young carers who every day get on with the job of caring for the people whom you love and they love.

...Many of you are trying to manage your schooling and some of you are trying to manage your university courses as well while you're undertaking your caring responsibilities.

...I hope that you learn some ways that you might be able to improve your juggling efforts meeting all of the different responsibilities you have but I also hope that as a result of you all coming here to Canberra, we're able to do a better job because we listen and take on board what you've got to tell us."

The Hon Bill Shorten, Parliamentary Secretary for Disabilities and Children's Services:

"I'm sure many people don't realise how many young carers there are and how hard you work because a lot of what you do is under the radar. You fly so close to the ground that, in fact, you just don't get picked up in a lot of the debates in the news and everywhere else. Sometimes some of you and others not here are so busy that you don't even realise that you fit into this category of being a young carer... The thing which really affects me when I read about you is the social isolation. You have a right to have friends, to have fun but your responsibilities make you mature beyond your years and you don't put up your hand and ask for anything special. You do need a hand sometimes."

Professor Saul Becker in his keynote presentation:

I have just finished doing lots of interviews all around the UK with 16 and 17 year olds and 18 to 24 year olds and I have been shocked and humbled by the stories that people tell me about their caring lives about the kinds of things that they do and the value and the importance they place and their sense of honour and duty towards other family members.

Ms Annette Ellis, MP reflecting on the feedback from visits across Australia during public consultations for the Inquiry into Better Support for Carers:

..."the lack of recognition, the lack of understanding, the lack of opportunity for complete educational outcomes, because of the role of caring, the lack of understanding by their peers as to the role and the pressure that they're facing in what they're doing were clear messages."

In their own words

Young carers stories reinforce the need for urgent action:

"I told all my teachers at the start of year and they were just like, okay. But when the assignments weren't in because I was helping look after my little brother and I couldn't do anything because he was screaming or something, I would tell them and they would just be like, hand it in, hand it in. Then I did an advertisement for young carers and the school saw them. When they saw visually my little brother that's when they started to actually realise. They needed the visual to understand that I couldn't get stuff in."

"I couldn't find a better way to put it. It is navigating through the maze. It would be a lot easier if people who were giving services to my mum would say, who's looking after you? Is there anyone at home looking after you? I think the perfect example is in our handbook, Centrelink, CentaCare, Carelink. If I was 10 years old looking for services I would be wondering what do these words mean? What services do they provide? It's a really tough thing to find out."

"I think that if someone had picked up in high school that I was a young carer and helped me to receive services earlier, I think it would have made a real difference to me maybe finding things to help me go to university while looking after mum and also to help me when I was doing my HSC."

Having teachers who understand what your role is and what young carers do and why you may not be able to get work in on time or why you may need to leave the classroom because you just can't think anymore is important. And having people that want to take the time to understand, that generally can give you an extension or offer you a bit of assistance because they know that you've got something else going on at home is important.

So the education of the teachers and making teachers aware of what young carers are, I think is vitally important. I know they say they don't have a lot of time, but just for them to know what a young carer is and what a young carer does, and so they are kind of aware of what their life is like. The teachers then may be a bit more understanding and emphatic.

Yes, I just said to the teacher, oh, I've just been looking after my mum and she just hasn't been too well and I didn't even finish telling what her situation was and instantly she just, took me into her office and she actually put me on the phone to Abe, who's left now, and he just said, Oh, I need to come and see you and I need to come and see you now. Yes, he came down to my house the next day and sat down and we had a chat so that was good. It was incredible, it was so good and I think the circumstances – I was so broken, like 16 years old and even though it had only just been me caring for my mum for six years, it was my life that I'd been living with and facing such hardship.

It seems part of these things of identification and respite is actually about gearing young carers to be able to continue doing this for a really long time and I don't want to. Apparently according to social workers, I've been doing this since I was eight and I think it's really important that at this forum we actually emphasise to young carers that at some point they're going to stop being carers and have to get on with their own lives. There's actually a really fundamental problem there. It's important to support young carers and recognise them and tell them that they're doing a great job. But it's also really important to actually try and dismantle why it is that so many young people are having to take up these caring roles.

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1. Executive summary

The main objectives of the 2008 Bring It! Forum were to:

- provide young carers, key stakeholders, academics and government representatives with the opportunity to have an input into the development of a young carers' policy agenda
- examine research and models of best practice in the key areas of concern previously identified:
 - access to government services
 - identification
 - respite
 - education
- build young carers' capacity in terms of self-confidence and advocacy.

Literature reviews in the four areas of concern to young carers provided the background papers for delegates. Each delegate was given a full set of papers prior to the Forum.

To achieve the objectives, the Forum was held over two days. Panel discussions on the first day provided an opportunity for young carers to present their views through interviews and panel discussions. Other panel members provided an insight into their particular area of expertise and all participants had the opportunity to ask questions and present their views for consideration.

The second day was a workshop style meeting using i-MEET technology that links a laptop on each table to a large electronic white board for instant discussions and feedback. The discussions and outcomes were used to begin the process of generating final recommendations.

Throughout the two days young carers met Ministers, other politicians and advisers as part of their advocacy and communication skills development. These meetings were highly successful both at the political level and for the young carers. Considerable interest was generated in young carers and their contribution to Australia.

The Hon Bill Shorten, MP Parliamentary Secretary for Disabilities and Children's Services and the Hon Jenny Macklin, MP Minister for Families, Housing, Community Services and Indigenous Affairs officially opened the Forum. In acknowledging the individual young carers who were at the Forum Bill Shorten and Jenny Macklin said that their contribution to our society was amazing and as a group of young people they went above and beyond what was normally expected of young people.

Professor Saul Becker, from the University of Nottingham in the UK was invited to give the keynote address. His presentation *Global perspectives on young carers: Findings and messages from research* was another highlight of the Forum. A summary of the presentation is at Section 3.

Following Professor Becker's presentation panel discussions addressed the four areas of concern. A summary of the discussions and conclusions for each area of concern is outlined in Section 4.

The main outcomes of the workshop on day 2 are listed below. Further information on the outcomes is outlined in Section 5.

Moving through the maze – access to government services

1. National legislation for young carers
2. All entry points (services, organisations) provide referral to all appropriate services – no wrong door
3. National government-funded awareness media campaign (print, online, radio)
4. No young carer will be missed if initial services for the person needing support are family focused
5. Whole of family approach with key worker – nationally-funded program

Put your hand up - identification

1. Young carer education and awareness be included in university training/education institutions for teachers, nurses, doctors, community sector service providers
2. A national policy that requires health/community services/education professionals to identify and respond appropriately to young carers
3. All government and non-government sectors are engaged in identifying young carers amongst their client groups
4. Targeted TV campaign

Give me a break - respite

1. Sufficient flexibility to allow young carers their own choice in the respite services they receive
2. Ensure equitable access for all young carers regardless of where they reside
3. All young carers have access to supports to enable their education, vocational and lifestyle choices to be realised
4. The option of direct funding for families
5. Young carers have a choice about being a carer

Young carers 101 - education

1. The education system be able to provide enough flexibility to ensure all young carers can attend, participate and achieve in education
2. All young carers including Indigenous, CALD, rural/remote to feel confident they can access a flexible learning plan to suit their needs
3. Strong partnerships are developed between schools (and other educational programs), carer services and the community so that coordinated, responsive, family-focussed support can be provided
4. Mandatory training for teachers, all school staff, students and in-school young carer advocates
5. Schools are accountable to education departments (national and/or state) re implementation of young carer policies

These outcomes formed the basis for the key messages that are outlined in Section 6.

Recommendations

The following recommendations were developed from the conversations during the panel discussions and the key messages developed during day 2 discussions. These recommendations will require a significant commitment from government.

1. That the government introduce, as a matter of priority, legislation to support and recognise carers. The national carer act should include specific clauses relating to young carers.
2. As a matter of priority, develop and implement a training program for Centrelink staff to ensure they have the skills, empathy and understanding needed to deliver a quality service to young carers and their families.
3. Review the '25 hour' rule as it currently applies in relation to income support – young carers consider study and work should be separated – study does not equal income.
4. Introduce a 'whole of family' approach and 'no wrong door' to service delivery.
5. Young carers are given the choice to care – appropriate support is therefore required for the person for whom they are caring.
6. Ensure support and information is available for young carers regardless of their geographical location or cultural heritage.
7. In developing and designing support and information resources use technology as a tool to assist access.
8. All information and resources should be up-to-date, current and age appropriate.
9. Undertake a national awareness raising campaign to promote self-identification by young carers and to increase awareness of young carers on the part of service providers, health professionals and educational institutions. Campaign material should be age, gender and culturally appropriate.
10. Undertake a national schools awareness and training program to ensure all schools and teachers have the knowledge needed to understand and support young carers throughout their education.
11. Encourage all educational institutions to put in place policies about the identification of young carers and how they will be best supported within these settings.
12. Establish an ongoing 'Young Carer Scholarship Program' aimed at assisting young carers through secondary education, TAFE and university degrees. This should be an ongoing commitment from government.
13. Provide ongoing funding for a 'professional development, leadership program' to support young carers as ambassadors and mentors.
14. Ensure government funding for the Young Carers Respite and Information Services Program is at a level to enable all young carers who identify and meet criteria to access support and information services.

2. Official opening

The Hon Bill Shorten, Parliamentary Secretary for Disabilities and Children's Services and the Hon Jenny Macklin, Minister for Families, Housing, Community Services and Indigenous Affairs congratulated the young carers on their efforts and achievements and acknowledged this group of young people as going above and beyond what is normally expected of young people.

Concern was expressed that only four per cent of carers between 15 and 25 are still in education compared to 23 per cent who are not carers. It is important that schools recognise the demands young carers are under and understand the demands of caring. Some schools do this well and have policies and programs in place to support young carers.

A further concern is that only nine per cent of primary carers aged 15-34 use respite services.

The barriers are seen as being:

- a lack of knowledge about the services available
- cost
- transport
- limited services in rural/remote areas.

A number of positive changes have been recently introduced to the Young Carers Respite and Information Services Program. These changes, aimed at improving services and support include:

- expansion of the eligibility for the program to include secondary young carers in a household and carers in primary school whose education may be affected by their caring role
- introduction of a more flexible format for respite
- funding for the Young Carers Respite and Information Services Program to continue over the next two years (at the current level, a total of \$15.7 million).

In addition to financial support, which is important, it is also about building support networks, being able to share experiences, and have somebody to talk to. Young carers should know that they are not on their own. There are other young people who are in similar circumstances.

In closing, Jenny Macklin said: "I really do think that this is an incredibly special occasion, an amazingly special occasion for you to be able to come together, for you to be able to meet each other, talk with each other. I'm sure there are some tears that have been shed as well as some happy stories shared. I hope that you learn some ways that might help to improve your juggling efforts meeting all of the different responsibilities you have but I also hope that as a result of you all coming here to Canberra, we're able to do a better job because we listen and take on board what you've got to tell us."

3. Keynote presentation

Professor Saul Becker, from the University of Nottingham in the UK was invited to give the keynote address. For 15 years Saul has been researching, writing and working on young carers issues in the UK and internationally. He has directed 30 research projects; published nearly 300 books, chapters and articles; and he has spoken at 150 conferences. During his childhood, Saul was a young carer. He is passionate about and committed to the development of research-informed and outcomes-based policy for young carers and their families.

His presentation Global perspectives on young carers: Findings and messages from research outlined the number of young carers in the UK, their characteristics, the number of hours spent caring each week, the tasks they undertook and the caring time span.

Table 1 – Number, % and age of young carers and young adult carers aged 0-24 in the UK, by hours caring per week (2001 Census)

Age	1-19 hours	20-49 hours	50+ hours	Total in UK
0-17	145,854 (83%)	16,113 (9%)	13,029 (8%)	174,996 (100%)
16-17	49,711 (81%)	6,935 (12%)	4,406 (7%)	61,052 (100%)
18-24	173,249 (75%)	29,128 (13%)	26,941 (12%)	229,318 (100%)

Source: Saul Becker Presentation to Young Carers Bring it! Forum

Table 2 – Caring tasks

Caring tasks	1995	1997	2003
Domestic	65%	72%	68%
General & nursing	61%	57%	48%
Emotional	25%	43%	82%
Intimate	23%	21%	18%
Child care	11%	7%	11%
Other	10%	29%	7%

Source: Saul Becker Presentation to Young Carers Bring it! Forum

Dr Becker compared figures across the UK, Australia, the US and sub Saharan Africa for young carers under the age of 18 and young carers in the age group 18-24. The comparison provided interesting data. For example, the numbers for young carers under the age of 18 was highest in Australia at 3.6% of all people under the age of 18 and lowest in the UK with 2.1%. For those in the 18-24 age group, the US has the highest number of young carers with anywhere from 14-29% of the population in that age group. 5.2% of the Australian population in that age group are carers.

It was also found that currently, young carers across the world may have more in common than that which separates them geographically, economically, politically, socially or culturally. Cross-nationally, their tasks and responsibilities are very similar.

Of particular interest is the level of awareness and response to young carers at the global level. For example, in the UK, young carers now have clear legal rights with policy and guidelines specifically for young carers. The table below compares the levels of awareness across different countries.

Table 3 – Comparison of awareness levels of young carers

Level	Characteristics	Country Example
'Incorporated/ Sustainable'	<ul style="list-style-type: none"> • Extensive awareness at all levels of the experiences of young carers and sustained and sustainable policies and interventions aimed at meeting their needs, built on a foundation of reliable research evidence and clear legal rights 	None
'Advanced'	<ul style="list-style-type: none"> • Widespread awareness and recognition of young carers amongst 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 	United Kingdom
'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 	United States
'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

Source: Saul Becker Presentation to Young Carers Bring it! Forum

Professor Becker noted that research in the UK shows that there are a range of outcomes that can be defined for young carers and it is clear that many are negative in their consequences:

- limited opportunities, horizons, aspirations
- limited opportunities for social and leisure activities
- lack of understanding from peers, restricted friendships
- 'stigma by association'
- feelings of exclusion or being 'outsiders'
- fear of what professionals might do
- 'silence' and 'secrets'
- emotional difficulties
- educational problems
- health problems
- difficulties in transition to adulthood
- employment difficulties.

It was also found that caring can:

- develop children's knowledge, understanding, sense of responsibility, maturity and a range of life, social and care-related skills
- bring children and parents closer
- allay some of the fears, concerns and anxieties that children have about their parent's condition
- make children feel included.

BUT, there is a price...

These findings reinforce research undertaken in Australia – that caring has negative outcomes for young people but with appropriate support there can be some positive outcomes.

A summary of Professor Becker's transcript together with the full PowerPoint presentation is available from the Carers Australia website www.carersaustralia.com.au

During question time, Professor Becker made the point there has now been enough research in the UK and in Australia and it is time to move forward. It is about a political commitment from policymakers and governments to invest in developing services. He added that if a national infrastructure of services for young carers and their families is developed, young carers will use those services.

One of the most pressing issues is to generate far more awareness of the issue of young carers amongst professionals. In the UK, for example, it has been found that social workers will go into families where there are severe mental health problems, alcohol or drug misuse or other forms of illness or impairment and there is no recognition that children are the carers. GPs, doctors, and other professionals deal with adults, parents who have Alzheimer's, Parkinson's, and other illnesses or conditions and they simply do not recognise that the child is the carer. They don't do the family tree which says who is the carer in the family. An awareness campaign for professionals is crucial.

Professor Becker noted that all the evidence from Australia and the UK shows that where schools are sensitive to young carers, where there is a policy to recognise young carers and to be flexible and supportive that young carers are likely to do the best at school.

In the UK young carers have clear legal rights with specific policy and guidelines. There has been nine television documentaries highlighting the experiences of young carers. As a result there is now extensive public and professional recognition of young carers.

Professor Becker reiterated the importance for governments at all levels to recognise that an investment in young carers and an investment in adult carers will pay dividends. This is consistently confirmed by research. It will sustain caring relationships and it will keep families together. The current world economic crisis must not be an excuse for not investing in carers.

4. Panel discussions – day 1

Moving through the maze – access to government services

The clear messages highlighted during the panel discussion on 'moving through maze' were:

- the importance of family relationships
- availability of appropriate support to stop family breakdowns, build resilience and help families through difficult times
- easier access to Centrelink payments
- increased awareness and understanding of young carers by professionals.

Accessing services is a major issue:

- young carers are worried about how people will see them and their family
- they are concerned about removal from the people they love
- they have had negative experiences with services, feel they have not been treated with respect and have been looked down on because they are children and young people.

These difficulties often mean young carers do not want to have support from services.

Additionally, disability services, housing services, homelessness services and drug and alcohol programs have generally focused on one person within the family context.

Accessing services at the local level was difficult. Limited funding is available for a number of national programs but at the local level, where young carers are more likely to access services funding for programs was not available and as a result services find it very difficult to provide support.

Flexibility of service delivery that meets the needs of the whole family is crucial. It should not be a standardised formula where clients are not the focus. Young carers should be included in planning and evaluating services. The importance of a whole of family approach was reiterated throughout the discussions.

Young carers saw accessing Centrelink payments as a major problem:

- Centrelink staff did not understand a young carer's role or requirements
- Centrelink staff tried to convince them they were not a carer
- the current 25 hour rule whereby eligibility for Centrelink payments is effected if the total hours of work, study or training (including voluntary work and travel time) exceeds 25 hours per week was of particular concern
 - this rule made it particularly difficult for young carers who were studying to receive support
 - young carers strongly believe that study does not equal income and there is an urgent need to review this rule.

It was agreed that specialist support to assist young carers through the maze at Centrelink would be beneficial.

Centrelink acknowledged the need to ensure staff at the local level were aware of the array of services that are available. However, it should be recognised that Centrelink have criteria and guidelines to follow when assessing clients payment eligibility and this could make it difficult. The rules for the income support payments are often very restrictive and this can impact on eligibility.

Conclusions – moving through the maze

- a case manager who understands young carers should be available to assist them through the maze of services and support
- young carers should always be treated with respect and dignity by adults in authority
- a whole of family approach to service provision is critical
- services should be flexible and delivered around all the clients' needs
- young carers to be involved in care planning and evaluation
- Centrelink staff to be appropriately trained to support and help young carers
- review the 25 hour rule – work and study should be separated – study does not equal earnings
- ongoing awareness raising of young carers and their needs is essential

Put your hand up - identification

A clear message identified under this topic was that young carers often do not recognise themselves as a young carer.

Young carers considered that at a broader level children and young people are not recognised for their worth in society:

- there is a need for greater acknowledgement and awareness across all levels of society that children and young people are performing adult caring roles.

Young carers considered that to resolve a number of issues around identification it was important that they should, in the first instance, feel comfortable with being a young carer. They should:

- have a voice
- be included in planning and care management
- be acknowledged by health professionals as an important partner in care delivery
- have their responsibilities understood by educational professionals.

Thinking family, the whole of family approach was again raised as a matter of importance. However, some of the complexities around service delivery include different service providers for individual family members – for example a person with a mental illness may have a case manager through the mental health sector, a young carer may get support from a Commonwealth Respite and Carelink Centre and there may be personal care attendants from another service which could be state based. Coordination across all levels of service delivery is crucial to an outcomes focussed concept of support rather than needs focussed.

This reinforced the concept of a key worker or case manager to assist with service provision and also raised the issue of 'no wrong door'.

At a health professional level, some of the difficulties faced in identifying and assisting young carers included:

- workforce issues and time constraints
- GPs run small businesses and get paid on a fee for service basis
- GPs may think they do not have a role in this area
- GPs don't necessarily have the relevant knowledge of what services and support are available

Suggestions for improving health professionals understanding of young carers included:

- timely, focussed and targeted ongoing awareness raising with all health professionals
- using the Divisions of General Practice Network as a conduit for awareness campaigns
- a roving social worker who could be part of a local GP network would also help deal with issues relating to young carers.

Workforce issues for GPs in rural and remote areas is a particular barrier for the provision of support. They are time poor, need to focus directly on their patient rather than the family and often cannot leave their practices to attend education sessions. There is an urgent need to address these workforce issues in rural Australia.

Technology can be a useful tool to assist young carers identify:

- there are now a number of websites available with useful information to assist young carers to identify, and find services and support
- technology also has the added advantage of being anonymous
- forums provide young carers with a network to engage with others who have similar problems – barriers drop and isolation is reduced
- information online that is written for young people by young people in a relevant way will facilitate self-identification
- connection with other young carers is like counselling and can also assist with identification.

However, in using technology as a tool to assist young carers it should be recognised that not all households in Australia have access to the internet. Information for young carers should be available in a number of formats to meet all needs. This should always be current, easy to access and age appropriate.

According to the ABS there has been significant growth in Australia's access to/use of the Internet between 2001 and 2006. In 2001, 35% of Australian dwellings had access to the Internet in the week prior to the Census date. In 2006, 63% of Dwellings had access to the Internet.

At the national level 66% of dwellings in major cities have access to the Internet, compared to 42% for very remote Australia. This gap is similar for Broadband access, the corresponding figures being 46% and 24%. Corresponding access rates for Inner Regional, Outer Regional and Remote Australia are 56%, 52% and 53% for Internet access and 32%, 27% and 28% for Broadband access.

Regression analysis results reveal that regional and remote areas are at least 40% less likely to have Broadband access relative to major cities. The likelihood of any Internet access is relatively higher, but still considerably lower than major cities.

ABS (2007) Patterns of Internet use in Australia, 2006

A major issue raised during this session was choice about caring: A number of concerns raised by young carers included:

- the lack of appropriate services for the family
 - part of the trauma associated with being a young carer would not be there if there were appropriate services available in the first place
- not all young carers wish to be labelled as a 'young carer'
 - however, it was acknowledged 'the 'label' had a very valuable political role in identifying a group of young people who are perhaps taking on more than they should
- the risk if the identify of young carers is constantly the major issue as opposed to their role as supportive people, more fragmentation will be created.

At a broader level, it is important to understand the challenges that young people face. Kids living on the streets, kids in detention, kids who are using drugs themselves, may be young carers or have had young caring experiences. It is essential this is understood and appropriate support is offered to those marginalised in our communities.

Conclusions – put your hand up

- young carers are brothers, sisters, sons, daughters and do not always recognise themselves as a young carer
- choice to care - consider the appropriateness of young people taking on a caring role
- ensure services are available to support those who require care
- value children's role in society
- think family – a whole of family approach to service delivery and support is critical
- no 'wrong door'
- provision of easily accessible, appropriate, up to date information
- ongoing targeted awareness campaigns for GPs and other health professionals
- government to look at initiatives for GPs that are not fee-for service based
- greater use of technology as a tool to help with self-identification
- availability of services if more young carers identify
- understand the challenges young carers face.

Give me a break - respite

The messages from discussions around respite were very clear:

- respite should be flexible and should be a mix of direct and indirect respite
- a whole of family approach to respite is essential.

Clear messages from young carers reiterated this point – if you want to help me, then help my family. Build trust with the family and the young carer.

Following a review of the Young Carer Respite and Services Information Program, the government made changes to the program in 2008-09 including:

- expansion of the eligibility for the program to include secondary young carers in a household and carers in primary school whose education may be affected by their caring role
- provision for service to be longer than 12 months and to be delivered during school holidays
- introduction of a more flexible format for respite.

FaHCSIA had commenced work on program redesign for the Young Carers Respite and Information Services Program. The outcomes of Bring it! would be taken into account particularly in relation to a whole of family approach to services. It was noted that:

- a whole of family approach to services would need a rethink on funding to break across the funding silos caused by program funding to specific client groups rather than families
- the current Coalition of Australian Governments (COAG) reform process of the roles and responsibilities of federal and state/territory governments for community services delivery would influence what can be done to break down funding silos
- many of these changes can influence access to services, and the services themselves
- consideration should be given to a national debate on respite
- currently in a policy sense, respite is considered as a substitute caregiver rather than as carer support.

A clear message from young carers and participants was that indirect support is valued highly. Innovative and creative solutions to respite should be a priority. It was noted that a number of Commonwealth Respite and Carelink Centres have developed creative solutions to assist young carers. For example one centre has developed a partnership with a hospitality school to bring young carers in to learn nutrition and preparing meals.

The importance of flexibility and the appropriateness of respite has been highlighted in research findings. Findings from research looking at which young carers are more likely to fall under the radar and not access respite show:

- very few Indigenous young carers and young carers from culturally and linguistically diverse (CALD) backgrounds access respite
- young carers in rural and remote areas have more difficulty in accessing respite services.

This is despite the fact that the statistics show that the prevalence of caring is greater in Indigenous families and families from culturally and linguistically diverse backgrounds.

Tailored, flexible respite options are needed. For example:

- young people at school have different needs to those entering the workforce
- Indigenous young carers will also have different needs
- one size does not fit all
- interagency cooperation and coordination is an important element in flexible respite programs
- young carers should have a voice in respite program design.

Conclusions – give me a break

- whole of family approach
- respite should be flexible, and tailored to support the needs of young carers – across the age spectrum
- young carers to have a voice in respite programs available to them
- innovative and creative approaches to respite
- direct and indirect support is needed
- university/TAFE students will have needs for respite and support
- improve access to respite for young Indigenous carers, young carers from CALD backgrounds and young carers in rural and remote areas
- a national debate on alternative approaches to respite, focusing on flexibility and appropriateness of respite is needed
- privacy laws can impact on information sharing.

Young carers 101 - education

Again, the messages were very clear in the education session:

- ensure schools and colleges are aware that they will have young carers
- more flexible learning options to be introduced to all schools such as on-line learning
- the governance structure across schools is not always flexible enough to take account of the issues that young carers face.

Identifying and supporting young carers in schools requires adequate resourcing. Research in the UK has shown that around one third of young carers have educational problems. This includes:

- not being able to attend school
- falling asleep in class
- unable to do homework on time.

School can be a sanctuary, a place to make friends, a place to engage with other young people or it can be 'hell'. What is now known is that if young carers have supportive teachers who understand their situation then the outcomes of school in terms of achievement and attainment can be much higher.

There is a need for a 'whole of school' approach to young carers. Teachers, principals, boards, and other staff need to develop a plan for responding to the needs of young carers. Young carers should be involved in discussions.

Understanding young carer issues should start with teacher training and should be part of the pre-service and in-service training. Governments must recognise that young carers have special needs and flexibility with education delivery is paramount.

Supporting young carers should not stop when/if they start university. Scholarships were identified as a way of assisting young carers to undertake university studies, particularly if they needed to move from their home town.

Another important issue discussed during this session was inappropriate caring. Why is it that so many young people are having to take on the role of carer? Young carers should have the same opportunities to lead full and active lives and participate in the whole social life around school.

Conclusions – young carers 101

- raising awareness of young carers
- flexible learning options
- supportive environment
- support for young carers should not stop at tertiary level education
- scholarships for young carers to undertake tertiary studies
- whole of school approach to young carer support – either at national level or at a school level
- teacher training should include information about young carers
- young carers should be involved in planning flexible learning options.

5. Workshop – day 2

The second day was a workshop style meeting using i-MEET technology. This technology links a laptop on each table to large electronic white board for instant discussion and feedback.

Participants worked in groups aligned to the four areas of concern. Each group were given a number of topics from day 1 to discuss and work through to develop key recommendations. Key recommendations from each session were developed and discussed. Final key messages and overall priority recommendations were presented.

Moving through the maze – access to government services

1. National legislation for young carers

- Comparative study on international and state/territory government equivalents
- Outline of specific young carers' rights
- To be included in national carer legislation

2. All entry points (services, organisations) provide referral to all appropriate services – no wrong door

- Identification of key young carer entry points, and symbol of accreditation (like safety house)
- Train Centrelink workforce to be sensitive and compassionate toward the complex needs of the family and the caring role
- Develop a national hotline specifically for young carers
- Compile and maintain a resource package of hard copy/online resources to refer young carers to appropriate sources of help
- Develop youth friendly and active and supported referrals
- Maintain a national, accessible, integrated and up-to-date information services database for service providers containing data from the three tiers of government and NGOs (all service providers)
- Easy to give out referral promotional items (key chains, DVDs)

3. National government-funded awareness media campaign (print, online, radio)

- A TV and radio campaign, with TV as primary tool for promoting fostered industry/business linkages for sponsorship and advocacy with input from young carers
- Support from corporate sector
- Web-advertising on websites likely to be frequented by young carers
- Partnerships with new mediums such as Facebook, myspace, twitter, bebo to engage with young carers
- A young carer focus for National Youth Week

4. No young carer will be missed if initial services for the person needing support are family focused

- All services should have an integrated young carer focus
- Common assessment tool (e.g. the CENA) which includes a whole of family approach and which is transferable between services be nationally available
- Toolkit available to service providers, schools, all possible entry points to be made in close consultation with carers and other stakeholders (siblings, parents, relatives, partners)
- Systemic changes to major service providers to encourage a family focused approach (Centrelink, GPs schools, pharmacists, allied health services)
- All levels of government (federal, state/territory, local) ensure that all services (health, welfare, community, mental health and education, disability) include holistic assessment around family and provision of options of information and referral

5. Whole of family approach with a case manager – nationally-funded program

- Scope, develop and pilot a model which has application for the diversity of caring situations in all geographical locations
- Perform a stock take of relevant programs and services
- Define roles and responsibilities and build formal referral paths if not already in place
- Incorporation of whole of family approach within relevant training bodies
- Appoint a lead agency within government to implement and monitor ongoing program

Put your hand up - identification

1. Young carer education and awareness be included in university training/ education institutions for teachers, nurses, doctors, community sector service providers

- Develop education modules for professionals with input from young carers and their families
- Get modules into tertiary institutions for all professionals
- Lobby ministers at the federal/state/territory level to include carer education in curriculums
- Legislative changes to include consultative mechanisms with all educational institutions

2. A national policy that requires health /community services/education professionals to identify and respond appropriately to young carers

- Consultation process - all carers/young carers, service providers, education departments to be included
- Bring all relevant senior policy people together to agree on a policy document - health, social inclusion, education, FaHCSIA, DEEWR

3. All government and non-government sectors are engaged in identifying young carers amongst their client groups

- Federal funding for training
- Preparation of national training modules
- Ongoing training of staff on identifying young carers and their needs
- Identify young carers at intake level of all services with all intake and assessment forms to include questions which identify young carers.

4. Targeted TV campaign

- Former young carer celebrities to raise awareness and be involved in marketing
- Federal budget allocation
- Regular prime time national advertisements
- Develop multi-media package targeting different audiences including young carers, teachers, community workers, health professionals and neighbours and friends during appropriate time-slots.
- Simple, clear, concise, eye catching
- Find a celebrity who identifies with the young caring/carer role

Give me a break - respite

1. Sufficient flexibility to allow young carers their own choice in the respite services they receive

- Start with a 'yes we can do that' attitude rather than a 'the guidelines don't allow that'
- Young carer respite guidelines to be flexible enough to be able to respond to evidence-based practice for young carers
- Funding model works from the premise of identifying the needs of young carers and finding solutions to meet those needs – 'thinking outside the square'
- Strategy voucher/token system with pre-purchased 'respite' services including family-focused activities
- Build the workforce capacity to provide service to young carers
- Ensure children's needs are fully met in accordance with age and development
- Young carers and their families are informed of their options for respite so they can make informed decisions
- Increase funding and resources for carer respite centres to enable more frequent and meaningful interactions (contacts) with young carers to monitor their changing needs (move to ongoing coordinated case management)
- Well skilled carer respite staff trained in appropriate interactions with young carers

2. Ensure equitable access for all young carers regardless of where they reside

- Find an alternative to competitive tendering to foster collaboration within the human services sector
- Develop strong partnerships between services and private industry
- Factor in the difference in unit costs when delivering services in rural/remote areas and apply funding appropriately
- National pilot project to research the comparative unit costs of delivery of services to rural/remote and metropolitan areas
- Ongoing mapping exercise to identify young carers and their needs re location
- Identify the gaps in service provision and the reasons they exist
- Develop a costed strategic plan to address identified gaps e.g. being able to identify young carers and give them information about what can help them, making sure the services are culturally appropriate and flexible enough to meet their needs

3. All young carers have access to supports to enable their education, vocational and lifestyle choices to be realised

- Support provided to enable young carers to complete tertiary studies through scholarships instead of only secondary education
- Additional funding allocated to young carer programs/services to provide flexible 'respite', including help with transport, to attend and participate in educational/vocational/lifestyle choice commitments.
- All services become equitable across the nation
- Career advisory services to be made available to all young carers
- Increase funding to enable infrastructure and support systems to change to enable this to happen
- Access to scholarships with support to identify possible scholarships and complete the necessary forms

4. The option of direct funding for families

- Initial identification/assessment based on whole of family needs
- Develop a policy/procedure enabling implementation of direct funding for young carers and their families with a strong focus on accountability
- Guidelines developed that include implementation, monitoring and evaluation of 'new' funding arrangements
- Guidelines take into consideration the potential difficulties this option could pose
- Establish a pilot program of direct funding for families support needs
- Changes in legislation and funding parameters needed

5. Young carers have a choice to be a carer or not

- Raising awareness amongst professionals and in society that the caring role cannot be expected or assumed, and that it is okay to transition out from the caring role
- At the point of diagnosis/discharge from hospital the impact of the disability or illness on the entire family is considered and taken into account in terms of developing care plans for the family
- A safe and supportive environment
- Enable young carers to have a care plan reviewed regularly so they can have an opt in/opt out clause.
- Support young carers to develop an 'Exit-Out Strategy' in relation to their caring role.
- Quality information on services and supports readily available
- Provide the opportunity for people needing support to access appropriate facilities or alternate care
- Increase funding for family support so that young carers can have a choice

Young carers 101 - education

1. The education system be able to provide enough flexibility to ensure all young carers can attend, participate and achieve in education

- Develop a good practice guide (similar to the Making it Work resource from the UK) that gives schools practical ideas, policy templates and strategies for helping young carers attend, participate and achieve
- Young carers to have funding support for educational costs
- Accreditation for their caring role towards their education - recognition of prior learning
- Carers Australia to lobby government to remove education fees for young carers
- Carers Australia to petition government to fund a scholarship scheme for further education of young carers and discuss with private business the possibility of sponsorships for young carers
- Consult with each state/territory education department, DEEWR and MEECTYA to develop a national picture of what is going on with young carers

2. All young carers including Indigenous, CALD, rural/remote to feel confident they can access a flexible learning plan to suit their needs

- Increased awareness of young carers in remote and culturally diverse communities
- Funding to access technology and resources to support all young carers to enable off campus learning
- State/territory education departments/national bodies develop framework, guidelines, and models so schools can deliver flexible learning plans
- Consultation and engagement with Indigenous and CALD communities to establish culturally appropriate local guidelines and frameworks
- Establish national guidelines and frameworks
- Develop individual support plans for young carers

3. Strong partnerships are developed between schools (and other educational programs), carer services and the community so that coordinated, responsive, family-focussed support can be provided

- More flexibility built into program design and delivery to ensure packages are responsive to young carers' individual needs
- Significantly more funding to provide increased support services for families
- Carers Australia takes a leadership role and makes links with relevant peak bodies and government departments for children, youth, families, disabilities, health to help raise awareness and facilitate better communication and partnerships
- Adequate staffing/funding resources to allow inter-agency networking resulting in collaborative work
- Inclusion in school newsletters information about young carers and available supports
- Continuous interaction between carers services and schools
- Point of contact person in student services in every school to facilitate inter-agency support of young carers

4. Mandatory training for teachers, all school staff, students and in-school young carer advocates

- Young carers are supported to share their stories at schools to raise awareness (this needs to be done in a way that is not taxing nor places the young carer at further risk)
- All schools to have stringent anti-bullying policies and guidelines in place to protect young carers
- Engage with state and territory education departments to encourage young carer training and awareness packages to be rolled in schools
- Professional development awareness of young carer issues for educational staff
- Carers Australia develop a training package to be rolled out through schools and universities for current and future teaching staff
- Induction manual should include young carer awareness for all new school staff
- National undergraduate education training to include young carer identification and support strategies
- Engage with the current national review / reform of the curriculum
- Young carer awareness in core units of new teacher training
- Develop partnerships with universities providing undergraduate/ postgraduate teacher training

5. Schools are accountable to education departments (national and/or state) re implementation of young carer policies

- Identifying young carers through enrolment procedures
- Mandatory reporting of number of young carers, academic results and service delivery models
- Education facilities comply with national young carers legislation and policies
- Establish a monitoring/compliance follow up procedure to ensure schools are implementing the policy

6. Key messages

Moving through the maze – access to government services

The key messages from this session include:

- legislation for carers with specific clauses for young carers giving them clear legal rights to recognition, assessments and services
- a “no wrong door” policy where:
 - (a) young carers and their families will be helped and signposted to appropriate help wherever they enter the system or whom ever they see
 - (b) the different departments need to agree on a joint protocol or way of working with agreed referral processes between them and arrangements for working across departmental boundaries, including a common assessment process
- a ‘whole of family approach’ to service delivery
 - services need to ‘think family’ and recognise the needs of all family members
 - this will ensure whoever enters the system first, or wherever they go, it will trigger a whole of family assessment
- whole of family approaches need to be evaluated to see what works
- ongoing national awareness raising of young carers and their families must continue by government
- young carers to be treated with respect and dignity by all areas of government
- Centrelink staff to be appropriately trained to understand carer issues.

Put your hand up - identification

The key messages for identification include:

- raising awareness of young carers among all professional groups
- helping young carers self identify so that they can access services and support
- using technology as one way to assist young carers identify
- all professional groups to understand the impact of caring on young people
- schools to have stringent anti-bullying policies and other support structures in place to enable young carers to feel comfortable in identifying as a young carer.

To achieve this there is consensus for:

- mandatory awareness raising, education and training about young carers to be included in the professional training programs of all workers (doctors, teachers, social workers, health, hospitals, with input from young carers themselves
- the responsibilities of these different groups are clearly stated in professional policies and guidelines, especially their responsibilities to identify, assess and meet the needs of young carers and their families.

“ Young carers must be seen and heard. “

Give me a break - respite

The key issue, agreed by the majority, is that young carers must have a choice about whether to care, how much care they provide and for how long they do it. For some young carers this will mean the choice about transitioning from their caring role.

To achieve this young carers need:

- ongoing, flexible support and services which help them in their caring role, reduce their caring responsibilities and which help to promote their access to education and the other things that young carers, like all other children and young adults should experience
- equal access to support and services which is not based on where they live, or cultural, religion or ethnic background
- services that are:
 - (a) culturally and age appropriate
 - (b) based on principles of best practice
- appropriate services to be available to support the person for whom they are caring.

It was also agreed that funding should be at appropriate levels to meet the current and future demands.

Young Carers 101 – education

The key messages from this session include:

- a greater partnership working between schools, colleges, universities and other education providers, local communities and carer services to
 - (a) recognise and identify young carers needs within educational settings and
 - (b) have appropriate, flexible and responsive support which helps them get the best out of their education – including attendance, achievement and participation
 - (c) young carers have access to scholarships – through government and the business community.

Participants stated clearly that:

- the “right” to a good education is universal and should not be affected by race, religion, ethnicity or geographical location
- educational institutions must work out and put in place policies about the identification of young carers and how they will be best supported within these settings. This will also require all staff in educational settings to have mandatory training and awareness of the needs of young carers and the educational implications.

7. Recommendations

The following recommendations were developed from the conversations during the panel discussions and the key messages developed during day 2 discussions. These recommendations will require a significant commitment from government.

1. That the government introduce, as a matter of priority, legislation to support and recognise carers. The national carer act should include specific clauses relating to young carers. For example, young carers 'right' to a good education is universal and should not be affected by race, religion, ethnicity or geographical location.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians. They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education. These rights should be mandated in legislation.

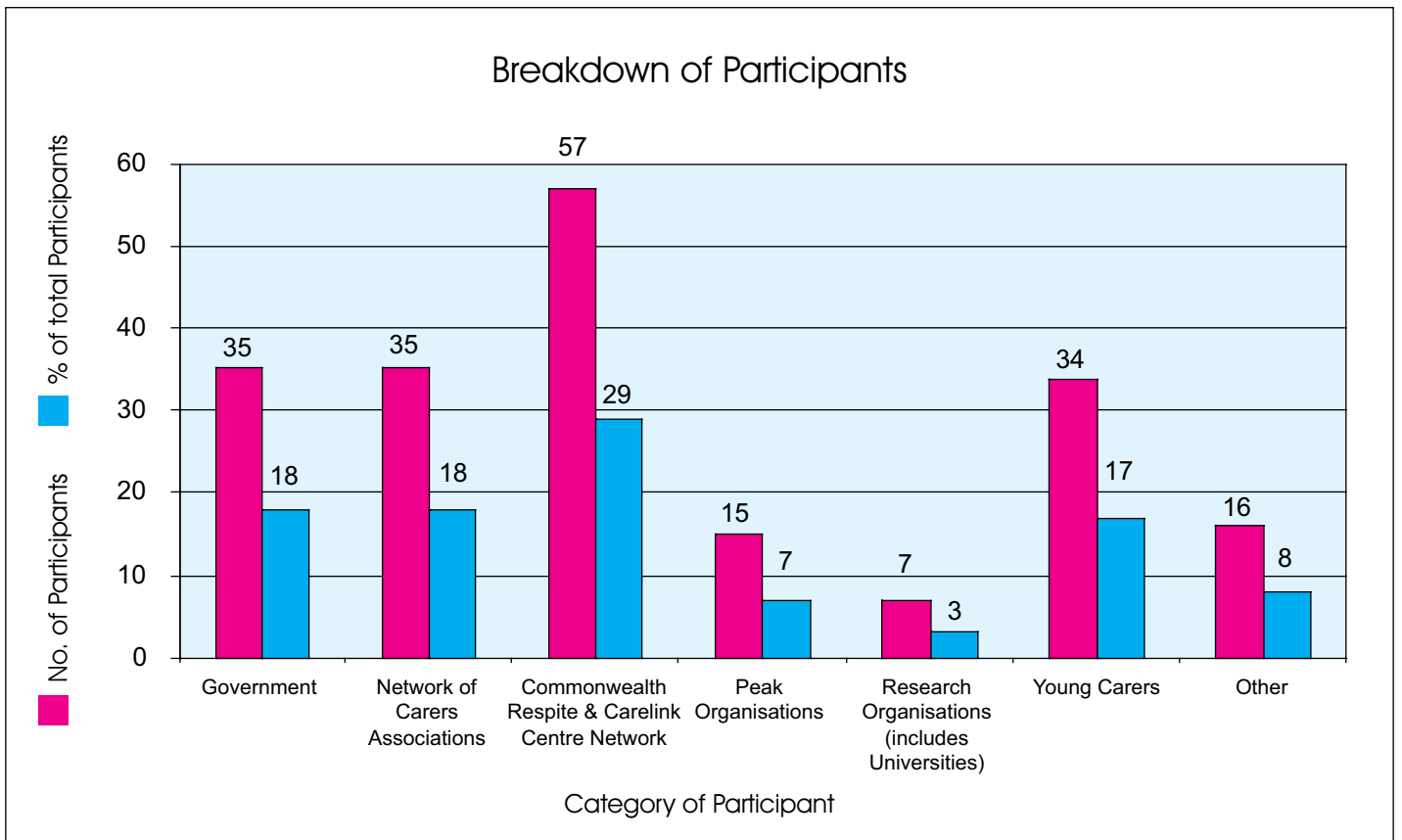
2. As a matter of priority, develop and implement a training program for Centrelink staff to ensure they have the skills, empathy and understanding needed to deliver a quality service to young carers and their families.
3. Review the '25 hour' rule as it currently applies in relation to income support – young carers consider study and work should be separated – study does not equal income.
4. Introduce a 'whole of family' approach and 'no wrong door' to service delivery.
5. Young carers are given the choice to care – appropriate support is therefore required for the person for whom they are caring.
6. Ensure support and information is available for young carers regardless of their geographical location or cultural heritage.
7. In developing and designing support and information resources use technology as a tool to assist access.
8. All information and resources should be up-to-date, current and age appropriate.
9. Undertake a national awareness raising campaign to promote self-identification by young carers and to increase awareness of young carers on the part of service providers, health professionals and educational institutions. Campaign material should be age, gender and culturally appropriate.
10. Undertake a national schools awareness and training program to ensure all schools and teachers have the knowledge needed to understand and support young carers throughout their education.

11. Encourage all educational institutions to put in place policies about the identification of young carers and how they will be best supported within these settings.
12. Establish an ongoing 'Young Carer Scholarship Program' aimed at assisting young carers through secondary education, TAFE and university degrees. This should be an ongoing commitment from government.
13. Provide ongoing funding for a 'professional development, leadership program' to support young carers as ambassadors and mentors.
14. Ensure government funding for the Young Carers Respite and Information Services Program is at a level to enable all young carers who identify and meet criteria to access support and information services.

8. Participants

Almost 200 people representing government, peak organisations, respite centres, carers associations and universities and young carers attended Bring it!. Carers Australia was pleased with the diversity of organisations represented and believes that the issues affecting young carers and their families has broad community support.

The graph below represents the number and percentage of participants from each category.



Graph 1: Breakdown of participants and percentage of representation from each category (participants numbers at left, percentage at right)

- Of the 34 young carers two were sponsored by their organisation. The remaining 32 were part of a leadership program that ran in conjunction with Bring it!
- There were also two other young carers who self-identified during the two days of Bring it!.

9. Program summary

The Bring it! Program was developed with input from the Steering Committee, the internal working group and ongoing consultation with young carers. At a previous summit in 2006, young carers had identified four major areas of concern – government, identification, respite and education. The program provided an opportunity for expert panel members and young carers to have an input across these four areas, presenting concerns and ideas. The day 2 program brought all participants together to simultaneously discuss issues of importance and develop priorities and recommendations.

Panel members

Session 1: - Moving through the maze (Government)

Tim Moore	Australian Catholic University
Sam Page	Family Relationships Services
Maria Bohan	Carers Victoria
Vivian	Community Options NSW
Paul Cowan	Centrelink
Jessica Willis	Young Carer

Session 2: - Put your hand up (Identification)

Ros Morrow	Curtin University
Kerry Graham	Inspire Foundation
Geoff Holloway	Australian Research Alliance for Children and Youth
Hester Wilson	GP
Sam O'Brien	Young Carer

Session 3: - Give me a break (Respite)

Bettina Cass	University of New South Wales
Connie Bruckard	Commonwealth Respite and Carelink Centre
Meghan Williams	Carers NT
Judy Phillips	Dept of Families, Housing, Community Services and Indigenous Affairs
Raynar Foldesi	Young Carer

Session 4: - Young carers 101 (Education)

Ms Annette Ellis, MP	Member for Canberra
Saul Becker	University of Nottingham, UK
Joanne Howard	ACT Department of Education and Training
Aaron Paul	Young Carer at University
Tabitha Wilson	Young Carer at High School
Kylie Whitehill	Young Support Worker, Caroline Chisholm School

A summary of the program follows. Profiles of the speakers are included at Appendix A.

Wednesday 26 November

9.00am	Welcome to Country – Agnes Shea
9.15am	Pam Webster, President Carers Australia – Welcome, Sets the Scene; introduces Minister
9.25am	The Hon Jenny Macklin, MP Minister for Families, Housing, Community Services and Indigenous Affairs
9.50am	Keynote Address – Professor Saul Becker, School of Sociology and Social Policy, University of Nottingham, UK
10.40am	<i>Morning Tea – Theatre Foyer</i>
11.10am	Session 1 – Access to Government Services Young carers identified access to government services and information as one of their four main areas of concern. Because three tiers of government are involved, each having several departments and agencies responsible for programs, services or funding the system becomes a maze for young carers.
11.10am	Our Story - Julie McCrossin – the views of young carers (Connections to Government Services)
11.20am	Moving through the maze (Government) – Panel discussion facilitated by Julie McCrossin
12.00	Questions of the Panel
12.15pm	<i>Lunch Mural Hall</i>
1.00pm	Hayley Bester – Young carer sponsored by beyondblue interviewed by Julie McCrossin
1.15pm	Session 2 – Identification Young carers named identification as one of their four main areas of concern. They recognise that there are many young carers who have not sought help from community services. They are keen to see these hidden young carers identified so they can receive support and services, benefiting both the care recipient and the carer.
1.15pm	Our Story - Julie McCrossin – the views of young carers (Identification)
1.25pm	Put Your Hand up (Identification) – Panel discussion facilitated by Julie McCrossin
2.10pm	Questions of the Panel
2.25pm	Session 3 – Respite Young carers identified respite as one of their four main areas of concern. They feel that support needs to be more flexible, more accessible and provide more options for young carers.
2.30pm	Our Story – Julie McCrossin – the views of young carers (Respite)
2.40pm	Give me a break (Respite) – Panel discussion facilitated by Julie McCrossin
3.10pm	Questions of the Panel
3.20	<i>Afternoon Tea – Theatre Foyer</i>
3.50pm	Session 4 – Education Young carers identified support in schools and other educational institutions as one of their four main areas of concern. They have reported a reluctance to identify as a young carer if the school or tertiary institution they attend do not have support in place and carer-friendly practices to assist them through their education years.
3.50pm	Our Story – Julie McCrossin – the views of young carers (Education)
4.05pm	Young Carers 101 (Education) – Panel discussion facilitated by Julie McCrossin
4.50pm	Questions of the Panel
5.15pm	<i>Finish</i>
5.30pm	Carnivale

Thursday 27 November

9.15am	<i>Australian Experience a Retrospective</i> – Joan Hughes, CEO Carers Australia (interviewed by Julie McCrossin)
9.50am	<i>Outline of iMeet Session and how it works</i>
	<i>iMeet</i> allows groups of people to simultaneously participate in discussions around important issues.
10.00am	<i>iMeet Interactive Workshop Sessions commence</i>
	<p><i>Group 1</i> Moving through the maze</p> <p><i>Group 2</i> Put your hand up</p> <p><i>Group 3</i> Give me a break</p> <p><i>Group 4</i> Young carers 101</p>
11.00am	<i>Morning Tea – Mural Hall</i>
11.30am	<i>iMeet session continues</i>
12.30pm	<i>Lunch – Mural Hall</i>
1.15pm	iMeet session wrapped up
1.45pm	<i>Developing recommendations, outcomes and priorities</i> Group 1 Group 2 Group 3 Group 4
2.45pm	<i>Afternoon Tea – Mural Hall</i>
3.00pm	<i>Where to now – key recommendations</i> (facilitated by Julie McCrossin)
3.45pm	<i>Forum closing session</i>
4.00	<i>Finish</i>

10. Meeting with parliamentarians

All the young carers who attended Bring it! were given the opportunity to meet with politicians, including a number of relevant Ministers and Shadow Ministers, and/or their advisers. In total, 27 half-hour meetings were arranged in the parliamentary offices of the politicians. The young carers were divided into groups of 3-4 and attended 2-3 meetings each.

The purpose of the meetings was to advise the politicians about young carer issues and to describe the personal impact of caring felt by those in attendance. The exercise was also part of the Leadership Program that the young carers had been involved in.

The feedback received from both the politicians and the young carers was very positive. Many of the young carers described these meetings as a highlight of the Forum and were very grateful for the opportunity to speak directly to the politicians. The politicians reported that they were very impressed with the presentations made by the young carers and were pleased to gain a better understanding of their roles and responsibilities.

Below is the full list of politicians and advisers with whom young carers met:

The Hon Tony Abbot MP	Mrs Sophie Mirabella, MP
Mr Tom Bentley (adviser to the Hon Julia Gillard)	Senator Claire Moore
Senator Cory Bernardi	Mr Scott Morrison MP
Senator Catryna Bilyk	The Hon Brendan O'Connor
Mr Russell Broadbent MP	The Hon Tanya Plibersek MP
Ms Anna Burke MP	Senator Louise Pratt
Mr Steven Ciobo MP	Mr Rowan Ramsey MP
The Hon Peter Dutton MP	Ms Amanda Rishworth MP
Ms Annette Ellis MP	The Hon Nicola Roxon MP
The Hon Kate Ellis MP	The Hon Philip Ruddock MP
Mr Chris Hayes MP	Senator the Hon Nigel Scullion
Senator Gary Humphries	Senator the Hon Ursula Stephens
Senator the Hon Joe Ludwig	The Hon Malcolm Turnbull MP
The Hon Jenny Macklin MP	

11. Evaluation

...It was an interesting, inclusive and energising conference with great participation by everyone but particularly the young carers.

(Peak organisation)

...This was one of the most enjoyable, informative conferences I've been to. (Service provider)

...Absolutely fantastic involvement of young carers. Great to hear their views to help shape service delivery, policy, training, funding etc.

(Service provider)

...It was FANTASTIC, GREAT, SUPERCALIFRAGILISTICALEXPALIODOCIOUS AWESOME! (Young carer)

...The best and most relevant and interactive conference I have ever attended.

(Peak organisation)

...Congratulations to the organisers – a job well done from the comprehensive delegates handbook to the great program (Government)

I have to say that this is the best event I've been to in 16 years in terms of participation. It's the best even in terms of actually hearing young carers speaking and having their voices integrated throughout the day. So it's not seen to me to be at all tokenistic, this is being mainstream. (Saul Becker)

A summary of the feedback received through evaluation forms is outlined below. Participants were asked if the Forum met their expectations; and how the Forum rated in nine specific areas, including the key areas of program, keynote presentation, panel discussions and interactive group discussions. Other areas related to non-young carer specific aspects such as venue and MC.

Responses to the key areas were overwhelmingly positive and particularly high for the program and the keynote presentation. Of the 199 participants (including speakers and panel members), 135 submitted responses.

Summary

Participants were asked if the Forum met their expectations on a scale ranging from 'met none' to 'exceeded expectations'. On this scale 91% of participants said the Forum met most, met all or exceeded expectations with 45% participants responding that the Forum exceeded their expectations.

Participants were also asked how the Forum rated in the key areas of the program, keynote presentation, panel discussions and interactive group discussions. Participants rated the forum on a scale from one to five as follows, where one was 'not satisfactory and five was 'excellent':

Overall feedback

- **94% rated the program a four or five.** A further 5% of participants rated the program at three. No participants rated the program as a one or two.
- **70% rated the keynote presentation as 'excellent'.** Overall, 93% rated Saul Becker's presentation a four or five. No participants rated the keynote presentation as a one or two.
- **76% rated the panel discussions a four or five.** It was rated a three by another 19% of participants. No participants rated the panel discussion as a one or two.
- **78% rated the interactive group discussions a four or five.** It was rated a three by another 17% of participants. Four participants (3%) rated the panel discussion as a two. Three participants (2%) did not respond or did not attend. No participants rated the panel discussion as a one.

Feedback from participants working in state and federal governments

Government participants used the same evaluation form as other participants, and their responses are included in the overall summary above. Their results echoed the general feedback, with some variations.

Government participants responded to the same question asking if the Forum met their expectations on a scale ranging from 'met none' to 'exceeded expectations':

- **87% said the Forum met most, met all or exceeded expectations.**
- **30% said the Forum exceeded their expectations.**

In the key areas of the program, keynote presentation, panel discussions and interactive group discussions, government participants also rated the forum on the scale from one to five using the same evaluation forms as other participants, where one was 'not satisfactory' and five was 'excellent':

- **100% rated the program was rated a four or five,** compared to 94% of overall participants.
- **86% rated the keynote presentation a four or five,** compared to 93% of overall participants.
- **63% rated the presentation as a five, the highest possible rating.** Two government participants (7%) rated the keynote presentation as a three. Two participants (7%) did not respond or did not attend. No government participants rated the keynote presentation as a two or a one.
- **63% rated the panel discussions a four or five,** compared to 76% of overall participants. It was rated a three by another 30% of government participants (compared to 19% of overall participants). One government participant (3%) rated the panel discussion as a two. No government participants rated the panel discussions as a one.
- **77% rated the interactive group discussions a four or five,** compared to 78% of overall participants. It was rated a three by another 23% of government participants, slightly higher than the 17% of overall participants who rated it as a three. No government participants rated the interactive group discussion as a one or a two.

While government participants' outcomes largely echoed those of other participants, they rated the program more highly than the overall responses. Government responses in other categories rated those other categories slightly lower.

Conclusions

The Forum feedback indicates participants rated the Forum highly in all functional areas. They were especially positive about the program itself, and the keynote presentation. Government participants' 100% positive response to the program itself is very helpful in understanding broadly what parameters government needs to gain useful information.

12. Literature reviews – background papers

Literature reviews were undertaken on each of the four areas of concern to young carers. These formed the basis of discussion during the Forum. Delegates were provided with a copy of the literature reviews prior to the Forum.

A full copy of each of the reviews is available from the Carers Australia website www.carersaustralia.com.au
A summary of the reviews is outlined below.

Moving through the maze - access to government services

Young carers have identified access to government services and information as one of their four main areas of concern. This literature review examined the issue of government services and information available for young carers and looked at recent developments in policy, practice and research.

Because three tiers of government are involved, each having several departments and agencies responsible for programs, services or funding, the governmental system becomes a maze for young carers. The review also provided a summary of overseas developments and identified two new approaches to policy and practice.

Young carers concerns

Young carers saw a disconnection between what was considered a family responsibility and what was seen as a government responsibility. A disconnection made more acute by the lack of coordination among different government departments and between the different levels of government. Services were frequently uncoordinated and developed in an ad hoc manner.

In addition to seeking greater resources and increased funding, they also sought more flexibility approaches to service delivery: more flexible guidelines, more flexible access and more flexible availability.

What young carers want

To avoid confusion, duplication and to assist with ease of access to information, support and services young carers want:

- all levels of government to work collaboratively to identify their roles and specific responsibilities in supporting young carers
- to be able to identify and follow the links and pathways between government departments and agencies at each level
- governments to commit to developing and implementing effective policy about young carers as a priority
- to fund young carers and support services at an appropriate level.
- greater awareness and understanding of the role of young carers by governments and service providers and improved communication with them as responsible carers.

Put your hand up - identification

Identification is one of the four main areas of concern to young carers. The literature review explored the issue of identification of young carers and looked at recent developments in policy, practice and research. It compares research and statistics from the UK and US and identifies innovative approaches.

Young carers recognise that there are many young carers who have not sought help from community services. They are keen to see these hidden young carers identified so they can receive support and services, benefiting both the person receiving care and the carer. There are a number of reasons for young carers not being identified, or choosing not to identify themselves, including:

- the perceived stigma of being associated with disability or illness
- the wish not to be labelled by others
- the fear that child protection services could see them as 'at risk' and remove them from the family.

What young carers want

Young carers want greater awareness and recognition from those in the health services, teachers and others in the education sector, and from those providing community services. These professions need to be better equipped to acknowledge and support young carers. They also want increased awareness and respect from the wider community.

Young carers found much of the language around caring to be emotive, open to misunderstanding, and obscured by jargon. They want information and services that are appropriate to their ages, their gender and their cultural backgrounds.

Identification is crucial

Identification gives carers and their families opportunities to:

- seek advice
- find practical help and services
- gain peer support
- access counselling and respite
- ascertain what financial support might be available.

Give me a break - respite

Young carers identified respite as one of their four main areas of concern. This literature review examined the issue of respite for young carers and looked at recent developments in policy, practice and research. It also identified some new approaches to providing respite.

Young carers' concerns

Young carers feel that respite needs to be more flexible, more accessible and provide more options. Their concerns regarding the accessibility of respite relates to:

- the costs
- their fear of removal from the family
- transport difficulties
- social isolation
- limited services available to those in rural and remote areas.

What young carers want

A number of issues have been identified around respite. Young carers want:

- respite to be redefined to become part of a broad support framework that focuses on alleviating the impact of the caring role on young people
- flexible support options to be made available to all young carers and their families, irrespective of location and financial and social circumstances.

Young carers 101 - education

Young carers have identified support in schools and other educational institutions as one of their four main areas of concern. The literature review explores recent developments in policy, practice and research for young carers and education. It also identified some innovative approaches in education and looks at the links between education and long-term earning capacity.

Young carers have reported a reluctance to identify as a young carer if the school or tertiary institutions they attend do not have support in place and carer-friendly practices to assist them through their education years.

What young carers want

Young carers have a number of priorities they would like to address. These priorities are fundamental to young carers continuing their education in a safe and supportive environment. Young carers want:

- to influence state and territory education departments to include young carer-friendly practices in schools and tertiary institutions
- teaching staff to receive training about caring so they understood the impact it might have on carer attendance or ability to do homework in times of difficulty
- schools to provide a safe environment for them without stigma or bullying from those who do not understand disability or ongoing illness
- confidentiality from those they talk to about their caring role
- support to help them connect to services
- opportunities to meet other carers in support groups
- access to flexible delivery methods
- a curriculum that covers caring skills and self care
- recognition of prior learning for their caring activities.

Appendix A - Speaker profiles

[The Hon Jenny Macklin, MP, Minister for Families, Housing, Community Services and Indigenous Affairs](#)

Jenny Macklin is the government Minister with primary responsibility for carers. Ms Macklin has been the Member for Jagajaga in Victoria since 1996 and has demonstrated a strong interest in social and community issues throughout her political career.

[The Hon Bill Shorten, MP, Parliamentary Secretary for Disabilities and Children Services](#)

Bill Shorten was elected as the Member for Maribyrnong in Victoria in 2007. Prior to entering Parliament, Mr Shorten was the National Secretary for the Australian Workers' Union. He also held the positions of Director, Australian Super and Director, Victorian Funds Management. Mr Shorten has demonstrated a strong commitment to people with a disability.

[Professor Saul Becker, School of Sociology and Social Policy, University of Nottingham, UK](#)

Saul is Director of Research and Professor of Social Policy and Social Care in the School of Sociology and Social Policy, University of Nottingham, UK. For 15 years he has been researching, writing and working on young carers issues in the UK and internationally. He has directed 30 research projects; published nearly 300 books, chapters and articles; and he has spoken at 150 conferences. During his childhood, Saul was a young carer. He is passionate about and committed to the development of research-informed and outcomes-based policy for young carers and their families.

[Pam Webster, President Carers Australia](#)

Pam Webster is the President of Carers Australia and has been a member of the Carers Australia Board since 2005. She has extensive personal experience as a carer, including having been a young carer for her younger sister who had serious, chronic ill health and who eventually died aged 32. She has also cared for her own daughter who has a severe, chronic illness and for several frail aged relatives.

[Julie McCrossin, Facilitator](#)

Julie McCrossin talks to people for a living. She began working for the ABC in 1983 and has presented many Radio National programs including "Background Briefing" and "Arts National", as well as stints on ABC Rural Radio and 702ABC Sydney. Currently Julie presents a travel program called Up and Away for Qantas in-flight entertainment, writes for the new ABC magazine Life Etc and facilitates conferences and training seminars nationally. Julie is an Ambassador for NAPCAN (The National Association for the Prevention of Child Abuse and Neglect).

[Hayley Bester – Young carer sponsored by beyondblue: the national depression initiative](#)

Over the last four years Hayley has been both a consumer and a carer. During this period she has learnt the importance of listening rather than just speaking; the importance of ensuring that as much as you need to look after the person going through a tough time you also need to look after yourself. She now uses her experiences to try and provide advice and equip other young Australians with the correct information and skills to look out for a mate.

[Maria Bohan, CEO Carers Victoria](#)

Maria Bohan has held this position for 13 years. Maria's career has journeyed through teaching in primary and secondary schools, adult education on international development issues, and education of women's health workers about empowerment and adult learning principles. She is passionate about working from a community development, system change and social justice perspective.

[Connie Bruckard, Manager Commonwealth Respite and Carelink Centre, Hobart](#)

Connie Bruckard has been the manager of the CRCC in Hobart, for over 11 years. Prior to this she spent time in the aged care sector. Connie also worked with young children and adolescents at Westmead Hospital in Sydney for 8 years. Connie has an MBA, a Masters of Health & Human Services and is a GAICD.

[Bettina Cass, Professorial Fellow, Social Policy Research Centre, University of NSW](#)

Research undertaken by Bettina Cass is concerned with analyses of caring, work, family, children and young people's well-being and social policies in Australia and internationally. She is currently carrying out research about the wellbeing, experiences and needs of young carers through an ARC Linkage grant with colleagues at the Social Policy Research Centre on "Young Carers: life-course impacts of the caring responsibilities of children and young adults".

[Paul Cowan, Acting General Manager Families, Seniors and Service Delivery Support Centrelink](#)

Paul is responsible for the management nationally of payments to families, the Aged Pension and Carer's Programs. Paul has a diverse background in the development and implementation of social policy. He has many years experience in the employment, education, seniors and carers program and policy spheres. Immediately prior to commencing in Centrelink in 2002 Paul held the post of Counsellor, Employment Education and Training at the Australian Delegation to the OECD in Paris.

[Annette Ellis, MP](#)

Ms Ellis has been the Member for Namadgi, in the ACT since 1996 and has served on many committees during her time in Parliament including Family and Community Affairs, Aboriginal and Torres Strait Islander Affairs, Employment, and Workplace Relations and Workforce Participation Ms Ellis is currently the Chairperson of the Standing Committee on Family, Community, Housing and Youth that has had responsibility for the Inquiry into Better Support for Carers.

[Raynar Foldesi, Young Carer](#)

Raynar Foldesi is 22 and cares for her 19 year old brother. She has accessed a range of services through Carers WA, Red Cross home help and respite from Gosnells Home Help and Identity.

[Kerry Graham, Inspire Foundation](#)

Kerry Graham joined Inspire Foundation in April 2007 and has over 15 years experience working with children and young people. A lawyer by training, Kerry has committed herself to service delivery and systems reform. She worked for a number of leading nonprofit youth services before undertaking leadership roles for the National Aboriginal Sports Corporation Australia (NASCA) and Good Beginnings Australia.

[Geoff Holloway, Research Manager Australian Research Alliance for Children & Youth](#)

Geoff has a PhD in sociology (University of Tasmania). He has taught in Curtin University, with specialities in Applied Sociology and the Sociology and Anthropology of Health and Illness, with a focus on people with disabilities and people from multicultural backgrounds. Geoff has also worked with the Disability Services Commission in Western Australia; Child and Family Services and the Children's Commissioner - both in Tasmania.

[Joanne Howard, Acting Executive Director, Schools ACT Dept of Education and Training](#)

Joanne Howard has responsibility for providing strategic educational leadership and management of ACT public school sectors (preschools, primary schools, high schools, colleges, special schools and early intervention centres), and the delivery of educational support services in these schools and settings.

[Joan Hughes, Chief Executive Officer Carers Australia](#)

Joan Hughes was appointed CEO in July 2006. She is an Honorary Associate in the Department of Nursing Research Centre, University of Sydney, was awarded a Churchill Fellowship in 2004, and from 1993 until 2006, Joan was CEO Carers NSW. In 2008, she was selected to attend Australia's 2020 Summit. Joan serves on many federal government committees as well as international carer advisory committees.

[Tim Moore, Research Fellow and Lecturer Australian Catholic University](#)

In 1997, Tim founded the ACT Young Carers Network and established St Nick's Young Carers Program, running camps and activities for young carers in Canberra. Tim has managed research projects to explore young carers' experiences in education, with service delivery and, in 2008, the needs of those caring for a parent with a drug or alcohol issue.

[Sam O'Brien, Young Carer](#)

Sam is 17 and cares for his mum. He has a range of interests including football, writing and music. In his caring role he has accessed a range of services through organisations such as the Commonwealth Respite and Carelink Centre.

Sam Page, Executive Director Family Relationships Services Australia

Family Relationship Services Australia (FRSA) is the national peak body for organisations that deliver family relationship services. Former roles have included social policy, service delivery and management consulting working with both government and non-government agencies. Her work has been characterised by a capacity to engage diverse stakeholders in policy and service innovation.

Aaron Paul, Young Carer at University

Aaron Paul is a young man who has provided care for his mother since age 11, studies Medicine at University and hopes to become a doctor. Aaron works with other young carers as a mentor and peer leader, and is a Carers Australia Ambassador.

Judy Phillips, Director of the Young Carers Respite and Information Services Program FaHCSIA

Judy has tertiary qualifications in psychology, special education and public administration. She has a background of working in the community with people with a disability. Areas of work include training people with disability in sheltered workshops in the 1980s; supporting people with a severe or profound disability to participate in their community through a community access program and nearly eight years as an advocate for people with a disability, people who are aged and their carers.

Vivian, Executive Officer Community Options NSW

Vivian has held this position for the past 10 years Her journey has been through both the Community and Health sectors.. Vivian currently sits on the Case Management Society of Australia Executive and is an active member of the Community Care Industry Council , the HACC Issues Forum, and acts in an advisory role to a variety of current policy and practice initiatives.

Kylie Whitehill, Youth Support Worker Caroline Chisholm School, Canberra

Kylie has had extensive training in the community development sector and is very passionate about young carers. Kylie first became involved with young carers when she started working at Lanyon High School in 1995. She started the support group for young carers based in schools. This group grew to encompass all Tuggeranong high schools. Kylie is now at Caroline Chisholm School where she started a Young Carers Support Group in term one with three Young Carers. There are now two groups with over twenty in each Group. These Programs are in conjunction with LITMUS and CYCLOPS Programs Angilcare Canberra and Goulbourn.

Meghan Williams, Carers NT

Meghan Williams has worked for Carers NT since 2003. Meghan is the parent of a 17 year old child with Special Needs as well as two children adopted from overseas. She has been active in the areas of disabilities in her role as a Member of NT Disability Advisory Council from 2003 and Secretary / Chairperson and Cofounder of Namarluk & Henbury Outside School Hours Care since 1997. Formerly Meghan's background was in the area of Health as an Associate Charge Nurse.

Jessica Willis, Young Carer

Jessica Willis is a 23 year old young woman who has been the primary carer for her mum. She has recently taken up a temporary part time post with Carers NSW as a "Young carer Intern with policy and media focus".

Dr Hester Wilson, General Practitioner

Hester is a Fellow of the Royal Australian College of General Practitioners, and a Fellow of the Chapter of Addiction Medicine in the Royal Australian College of Physicians. She has extensive clinical experience working with drug and alcohol and mental health co morbidity. Currently working in private general practice in Newtown, she believes that mainstream general practice is ideally placed to assist young people and their families and carers. Hester's involvement in the Forum has been supported by the Australian General Practice Network.

Tabitha Wilson, Young Carer at High School

Tabitha Wilson is 16 and lives in Wagga in New South Wales. She cares for her dad and older sister. Tabitha enjoys art, music, photography, reading, cooking, dancing, shopping, and being involved in things that she is passionate about such as the great outdoors



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