

## **Queensland Government Submission to the Commonwealth Government Parliamentary Inquiry into “Better Support for Carers”**

### **Executive Summary**

The Queensland Government welcomes the opportunity to provide a submission to the Commonwealth Government Inquiry into “Better Support for Carers”.

The Queensland Government recognises the remarkable support the estimated 536,000 carers in Queensland provide to family members, loved ones, friends and neighbours on a daily basis and the immense benefits their unpaid efforts bring to our community.

Whilst recognising the mutual and reciprocal relationships between carers and the person receiving care, the Queensland Government also acknowledges the challenges carers face in their caring role including increased risk of social isolation, health problems, increased financial pressure and limited opportunities to pursue social, educational and economic activities.

In 2003 the Queensland Government introduced the Carer Recognition Policy, as a first step in recognising the significant contribution carers make to Queensland. The policy provides clear principles and guidelines for Queensland Government agencies to adopt so that carers’ roles are appropriately considered when designing and delivering relevant policies, programs and services.

In December 2006 the Queensland Government Carer Action Plan 2006–10 was launched to translate the Carer Recognition Policy into action to improve the lives of carers and the people for whom they care.

The Carer Action Plan responds to carers’ diverse characteristics and circumstances and reflects the needs and issues raised by carers during consultation when developing the Carer Recognition Policy. These include balancing employment and caring responsibilities and returning to the workforce, education and training, support and respite for ageing carers, access to information and recognition of carers as partners in care.

The Queensland Government consults with carer organisations on policy issues through departmental Reference Groups such as the Disability Services Queensland ‘Reference Group on Disability’ and the Queensland Police Service ‘Disability Reference Group’. Queensland Health also engages with carers through a number of initiatives on the Carer Action Plan designed to increase consumer and carer participation in the mental health system. These include the Carers Matter website, development of a (draft) Consumer and Carer Participation Framework to guide services including carers and consumers in mental health processes, training for consumers and carers and a Consumer and Carer Voice project.

The Queensland Government Submission to the Inquiry provides information on existing initiatives in Queensland that recognise and support carers and provides recommendations on future actions for consideration. It is recognised that enhancements to existing programs or the development of new initiatives will need to be considered within available resources at the State and Federal level.

Given the complexity and diversity of individual carers' circumstances it is proposed that a suite of flexible practical supports be considered that recognise the changing needs of carers and the person for whom they are providing care over a lifetime.

Rigorous evaluation of available evidence in addition to consultation with relevant stakeholders and carers would inform the identification of key priorities for actions/practice measures to support carers.

Some suggested principles for informing the key priorities for action may include:

- Co-ordinated and well-resourced measures that address the holistic and changing needs of carers
- Positively framed social inclusion frameworks to raise awareness, knowledge and recognition of carer roles
- Focus on transition points (especially for young carers)

A suite of recommendations to better recognise and support carers is outlined against the four areas of concern, it should be noted that some of these recommendations could cross more than one area:

1. The role and contribution of carers in society and how this should be recognised:
  - Attributing greater value to carer roles in society generally through public sector and community awareness programs.
  - Recognition and inclusion of carers needs and issues in the design and delivery of relevant mainstream policies, programs and services.
  - Recognition of carers roles and expertise and partnership with carers in policy development, service planning and service delivery to care recipients.
2. The barriers to social and economic participation for carers with a particular focus on helping carers to find and/or retain employment:
  - Financial recognition of carers in lieu of paid employment where appropriate.
  - Recognition of the needs of carers independent of their caring role (for example providing supports that will enable carers to maintain social networks, pursue interests or engage in education, training or employment opportunities).
  - Advocacy with schools or training institutions and employers to encourage flexible education and employment options.
  - Access to education and training which could include learning about their role as a carer.
3. the practical measures required to better support carers, including key priorities for action:
  - Ensuring responses to carers acknowledge and are responsive to the diversity of carers' individual needs, taking into consideration cultural differences, age, disability, religion, socio-economic status, gender identification and locality.
  - Increased availability of community-based care, including respite services, especially in discrete or remote communities such as Indigenous or culturally and linguistically diverse communities.
  - Access to aids and equipment that will support carers in the provision of care.
  - Access to a range of accommodation, respite care and support options that recognise the diverse needs of carers and those receiving care when the carer is no longer able to provide 24 hour care.

- Access to programs and services that are responsive, timely, coordinated, innovative, flexible and appropriate to carers' differing needs and circumstances.
  - Housing and support programs that recognise the changing needs of carers including older carers.
  - Preventative health and well-being programs that are tailored to carers.
  - Early intervention programs that provide support to carers in the early stages of their caring role.
  - Access to information that will support carers in their role.
4. Strategies to assist carers to access the same range of opportunities and choices as the wider community including strategies to increase the capacity for carers to make choices in their caring role, transition into and out of caring and to effectively plan for the future.
- Ensuring the appropriate sharing of information and decisions on care in matters that affect carers or the care they provide.
  - Assistance with planning for the future care and support needs of the person requiring care.

# **Queensland Government Submission to Commonwealth Government Parliamentary Inquiry into “Better Support for Carers”**

## **Purpose:**

The purpose of the Parliamentary Inquiry into better support for carers is to gain an improved understanding of the challenges facing carers and their support needs.

Carers play a vital role in sustaining Australia’s system of community-based person-centred care. However carers are often at increased risk of:

- Social isolation
- Disconnection from mainstream employment
- Poorer physical health and psychological wellbeing compared to the rest of the population
- Problematic access to services and support
- Increased financial pressure including limited opportunities to accrue savings, accumulate superannuation and save for retirement.

## **Definition of Carers:**

For the purpose of the Inquiry carers are defined as ‘individuals providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty’.

## **Structure of Queensland Government Response**

The Queensland Government response to the Inquiry provides information on a range of existing initiatives that recognise and support carers in Queensland (Part A) and provides recommendations on future actions for consideration (Part B).

The recommendations in Part B are structured around the four areas of concern identified in the Terms of Reference to the Inquiry:

- 1) The role and contribution of carers in society and how this should be recognised;
- 2) The barriers to social and economic participation for carers with a particular focus on helping carers to find and/or retain employment;
- 3) The practical measures required to better support carers, including key priorities for action; and
- 4) Strategies to assist carers to access the same range of opportunities and choices as the wider community including strategies to increase the capacity for carers to make choices in their caring role, transition into and out of caring and to effectively plan for the future.

As per the Terms of Reference, the Queensland Government has also provided information on the particular needs of groups of carers including new carers, younger carers, older carers, Indigenous carers and those with multiple care responsibilities.

## **Part A - Existing Queensland Government Initiatives to Support Carers**

The Queensland Government has a number of projects/programs with infrastructure in place to support carers. It should be recognised that any enhancements to existing programs/services or new actions to support carers as per the recommendations in the submission, would need to be considered within the context of available resources and the priorities of the State and Federal governments.

In 2003 the Queensland Government introduced the *Carer Recognition Policy*, the first official step in recognising the significant contribution carers make to Queensland. The policy provides clear principles and guidelines for Queensland Government agencies to adopt to ensure that carers' roles are appropriately considered when designing and delivering relevant policies, programs and services.

In December 2006 the *Queensland Government Carer Action Plan 2006–10* was launched to translate the Carer Recognition Policy into action to improve the lives of carers and the people for whom they care.

The plan responds to carers' diverse characteristics and circumstances and reflects the needs and issues raised by carers during consultation when developing the *Carer Recognition Policy*. These include balancing employment and caring responsibilities and returning to the workforce, education and training, support and respite for ageing carers, access to information and recognition of carers as partners in care.

Key initiatives featured on the Queensland Government Action Plan 2006-10 include:

- Introduction of a Carer Business Discount Card issued to eligible carers to provide discounts at participating businesses
- Introduction of a Companion Card (issued to the eligible person with a disability) – which allows admission at no extra charge to a person accompanying the person with a disability, at participating venues or activities
- Funding for a succession planning project to help families map out the future care needs of relatives with a disability
- Additional respite for non-Indigenous older parent carers aged 70 years and over and Indigenous older parent carers aged 50 years and over through a joint Commonwealth/State Government initiative governed by a Bilateral Agreement. The Bilateral Agreement recognises the diverse range of family structures operating within Australian society and culturally diverse definitions of “parent”, “son” and “daughter”, especially in relation to Aboriginal and Torres Strait Islander people.
- Implementation of a range of state-wide strategies to increase carers and consumers participation within the mental health system
- Increased awareness, understanding and support of young carers in schools
- Flexible training through the TAFE system to support young carers to continue their education
- A community education strategy on work/life balance and self-assessment measures for businesses to evaluate work/life balance policies
- Programs to assist parents and carers who have been out of paid employment to update their skills and re-enter the workforce
- Improved information and resources to support carers in their role.

Following are details of several initiatives in Queensland, which relate closely to the areas of concern identified in the Terms of Reference. These include processes within the Department of Housing which recognise the role of carers in housing provision, support to young carers in education and training and assistance to carers who wish to re-engage with the paid workforce.

#### Social Housing

The Queensland Department of Housing ensures that the role and contributions of carers are recognised and that the Government's specific commitments in relation to carers and their role are met in the operation of its directly managed social housing programs through specific policy and procedures including:

1. Identifying Carers - clients are offered the opportunity to identify and have carer details recorded.
2. Information Exchange – clients can include their carer in an exchange of information by completing an Authority to Request or Disclose Personal Information to Third Parties Form.
3. Bedroom Entitlements – clients can be allocated a separate bedroom for a live in carer or support person, who provides care either full time or over 50% of the time. Discretion may be exercised for applicants who only require a carer on weekends for three nights, which is less than 50% of the year.
4. Rent Assessment - Carers who reside in the public housing property as their principle place of residence have their income assessed as per normal rent assessment rules. However, carers who do not reside in the public housing property as their principle place of residence do not have their income included for rent assessment purposes e.g. the carer may sleep over through the week to provide 'on call' support but return to their own home for the remainder of the time.

In addition to the policies and procedures outlined above the Department of Housing provides a range of practical supports to assist carers including:

- Continuous improvement in the coordination and planning of housing and support for people with a disability across government agencies.
- Planning to take account of the future housing design and support requirements for people with disabilities including the implications of having ageing carers.
- Universal design of properties to assist people who are ageing and/or with a disability and their carers to remain in their homes.
- Home modifications and Home Assist Secure programs which provide practical assistance to enable people with a disability or those who are frail aged to remain in their homes. These modifications will also benefit carers.

The Department of Housing's commitment to improving the way in which housing and support is coordinated, assessed and delivered across Government will benefit people with disabilities, people with a mental health illness and people at risk of homelessness and their carers.

#### Young Carers

Queensland's Department of Education, Training and the Arts, through its training portfolio, employs the strategies below, to facilitate pathways to training and employment for young carers.

Queensland's Department of Education, Training and the Arts training portfolio administers vocational education and training investments which are primarily focused on workforce skills development. The Department is also involved in various initiatives that accommodate carers' access to education and training, enhancing their capacity to provide support to a family member or friend. These initiatives include the implementation of industry engagement models to capture workforce skilling issues, including those in the community services and health industry. These models include skills alliances, skills formation strategies and direct industry engagement, including cross-government skilling partnerships with lead agencies.

The focus of TAFE Queensland is on young carers in vocational education and training programs which lead to employment in areas not necessarily related to their role as a carer. This is to ensure that carers are able to commence and maintain

education and training opportunities. Through identifying and recognising carers as a group, TAFE Queensland can provide support services that are specific to the needs of young carers.

As well as promoting pathways for those young people in vocational education and training programs which lead to employment in areas not necessarily related to their role as a carer, TAFE Queensland also provides a range of qualifications in the community services and health areas that are suitable for carers, and there should be no obstacle to carers on welfare accessing such training. In demonstrated cases of financial hardship, it is possible for fees to be waived.

Within the state education system, a number of policies encourage schools to take a flexible approach with timetabling and curriculum to support the engagement and participation of students at risk, including young carers. Agreed and approved alterations may be made to a student's educational program, including a formal flexible arrangement where outside providers are involved. Young carers in state schools can seek advice from Guidance Officers and other school support staff who may also refer them to appropriate community support services.

The Youth Support Coordinator Initiative, as a joint initiative of the Department of Communities and the Department of Education, Training and the Arts, has been an integral component of the Queensland Government's Education and Training Reforms for the Future. The Department has committed \$9.6m per annum across 2006 - 09 to the program. Funds are administered by the Department of Education, Training and the Arts and transferred to the Department of Communities on a quarterly basis through a Memorandum of Understanding between the two departments

This initiative has proven successful as a support mechanism for young people at risk of disengagement from learning to move into and through the Senior Phase of Learning. There are 113 Youth Support Coordinator positions (YSCs) employed by non-government organisations in Queensland to deliver welfare, social and emotional support services to young people enrolled in school, including those who perform carer roles, to assist them to successfully complete secondary school and training. As YSCs are based in community organisations, they are well placed to work with schools to support young carers by coordinating and facilitating case management responses across a number of government and non-government service providers.

- Besides individual support services, YSCs also support young people who perform carer roles by:
  - engaging in community development / awareness raising activities within the school community that de-stigmatise the illnesses / issues that require care responses.
  - working collaboratively with educational / training institutions to facilitate understanding of the social issues associated with young people who perform care roles.

The YSC initiative enables young people to balance their studies with their responsibilities as carers. Continuation of study maximises employment opportunities at a time in the future when the young person's caring responsibilities may have ceased. With the cost saving to the community realised by family members accepting carer roles recognised by government, supporting individuals to achieve a balance between study and a carer role clearly provides short and long-term benefits to both the individual and the broader community.

## Employment

The Queensland Government through the Department of Employment and Industrial Relations (DEIR) manages a *Skilling Queenslanders for Work* program to increase workforce participation of disadvantaged jobseekers, underemployed workers and those not in the labour force.

In recognition of the disadvantage in the labour market faced by parents and carers, *Skilling Queenslanders for Work* incorporates a Parents and Carers Strategy which assists these groups to gain the confidence and social and vocational skills necessary to rejoin the workforce. Assistance is provided to those parents and carers who are in a position to return to the workforce or to training.

Under the Parents and Carers Strategy, a target of 1000 parents and carers are assisted across Queensland each financial year. Carers (and parents) are offered a personalised package of assistance which may include: job preparation, paid work placements, accredited vocational education and training and post-participation support for up to six months, mentoring and a contribution to transport and childcare costs.

Because it is predominately women who withdraw from the workforce to take on parenting or caring roles, most of the participants on Parents and Carers projects under *Skilling Queenslanders for Work* have been women. As a result, the training provided has been in industries which offer flexible hours, such as retail, aged care and child care.

The Parents and Carers Strategy, provides assistance to carers to transition out of their caring role into employment or training. Under *Skilling Queenslanders for Work* there are also strategies to assist other groups disadvantaged in the labour market including young people (Youth Worx), Indigenous people, mature age people (Experience Pays Strategy) and those from culturally and linguistically diverse backgrounds (Multicultural Employment Strategy). Carers belonging to these groups can also access assistance from these alternative strategies.

The Work and Family Unit established within DEIR promotes and encourages employers to accommodate employees' needs to balance work and caring responsibilities. The importance of this issue has grown as the available labour supply is shrinking and competition for staff is intensifying. Part of being an attractive, competitive employer involves the provision of work-life balance policies, which can attract carers who have been out of the workforce due to their caring responsibilities. Resources, such as the Better Work-Life Balance Survey, developed by DEIR in collaboration with the University of Queensland, provide importance means for employers to better accommodate employees' need to balance responsibilities at work and outside of work.



## **Part B - Areas of Focus for the Parliamentary Inquiry**

### **1. Recognition of Carers**

#### **Recommendations:**

- Development and delivery of programs to raise awareness of and responsiveness to carer's needs and issues within services, government agencies, businesses, and educational institutions. Social marketing strategies could be employed to raise the awareness and knowledge of the broader community about the unique and challenging role and contribution of carers in society. It is important that programs to increase awareness of carers recognise that the interests of carers and those for whom care is provided are not always the same. This principle should also apply in programs to increase awareness of those receiving care. Policy decisions need to reflect this understanding, promote appropriate balance and avoid unintended consequences for either group.
- Practical strategies and funding (e.g. through whole-of-government Action Plans) to assist:
  - carers in their roles as carers (for example through access to information; training; processes to recognise and increase participation of carers and consumers in service planning and service delivery; access to respite care and in-home support; and support and assistance to plan for the future).
  - carers as individuals with their own diverse needs. This includes developing appropriate strategies that recognise the impact of low socio-economic status, age, culture, religion and location as well as the fact that many carers have a disability.
  - carers undertake roles beyond their caring responsibilities (for example through programs and policies to enable carers to balance learning, employment and caring).
  - Indigenous carers.
- Formal recognition of the role of carers when developing mainstream policy and including views of carers and/or carer peaks in policy development processes (for example through formal consultation mechanisms or through consideration of carer impacts in the development of policy submissions).
- Representation of carers in policy matters relating to the structural changes that are required to increase carers participation in social and economic opportunities.
- Consideration of carers' roles and responsibilities when developing policies which may impact on their ability to carry out duties and activities for their family member or friend.
- More research into the cost of caring to families so that Governments can provide adequate financial support to assist families in their caring roles.

#### **Recognition of Young Carers**

Options to recognise the role and contribution of young carers in society include:

- State/Territory and Federal Governments working together to explore the potential for coordinated responses to achieve a holistic range of responses focussed on meeting the needs of young carers in schools and training programs.
- Raising awareness of young carers and their needs in schools and districts. Schools acknowledge that amongst their student population there are likely to be some young people who are taking on a caring role within their family, and that this may affect their schooling experience. Building awareness of the responsibilities faced by these students and providing support and advocacy at

school whilst respecting their privacy and desire for confidentiality will promote recognition of the contribution made by these young people.

- Developing and implementing strategies to identify, recognise and support young carers in vocational education and training programs with a focus on supporting young carers to commence and maintain education and training opportunities.
- Recognition that Indigenous young people may be more likely to provide carer roles and responsibilities for their peers and family members, and that specific, culturally appropriate strategies that recognise the contribution of Indigenous young people may need to be identified and implemented.

### **Recognition of Diversity amongst Carers**

- The multiple caring roles of some community members should also be recognised in legislative and policy frameworks. For example, many Aboriginal people, usually women, may care for a family member with a disability and, at the same time, provide support or care for others such as grandchildren or older parents.
- Recognition of the role of carers and understanding of the term 'carers' also varies among different cultural groups. People from some cultural backgrounds may be unfamiliar with the specific notions of 'care' and 'carers', believing that the role of caring is a natural duty of particular family roles, for example mother, daughter. These different understandings within some segments of the community can make appropriate recognition of carers and their contributions difficult. Some groups may also believe that identifying as a carer also identifies the family member to whom care is given as having a disability – which in some communities may attach much stigma and shame. Promoting the positive contribution that carers make to society is a way of increasing recognition of the role.
- Generational differences in attitudes towards the caring role need to be considered in policy frameworks. For example older carers may have an expectation that siblings will continue to provide care and support to family members with a disability once the ageing parents are no longer able to fulfil this role. Siblings or other family members may however carry a different view to this and hold an expectation that Governments will take on this responsibility once parents are no longer able to provide care to their son or daughter with a disability.

## **2. Barriers to Social and Economic Participation for Carers**

### **Background:**

- It is estimated that Carers provided 1.2 billion hours of care in Australia in 2005. This equates to the equivalent of \$30.5 billion of formal aged and disability care services in Australia (Access Economics).
- The contribution that Carers make is not matched by Government funded services and income support payments.
- It is estimated that collectively the cost to Carers (and to the economy), in terms of lost wages, is \$4.9 billion annually (Access Economics).
- In relation to the figures provided by Access Economics what is not considered or costed is the diminution of leisure time, as well as employment time and the costs to health and wellbeing. Carers often experience income inequality because of their reduced levels of paid employment. ABS (2004) data indicated that carers are over-represented in the two lowest household income quintiles. Only 33.9 per cent of primary carers received a wage or salary.
- Indigenous carers have a lower than average socio-economic status. The 2006 Census indicated that non-Indigenous carers were one and a half times more

likely to be employed than were Indigenous carers and the median weekly income for Indigenous carers was lower than that for non-Indigenous carers across all age groups. Many Indigenous families face other pressing issues, such as health and housing needs.

- While Queensland's unemployment rate has fallen to its lowest level in a generation (3.6 per cent in April 2008), there are several groups in the community who are struggling even in a buoyant job market. Parents and carers are among the groups who fall into this category.
- The most recent data for Queensland carers, which dates from 2003, shows that primary carers are predominately women (74.0%).
- In 2003, Queensland primary carers had an unemployment rate of 6.1%<sup>1</sup>, which compared favourably with the 9.4%<sup>2</sup> unemployment rate of the wider community at that time. However, the labour force participation rate of Queensland primary carers at 35.2% was considerably lower than the wider Queensland community at 60.0%.

#### **a) What are the barriers to social and economic participation for carers?**

The low participation rate of carers in the workforce reflects the high number of hours primary carers spend in their caring duties. It also may reflect that carers are discouraged from participating in the labour force. Due to caring responsibilities, many carers can be discouraged from labour market participation because they:

- cannot find flexible work that allows them to combine their work and caring responsibilities;
- are unable to undertake paid work, or are only able to work limited hours;
- lack recent work experience and therefore lack referees;
- lack social and workplace networks necessary to find work once their caring responsibilities are eased;
- have difficulty accessing appropriate day or respite care to enable them to participate in the workforce, even on a part time basis;
- have little opportunity to undertake vocational training or higher education; and
- have lost work skills due to time away from their usual employment which has a detrimental impact on career pathway/promotion.

#### **Additional barriers to social and economic participation include:**

- Carers would often like to work to broaden their horizons and enjoy some interaction with others however this is not a financially viable or advantageous option due to Commonwealth income support restrictions. For example, when a carer works in a paid capacity care payments are adjusted accordingly by Centrelink in applying income support policies.
- The ability of carers to participate in social and community activities may be limited by a range of factors including the demands of caring, lack of alternative support options, available income and accessibility issues.
- Young carers are recognised as being at risk of not completing secondary schooling, which has long term social and economic effects on the individual. They are also unlikely to be able to fully participate in many school related activities and be restricted in normal social activities by their caring responsibilities. These children and young people are often economically

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<sup>1</sup> ABS, Cat no.4430.0 Disability Ageing and Carers 2003, Table 29

<sup>2</sup> ABS, 6202.0.55.001, Labour Force Australia Spreadsheets, Table 06, Labour Force Status by Sex Queensland, Series A18373R, (December 2003)

disadvantaged as the family income is usually affected by inability to engage in full time employment.

- Young carers may be more likely to experience barriers to accessing the resources needed to support their educational and economic engagement. This may be because of:
  - concerns about a lack of confidentiality particularly if they are concerned that their family situation will become known within a broader community;
  - concern regarding a school triggering a child safety notification process; and
  - an inability to negotiate with educational providers or employers for the necessary adjustments to study schedules and workplace attendances.
- Carers from culturally and linguistically diverse backgrounds may experience additional barriers to social and economic participation including:
  - limited English language proficiency, which can exacerbate other barriers to participation, as well as to accessing mainstream support services;
  - a lack of culturally appropriate support services, such as respite services;
  - low levels of awareness about available support services, due to a lack of written information and other resources in languages other than English;
  - loss of extended family support and networks following migration, and beliefs that caring roles should be filled by family or friends, rather than by accessing outside help;
  - different experiences and/or perceptions of support services in their country of origin – for example, there may not have been support services in the country of origin, or there may be fears that seeking help will result in the institutionalisation of the person who needs care;
  - preferences for traditional remedies and/or differing concepts of health and well-being, which may be barriers to carers accessing services;
  - stigma associated with disability, mental illness, and/or seeking assistance;
  - previous experiences of discrimination and/or racism, either in Australia or their country of origin;
  - trauma or stress due to the migration experience – a particular concern in the case of refugee families, who often arrive with very few resources and have often suffered severe hardships in their countries of origin, in addition to the stress involved in caring for a family member with a disability or mental illness;
  - cultural beliefs about intergenerational and/or gender roles – such as that caring is the responsibility of women and girls. In some cultures older siblings may be expected to care for younger siblings, with negative impacts on their education; and
  - Deinstitutionalisation and the ageing of the population will predictably see a transition of long term carer roles from parents to siblings or an increased reliance on government intervention (due to generational changes in attitudes towards caring responsibilities). Where siblings or other family members adopt caring roles there will be implications for future access to life long learning opportunities and consistent economic participation (and thus security) for this group of new or successive carers. This will create economic and social vulnerabilities for this group of people.

**b) What steps need to be taken to increase carer's social and economic participation and to assist carers to find and/or retain employment?**

**Recommendations:**

- Address systemic disincentives towards earning a higher income whilst retaining a focus in government service provision for those in greatest need of assistance.

- Introduction of legislation for the Carer Bonus to become an annual, indexed payment to recognise “the extraordinary effort of carers.”
- Extension of the Carer Bonus to carers who receive the Carer Allowance and who also receive Centrelink income support (other than the Carer Payment), particularly carers who are recipients of the Age Pension and sole parent benefits.
- A carer often unexpectedly needs to return to the workforce because the individual needing care requires full-time residential care or dies. There is a role for Centrelink to meet with the carer periodically to discuss future options including pre-employment assistance or training options in preparation for such an eventuality.
- Adjust Centrelink processes to become more consumer and carer friendly and less confusing.
- Introduction of legislation to provide employed carers with the right to flexible working hours and appropriate carer leave as recommended by the Australian Human Rights and Equal Opportunity Commission.
- Offer incentives, including a range of appropriate jobs and flexible work place conditions to enable carers to participate in employment opportunities while balancing their carer responsibilities.
- Instituting “reasonable adjustment” arrangements with government employers initially, then generalising the practice to all employers with the support of legislation and community awareness programs.
- Expansion of community and work-place education strategies to provide information and advice to carers and employers on work/life balance.
- Promoting the benefits of employing carers, similar to the advertising campaign encouraging the employment of older workers.
- Development of tailored employment programs that recognise and cater for the unique situations and challenges carers face in re-entering the paid workforce, including access to alternative and affordable care/respite options for the person for whom they are providing care.
- Increase access and availability of part time work, particularly in higher paid/skilled work. [Noting that part time work tends to be more readily available in lower paid or unskilled jobs and that this factor may contribute to social and economic marginalisation of carers and their families.]
- Peak organisations should be adequately funded to continue to facilitate an understanding of employment and training issues which impact on carers.
- Disability Employment Networks (DEN) provide help for people with a disability in “job in jeopardy” situations. Disabled employees who are likely to lose their jobs as a result of their disability may be able to receive immediate help or support from a DEN member to keep their job. This type of employee support could benefit carers who are likely to lose their job as a result of their caring responsibilities.
- Implementing strategies which support young carers to remain engaged in education and/or training assists them in accessing employment. Assisting and encouraging young carers to find appropriate and reliable respite care will enable them to develop the skills and independence required to access employment opportunities.

### **Strategies to support carers from culturally and linguistically diverse backgrounds to gain employment**

The following steps may assist in increasing the capacity of people from culturally and linguistically diverse backgrounds to maximise their employment opportunities:

- Improved linkages between the Integrated Humanitarian Support Services (which are generally the first contacts in Australia for refugees), support services providers, and employment services would allow more referrals between agencies, so that carers are given the support they need to find and retain employment.
- Development of strategies to assist carers to access existing support services that would enable them to participate in employment – for example, production of information resources in languages other than English, making existing services more culturally appropriate, and awareness and education campaigns to break down the stigma often associated with disability and mental illness in culturally and linguistically diverse communities and encourage carers in these communities to seek help outside the family.

### **3. Practical Measures Required to Better Support Carers, including Key Priorities for Action**

#### **General Recommendations (others identified in the Summary Section of the submission).**

- Providing all carers, young and old, with an assessment, similar to a workplace, health and safety assessment, to eliminate and reduce risks. This initiative would reduce back injuries and other injuries relating to the carer role. In addition education and training could be provided in relation to stress and resilience.
- Additional funding for the National Respite for Carers Program, and amendments to the program guidelines, to provide flexible respite to allow all carers to participate in health maintenance activities.
- Increased funding for the National Carer Counselling Program to provide adequate counselling services to carers in need.

#### **Practical Supports for Older Carers**

- More resources allocated to succession planning to enable older parent carers to plan formal and informal supports for their son or daughter when they are no longer able to provide care for them and to explore alternative accommodation and support options.

#### **Practical Supports for Younger Carers**

- Raising awareness of the needs of young carers in education
- Providing flexibility in timetabling, attendance and assessment requirements where appropriate, to support young carers to complete schooling .
- Assisting young carers to engage with support agencies and respite care providers.
- Articulating the voice of young carers in post-compulsory education to improve responsiveness to their needs.

#### **Practical Supports for Carers from Culturally and Linguistically Diverse Backgrounds**

For people from culturally and linguistically diverse backgrounds practical supports include:

- Increasing the cultural competency of existing support services, through training for staff, and employment of bi-cultural and/or bilingual staff;
- Ensuring that support services have the resources and skills to engage accredited interpreters, including staff who are trained in using interpreters;
- Establishing carer support groups, within cultural groups, to develop culturally appropriate and informal support networks; and

- Appropriately targeted awareness campaigns to increase understanding of the services available and how to access them.

Provision of culturally competent support mechanisms for Indigenous people is also important. Many Indigenous carers do not have sufficient support, and may not be aware of available services or where to seek support. Strategies to provide appropriate supports for Indigenous people should consider that whilst Indigenous people may prefer to seek assistance from other family members rather than bringing in assistance from external providers, some Indigenous carers do not have extended family willing or able to assist. This can leave the carer without support and in danger of burn out or unable to follow their own interests. A possible solution could be to recruit paid respite workers within the extended family or community.

Developing services to support carers must be done in partnership with Indigenous people to respect local family and community preferences.

#### **4. Strategies to assist carers to access the same range of opportunities and choices as the wider community including strategies to increase the capacity of carers to make choices within their caring roles**

##### **Recommendations**

- Improve access to information and advice for carers, including information available from government – information providers should also recognise that many carers, particularly young carers, do not see themselves as ‘carers’. Carer organisations have articulated the need for carers to have knowledge of how to negotiate systems and government departments, their rights and responsibilities, decision making principles; and to have support to do this.
- Investment in improving carer capacity and well being. Specifically the strengthening of capacity of discrete carer groups such as – Indigenous carers, young carers, carers of people who have a mental illness, carers who are sole parents and carers who have multiple care responsibilities.
- Increase availability and improve access to services which offer support and respite to carers.
- Consult with identified carer groups to establish specific focus areas and to influence future policy developments.
- Strategies for young carers should recognise young people may need additional counselling and support to build and strengthen their confidence in making choices about their caring roles. Young people who perform carer roles also identify that educational providers that over-compensate for their carer role by diminishing educational expectations is as detrimental as ignoring the implications of their role as carers. Consequently, educational responses need to be developed and reviewed based on individual circumstances.
- The key transition points and different developmental stages experienced through adolescence would require review and adjustment of interventions, resources and supports needed by the young carer. Consequently, engaging in a regular process of case review and management involving care recipient, care provider and support agencies would be required (Adequate resourcing would need to be available to support this kind of response to young carers).
- Culturally appropriate support services for Indigenous people who perform carer roles would assist carers in making choices regarding their caring role. Access is a significant concern for Indigenous people living in rural and remote locations. Strategies to increase participation in these support services would also be necessary.

- For people from culturally and linguistically diverse backgrounds, availability of information in languages other than English and cultural competence of services providers would assist.
- ❖ *Strategies to enable carers to transition in and out of caring roles*
  - Provide training and employment opportunities, to enable carers to move in and out of caring roles.
  - Development of respite services so that carers including young carers can maintain social networks and engage in social activities in an ongoing manner.
  - Allocation of additional resources to support engagement of priority groups such as women and Indigenous young people (who are more likely to perform carer roles) in educational and vocational activities. Given their economic vulnerability, support needs to be offered for participating in education and vocation pathways as a means of facilitating future economic security.
- ❖ *Strategies to assist carers to plan for the future care and support needs of their son or daughter*
  - Increase funding for Succession Planning initiatives to assist carers in making plans for future care options for the person for whom they provide care. Improving coordination between Commonwealth and State and Territory Succession Planning initiatives.
  - A range of targeted and innovative economic and social inclusion strategies to assist carers to plan for the future and the support needs of their children will need to be identified. These strategies may include:
    - Allocating resources to provide additional respite care places for people in need of care;
    - Strengthening capacity of human service providers to provide regular, temporary home-care for families in need of respite care; and
    - Supporting the development of support networks to assist carers with developing plans for future care of their family member/s.

### **Recommendations related to Housing Provision and Carer Recognition**

*Strategies to enable carers to transition in and out of caring roles include:*

- Zoning, land use provisions and building regulations to help people with disabilities to 'age in place', eg:
  - housing to be more easily adapted for caring needs – eg. granny flat type extensions;
  - temporary extensions to enable additional people to share housing (might include demountable or caravan type accommodation);
  - higher focus on adaptable design (see below).
- General housing designs need to be "supportive and enabling"<sup>3</sup>.
- Wider application of Adaptable and Universal housing design.
- Housing that is designed to suit the cultural needs and norms of families. For example, Indigenous families may need to accommodate relatives for extensive periods from time to time.
- More flexible housing forms that can be adapted to housing additional adults (as opposed to housing which is mainly suited to nuclear families only).
- Assistance with modification to the family home to enable families to continue to support family members at home.
- Address the income support disincentives to increasing income through paid work.

<sup>3</sup> AHURI, *Improving housing and care for adults with disabilities*, June 2002.



- Local area coordination strategies to coordinate support services as needed.
- Provision of services on an as-needs basis rather than being rigidly restricted within funding periods.

### **Summary**

Given the complexity and diversity of individual carers' circumstances it is proposed that a suite of flexible practical supports be considered that recognise the changing needs of carers and the person for whom they are providing care over a lifetime.

Rigorous evaluation of available evidence in addition to consultation with relevant stakeholders and carers would inform the identification of key priorities for actions/practice measures to support carers.

Some suggested principles for informing the key priorities for action may include:

- Co-ordinated and well-resourced measures that address the holistic and changing needs of carers
- Positively framed social inclusion frameworks to raise awareness, knowledge and recognition of carer roles
- Focus on transition points (especially for young carers)

A suite of recommendations to better recognise and support carers is outlined against the four areas of concern, it should be noted that some of these recommendations could cross more than one area:

1. The role and contribution of carers in society and how this should be recognised:
  - Attributing greater value to carer roles in society generally through public sector and community awareness programs.
  - Recognition and inclusion of carers needs and issues in the design and delivery of relevant mainstream policies, programs and services.
  - Recognition of carers roles and expertise and partnership with carers in policy development, service planning and service delivery to care recipients.
2. The barriers to social and economic participation for carers with a particular focus on helping carers to find and/or retain employment:
  - Financial recognition of carers in lieu of paid employment where appropriate.
  - Recognition of the needs of carers independent of their caring role (for example providing supports that will enable carers to maintain social networks, pursue interests or engage in education, training or employment opportunities).
  - Advocacy with schools or training institutions and employers to encourage flexible education and employment options.
  - Access to education and training which could include learning about their role as a carer.
3. The practical measures required to better support carers, including key priorities for action:
  - Ensuring responses to carers acknowledge and are responsive to the diversity of carers' individual needs, taking into consideration cultural differences, age, disability, religion, socio-economic status, gender identification and locality.
  - Increased availability of community-based care, including respite services, especially in discrete or remote communities such as Indigenous or culturally and linguistically diverse communities.
  - Access to aids and equipment that will support carers in the provision of care.

- Access to a range of accommodation, respite care and support options that recognise the diverse needs of carers and those receiving care when the carer is no longer able to provide 24 hour care.
  - Access to programs and services that are responsive, timely, coordinated, innovative, flexible and appropriate to carers' differing needs and circumstances.
  - Housing and support programs that recognise the changing needs of carers including older carers.
  - Preventative health and well-being programs that are tailored to carers.
  - Early intervention programs that provide support to carers in the early stages of their caring role.
  - Access to information that will support carers in their role.
4. Strategies to assist carers to access the same range of opportunities and choices as the wider community including strategies to increase the capacity for carers to make choices in their caring role, transition into and out of caring and to effectively plan for the future.
- Ensuring the appropriate sharing of information and decisions on care in matters that affect carers or the care they provide.
  - Assistance with planning for the future care and support needs of the person requiring care.