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Submission No. 1039
(Inq into better support for carers)
AOC 30/7/08

DISABILITY SERVICES COMMISSION
making a difference

Mr James Catchpole
Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Mr Catchpole

INQUIRY INTO BETTER SUPPORT FOR CARERS

Thank you for your letter dated 20 May 2008 inviting the Disability Services Commission to make a submission to the inquiry.

The inquiry covers a very important matter – the wellbeing of carers — that is at the core of the Commission's considerations and daily operations. I am very pleased to provide the attached submission, which broadly addresses the terms of reference.

The attachments include a submission from the Fitzroy Valley Advocacy Group, which is a unique advocacy group for Aboriginal people with disabilities and their carers located in Western Australia's remote Kimberley region. The Commission received this information for inclusion within its submission, however considered that the material, while referred to throughout the submission, deserves to stand alone as a clear statement reflecting the perspectives of Aboriginal carers.

I look forward to following the progress of the inquiry and reading the final report and recommendations in due course.

Yours sincerely

Dr Ron Chalmers
DIRECTOR GENERAL
DISABILITY SERVICES COMMISSION

15 July 2008

Att
W:\Director\W08\DG\Correspondence\C-DG1220 covering letter- Better Support for Carers Submission- lselepak.doc

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SUBMISSION TO THE HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON FAMILY, COMMUNITY, HOUSING AND YOUTH INQUIRY INTO BETTER SUPPORT FOR CARERS

DISABILITY SERVICES COMMISSION, WESTERN AUSTRALIA

Summary and Introduction

This submission recognises the vital contribution made by carers of people with disabilities. It canvasses some of the major issues concerning carers including poverty, health and wellbeing, issues for groups including new carers, older carers, young carers, people from culturally and linguistically diverse (CALD) and Aboriginal backgrounds, rural and remote issues, access to specialist disability and mainstream services, and workforce issues, among others. Key strategic issues requiring attention include the alleviation of financial disadvantage among carers, and the development of long-term measures to address shortcomings in the service systems on which people with disabilities and their carers rely. These matters involve complex and high-level debate and attention across all jurisdictions.

While the Disability Services Commission has a broad interest in the wellbeing of all carers, the primary focus of this submission is on carers who fall within the Commission's target population. Essentially this includes people whose disability was manifest before the age of 65 years and excludes those with a primary psychiatric diagnosis.

The submission is organised under the terms of reference, however practical measures and strategies are considered together. Attachment 1 includes a copy of a monograph, providing an overview of contemporary research and issues relating to carers, which was recently completed to help inform the development by the Disability Services Commission of a long term plan for disability – Disability Future Directions 2025. The attached monograph is one of a series of papers which have been developed to help inform an environmental scan about the future trends and issues to face people with disabilities, their families, carers and service providers over the next 15 to 20 years.

Recent work undertaken by the Commission to increase the responsiveness of its services to Aboriginal people included extensive consultation with Aboriginal people with disabilities, their carers, service providers and relevant others[1]. A body of work has been developed and is being implemented including a policy and practice framework[2], a package for service providers (Getting Services Right) and a Reconciliation Action Plan 2008-10. The latter was launched in June 2008 and is a first for the States/Territories.

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[1] The Commission uses the term Aboriginal in preference to Indigenous as, during the consultation process to develop a policy framework, most Aboriginal people preferred to use either this term or the name of their specific language group to denote their cultural identity.

[2] *Access for Aboriginal and Torres Strait Islander People Policy and Practice.*

As part of the Commission's ongoing involvement with Aboriginal communities, the opportunity arose for a Local Area Coordinator, a local Home and Community Care (HACC) provider and an external consultant to convene a meeting with the Fitzroy Valley Advocacy Group to discuss carer issues within the context of the present inquiry. The Fitzroy Valley is a large area (some 52,000 square kilometres) in the Kimberley region and includes around 40 Aboriginal communities. The Fitzroy Valley Advocacy Group was formed in 2003 and is the only Western Australian advocacy group representative of Aboriginal people with disabilities and their carers. This produced a rich body of discussion which, while referred to in the submission, stands alone and speaks for itself, as outlined in Attachment 2.

The role and contribution of carers in society and how this should be recognised

Carers make a substantial contribution to the social and economic wellbeing of the community and provide around 70 per cent of care to people with disabilities. On the economic front alone, an estimated 1,039,000 carers[3] provided care estimated in 2005-06 was estimated at $41.4 billion nationally.

Western Australia has legislation (including the Disability Services Act 1993; Carers Recognition Act 2004; Equal Opportunity Act 1984) and also many policies and programs that benefit carers. State-based legislation and services complement the range of national measures for people with disabilities, their families and carers.

The Commission recognises that carers are essential to the wellbeing of people with disabilities in WA. At the highest level, carers are specifically recognised in the Commission's governing legislation – the Disability Services Act 1993 – which has been amended to align with the State Carers Recognition Act 2004[4]. Carers are involved at all levels of policy formulation, and legislation provides for inclusion of members with recent caring experience on the Board of the Disability Services Commission[5]. Carers are represented on the Ministerial Advisory Council on Disability (MACD) and both the Commission's Board and MACD consult with carers on a regular basis.

Carers are included at all points of the service system and are consulted widely with regard to service design for the people they support. Other ways in which the Commission supports and recognises carers includes the provision of:

- funding (including for respite, accommodation support, alternatives to employment, small individual grants);
- information, advocacy and referral (by service providers and also the state-wide Local Area Coordination network, which has close connections with carers at the community level); and

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[3] Includes carers of aged people and people with disabilities.

[4] The Disability Services Act and Recognition Act are currently under review. The Commission is one of the reporting organisations required to submit annual reports to the Carers Advisory Council under the *Carers Recognition Act 2004*.

[5] While the Disability Services Commission is a State Government Department, it is also a Statutory Authority, and hence has a Board, as prescribed in the *Disability Services Act*.

- grants and programs delivered through non-government providers and the Commission.

The introduction of national legislation recognising carers may bring many benefits to carers, including raising community awareness about the vital contribution that carers make on a daily basis. However there are some important aspects that need careful consideration:

- Not all people with caring responsibilities identify themselves as carers, or wish to do so. Many carers see what they do as a normal extension of their family/friendship/community role. Legislation needs to take into account the heterogeneity of carers.

- It is important that any carer legislation does not overshadow the need for fundamental changes in the broader systems affecting carers of people with disabilities, for instance:
  - ⇒ adequate income support (such as increases to Carer Payment and Carer Allowance; provision of superannuation support for carers unable to enter the workforce);
  - ⇒ removal of barriers to carers entering and remaining in the workforce;
  - ⇒ adequate funding for disability services including accommodation support, respite, community access, and aids and equipment; and
  - ⇒ improved access to mainstream services including housing, transport, health and education, especially for people living in rural and remote areas.

The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment

Carers typically face many barriers to social and economic participation, and any combination of these may affect a carer's ability to enter or retain employment.

Poverty and the cost of caring

Many carers experience poverty and almost all carers face financial challenges

Carer health and wellbeing

Carers frequently experience poor health. Research conducted by the Carers Association of Australia in 1999 found that the physical, mental and emotional health and wellbeing of most carers is poorer than the general population. A survey of some 30,000 carers conducted by Deakin University found that carers have the lowest collective wellbeing index of any demographic group the researchers had encountered. The Fitzroy Valley Advocacy Group has noted some of the health difficulties currently experienced by Aboriginal carers, including difficulties with the health system.

Cultural factors

Aboriginal carers and carers from culturally and linguistically diverse (CALD) backgrounds[6] may experience a range of difficulties including language problems; differing cultural beliefs regarding the type of personal care that can be provided and by whom; varying levels of knowledge and understanding about available services; and a reluctance to use services and supports. Carers in the Fitzroy Valley highlighted some of their concerns including inability to participate in cultural obligations due to limited respite options, and different cultural protocols that limit the provision of respite, other services and support.

Rural and remote issues

Carers living in rural and remote areas experience many difficulties including travelling long distances to access services; additional costs for services; lack of knowledge, skills and awareness among service providers; physical isolation; and strong cultural ties and obligations. The Fitzroy Valley Advocacy Group highlighted the many issues faced by Aboriginal carers in remote areas including difficulty accessing services (especially housing, transport, health, education, aids and equipment), high living costs and isolation.

Complex and multiple care responsibilities

Carers of people with complex needs face particular challenges. Some carers have multiple caring responsibilities, for instance providing care for both a child with disabilities and a spouse or ageing parent. Carers' needs may be exacerbated by factors including cultural issues, health problems, poverty, housing stress, isolated location and poor education. Carers in the Fitzroy Valley noted that Aboriginal carers often face multiple care responsibilities.

Carer supply and labour market pressures

Australia is currently experiencing dual pressures — to increase labour supply as well as maintain the support by carers. The Taskforce on Care Costs report notes demographic trends that contribute to Australia's current work/care pressures

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[6] It is noted that this inquiry's terms of reference omitted reference to people from CALD backgrounds among the listed carer groups whose particular needs will be identified.

including: a declining total fertility rate over the long term; increased life expectancy; and an increased proportion of older Australians.

Unmet need in disability services

The high level of unmet demand across all disability services — particularly accommodation support, respite care and alternatives to employment — are well documented. The Senate Community Affair Committee inquiry into the Funding and Operation of the CSTDA noted that family members carry the main responsibility for meeting the needs of people with disabilities. Evidence to the inquiry illustrated that carers continue to experience huge stress.

Access to mainstream services

Access to other essential services — especially housing, transport, education and health — is a constant struggle for many carers. Housing in particular is essential to health and wellbeing, yet the cost of housing places a major burden on many low and moderate income households. Carers in rental situations face many challenges. People living in rural and remote locations are under particular stress with regard to accessing services. Aboriginal carers in the Fitzroy Valley noted the difficulties they face in accessing appropriate housing, transport, education and other services.

The practical measures required to better support carers, including key priorities for action

and

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 within their caring roles, transition into and out of caring, and effectively plan for the future

Several factors combine to reinforce the need for prompt action to develop additional measures and strategies to support carers, particularly regarding employment-related concerns. These include: the ageing of the population; the fact that people with disabilities are living longer; and an increasing desire by people with disabilities to live independently in the community. Such trends will see an increasing proportion of employees with carer responsibilities, and a need for workplaces to be more flexible and adaptable to workers' care responsibilities. There will be a shortage of people to provide care to their family members and others, resulting in increased demand on formal service systems.

Key strategic issues to be addressed are the alleviation of financial disadvantage among carers, and the development of long-term measures to address shortcomings in the disability and related service systems on which people with disabilities and their carers rely.

Alleviating poverty - income support throughout the life cycle

In view of the considerable body of evidence demonstrating high levels of poverty among carers, with subsequent ramifications on levels of health and wellbeing, arguably the highest priority for action should be the alleviation of poverty. There is an urgent need to ensure income support arrangements for carers, including Carer Payment and Carer Allowance, more adequately take into account the additional costs borne by carers. The additional costs borne by carers in more remote areas also need to be recognised.

One-off bonus payments are better incorporated into regular income support measures. Consideration could be given to wider availability of no and low-interest loans for essential household goods and costs that cannot be met through existing provisions.

Information strategies around available entitlements need closer attention. Many carers lack knowledge about what is available to assist them and fail to receive entitlements and assistance. Service systems are often unwieldy and don't take sufficient account of cultural factors or language needs.

Many carers of workforce age are unable to enter into or remain in the workforce due to factors such as the intensity of their caring roles, inability to find sufficiently flexible employment and geographic location. Such carers have no or limited means of providing for themselves in 'retirement'/old age. Consideration should be given to superannuation to working-age carers who depend on Centrelink payments. Consideration could also be given to payment of the superannuation co-payment for carers holding superannuation accounts who contribute additional funding (in line with the Government co-contribution paid to workers on low incomes).

Equipment and access issues

While there are schemes to provide aids and equipment to people with disabilities, items that would ease the demands on carers but that are not directly required by the person receiving care are often not covered. Equipment lists vary from state to state, so that items available in one state may not be universally available. There is a need for equipment to be provided that ensures carer safety and meets the needs during all caring activities so that carers can continue in their caring role. Exploration and assessment of these needs — and the funding needed to support them without detracting from the funds available for equipment for individuals with disabilities — is required. Information provided by the Fitzroy Valley Advocacy Group highlights some of the difficulties Aboriginal carers in remote areas experience in terms of aids and equipment and broader access matters.

Planning and service design

It is essential that carers are involved at all levels of the service system, so that planning and service design takes into account not only the impact on the person with disability but also carers. In particular there is a need for any consultations with carers from Aboriginal and CALD backgrounds to be sensitive to cultural needs. The information from the Fitzroy Valley Advocacy Group underscores many of the issues for Aboriginal carers in remote areas.

In Western Australia, disability providers, professional and support staff and the state-wide network of Local Area Coordinators incorporate consultation with carers and family members as an essential component of their daily role. This applies as much to people living with their families as to people living away from their families in community and residential settings. The Fitzroy Valley consultation is a potent example of the level of active engagement with Aboriginal carers and collaboration between services (DSC and HACC) that occur at field level.

Information, education, training and support

Carers need to receive accurate and timely information about the person's disability and the range of services and supports available. There are many carer support services provided both by government and non-government providers. Despite the assistance available, some carers either do not use available services — for instance through choice or language and cultural barriers — or lack knowledge about what is available and how to access services. Research indicates that this may particularly be the case among many Aboriginal and CALD carers.

There is a place for national information and awareness-raising strategies highlighting the valuable contribution made by carers. Also, increased efforts are needed to ensure that carers have access to better information about the services and supports that can assist them. Greater use can be made of public facilities including local libraries, schools and health and community services to increase the avenues where information is available.

Creative measures should be explored to meet the information and training needs of isolated carers, particularly those from CALD and Aboriginal backgrounds and people living in rural and remote areas. The Fitzroy Valley Advocacy Group highlighted the difficulties in accessing information and supports, including the need for training in manual handling and first aid.

Better resourcing for disability services

There has been significant additional funding announced recently for disability services as a part of the negotiations for a new national disability agreement. Funding pressures remain however, both in terms of unmet demand for new and additional services, along with the need to ensure adequate levels of indexation to maintain existing service levels.

Carers need assurances of adequate funding for accommodation support, and flexible and responsive respite options, so that they can choose to support the person with a disability in the most appropriate setting and assist a move to independent living/out-of-home care at an appropriate time.

Families caring for sons or daughters with disabilities, particularly those with high support needs, are experiencing significant distress and dislocation with their child's move from school to post-school life. Lifestyles and coping strategies crafted around thirteen years of school attendance are made redundant in a post-school environment in which many people with disabilities access limited hours of employment or day options. Many carers face the choice of leaving the workforce, reducing their work hours or devising various short-term measures to support the person during working hours. Siblings are also vulnerable to this disruption, often at crucial times such as matriculation, entry to further education or commencement of their working life. More sustainable models and options need to be developed to ensure the viability of these families.

Easier and more planned access to disability services and support would help alleviate the concerns of many carers at different stages of the life cycle and would have positive flow-on effects – for instance personal (benefits to physical and emotional health; fewer family breakdowns) and economic (greater capacity to save for retirement/the future; fewer workforce staffing problems; reduced demands on government income support provisions). Younger carers and people in mid-life would have the security of knowing that they could enter into or remain in the workforce if there were more flexible respite and family support options. Aged carers could feel secure knowing that they did not have to compete for scarce resources but that their son/daughter with a significant disability would be well provided for in the future and could live independently in the community.

There are models being implemented and investigated at federal and state levels that promise a somewhat brighter future for people with disabilities and their carers – for instance disability trusts; community housing models and models such as Planned Individual Network in WA.

Conclusion

Carers of people with disabilities make a contribution whose value in social and economic terms cannot be over-estimated. There is now a wide body of knowledge from national, state and local research, inquiries and studies that richly documents the many challenges and difficulties faced by carers.

There is a need for continued concerted action to address the many issues faced by carers around poverty, health and wellbeing, workforce participation and access to services.

Whereas legislation can provide a positive basis to build greater recognition of the role of carers, legislation needs to be supported by policies and strategies to address the issues as outlined above, with regard to social and economic security, and access to more adequate levels of support. Future directions which have the potential to significantly impact on the future support for both people with disabilities and their carers include consideration of the proposal from the Australia 2020 Summit to establish a National Disability Insurance Scheme.

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ATTACHMENT 1

CARERS MONOGRAPH

1. ABSTRACT

This paper provides an overview of some key considerations regarding carers. It notes the large number of carers who provide the bulk of support to people with disabilities, both nationally and in Western Australia, and the immense contribution carers make to the community. There has been considerable research on carer issues. Key issues that have been highlighted include effects of caring on health and wellbeing; the various demands on sub-groups of carers including older carers, young carers, carers from overseas and Aboriginal backgrounds, and those living in rural and remote areas; high levels of poverty and economic disadvantage; issues for working carers; and unmet needs and increasing demands for disability resources. In the future, Australia is likely to be confronted with critical social and economic problems if carers' needs are not addressed in a systematic and sustainable manner.

2. INTRODUCTION

Under the *Disability Services Act 1993* (amended), a carer is a person who provides ongoing care or assistance to a person with a disability. The term does not cover a person providing care and assistance under a contract of service or while doing community work. A detailed definition is contained in the Western Australian Disability Services Act section 3A. The definition is congruent with the meaning of carer under the *Carers Recognition Act 2004*[7].

This paper provides an overview of key issues and considerations concerning carers within the context of Western Australian disability services. The purpose of the paper is to help inform consultations about both current and long-term issues and needs of carers of people with disabilities.

The paper draws primarily on the Australian literature, much of which concerns the broad group of carers - including carers of older people, people with mental health conditions and people with chronic medical conditions. Thus it may not make specific reference to disability. Where possible the paper uses data and references for carers of people with disabilities, however more general sources are also used.

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[7] Both the Disability Services Act 1993 and the Carers Recognition Act 2004 are under review.

3. KEY ISSUES

a) Background

Carers are vital to the wellbeing of people with disabilities. Carers make a substantial contribution to the social and economic wellbeing of the community, providing around 70 per cent of care to people with disabilities. The imputed value of the unpaid workforce in 2005-06 is estimated to be $41.4 billion nationally – for an estimated 1,039,000 carers[8]. This compares with the estimated $28.9 billion of total government expenditure on welfare services in 2005-06 (AIHW, 2007:310).

Governments, both in Australia and many developed countries, are paying increasing attention to addressing the issues affecting carers (for example see AIHW 2004:1). Australia has a range of national initiatives that benefit carers - from legislation to specific policies and programs (including Commonwealth Carelink Centres; Carer Resource Centres and Carer Respite Centres, Centrelink). Similarly Western Australia has legislation (including the *Disability Services Act 1993*; *Carers Recognition Act 2004*; *Equal Opportunity Act 1984*) and also many policies and programs aimed both specifically at carers and also that benefit carers more generally. Despite present initiatives, however, much remains to be done.

Who are the people who provide ongoing care and assistance to people with disabilities? Carers are a diverse group of all ages and varied ethnic, educational and socioeconomic backgrounds. Most primary (principal) carers are women, although men and children are also carers. Many people do not see themselves as carers but see their role as an extension of their relationship with the person (Creative LINKS and Associates, July 2003:18).

Carers' needs, and the needs of the people they assist, often vary over time with changes in the clinical condition and function and at different stages of the lifespan. Some carers provide ongoing assistance over many decades, while others may provide care until the person is a young adult or until they enter a residential facility. Although in such cases the family's caring role may not be as constant, close involvement often continues, sometimes in a shared arrangement on weekends. Research shows that most carers want continued involvement once their relative is in residential care (Creative LINKS and Associates, July 2003:24; NATSEM 2006).

Carers typically face heavy demands and may experience many stressors such as poor or reduced physical and/or mental health; poverty; limited educational and workforce opportunities; social isolation and housing stress. However the caring role also has many positive aspects. It may bring a closer relationship between the carer and the person with a disability, may bring a sense of purpose and personal achievement, and lead to the development of a specialised set of skills and new social networks.

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[8] Includes carers of aged people and people with disabilities.

b) Data

How many carers are there? The most recent national Survey on Disability, Ageing and Carers (ABS, 2004) found that in 2003, 13 per cent of people living in households (2,557,000 people) were carers of people who had disabilities or were aged. There were approximately 474,000 primary carers of people with a disability, with most (71 per cent) being female. Most primary carers were aged between 45 and 54 years. The most common reasons given for providing care were 'family responsibility', 'could provide better care' and 'emotional obligation'. Primary carers had a lower labour force participation rate (39 per cent) than non-carers (68 per cent).

The same survey revealed that in Western Australia in 2003 there were an estimated 38,000 primary carers of people who had disabilities or were aged - 28,400 female and 10,400 male. There were 13,500 primary carers aged 15-44; 16,400 aged 45-64; and 8,900 were aged 65 and over (ABS 2004, table 27). Across all age groups, most carers provided 40 hours or more of care each week (ABS 2004, table 32).

The most recent published data on people using services funded or provided by the Disability Services Commission is contained in the Commission's 2006-07 annual report. The information about carers is not complete as only 72 per cent of disability service users provided the specific data on carers. Notwithstanding this limitation, we know that 79% of respondents (11,756 individuals) indicated that someone, such as a family member or friend, provides care and assistance on a regular and sustained basis. Eighty-six per cent of assistance was provided for self-care, mobility or communication; nine per cent was provided in other areas of care; and five per cent was not stated.

Many carers continue to provide ongoing assistance once the person has left the family home. Of the 1,623 people receiving hostel and community residential support, 30 per cent of respondents indicated that carers were providing care and assistance on a regular and sustained basis.

Two per cent of carers (218 individuals) were aged below 25 years of age; 55 per cent (6,545) were aged 25–44 years; 32 per cent (3,757) were aged 45–64 year age group; and eight per cent (905) were over 65 years of age. No age was stated for three per cent (448).

There were 10,520 female carers (89 per cent) and 1,236 (10 per cent) male carers. No gender was specified for 117 carers. Most care (79 per cent) was provided by mothers; five per cent of care was provided by fathers; six per cent was provided by partners; and eight per cent was provided by other relatives or friends and neighbours.

c) Current Issues

Diagnosis/onset of disability

At any stage of the life cycle, a diagnosis of severe disability is likely to be a particular stressor for carers. Parents of a child born with a severe disability may experience a range of emotions on receiving a diagnosis, including shock, disbelief, grief and panic. They may face the loss of future dreams for their child, social isolation, and the need to communicate with a bewildering range of medical and other professionals in the health, disability and welfare systems. Marital, family, social and work relationships may change dramatically during this time, as may the health of carers and other members of the family.

The onset of disability is often not predictable; for instance disability may occur in the mid-years and cause many changes to an anticipated life pattern – for instance financial insecurity, delays to retirement plans, social isolation and the need to acquire new knowledge and skills.

Information, education and support

Research indicates the need for carers to receive accurate information about the person's disability and the range of services and supports available (such as counselling, respite and community care). There are many carer support services provided both by government (for instance the Disability Services Commission; Commonwealth Carer Resource Centres) and non-government organisations (including Carers WA, disability organisations funded by the Commission, and Home and Community Carer providers).

Despite the range of assistance available, some carers either do not use available services - for instance through choice or language and cultural barriers - or lack knowledge about what is available and how to access services. Research indicates that this may be the case among many Aboriginal and culturally and linguistically diverse (CALD) carers (Creative LINKS and Associates, July 2003). The recent review of the carer payment (child) highlights some difficulties carers face in accessing information and support (Commonwealth Government, November 2007).

Older carers

Older carers often face special concerns. There may be generational cultural issues relating to willingness to accept services, and difficulty with transport and accessing services (Creative LINKS and Associates, July 2003:21). One of the primary concerns of ageing parents of adult children with significant disability is the question of who will care for their adult son or daughter when the carer's health fails or the carer dies (for example, Commonwealth of Australia, February 2007:119-122). The Senate inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement (CSTDA) includes a recommendation regarding life-long planning so that adequate options can be explored for individuals and carers to plan for their futures (Commonwealth of Australia, February 2007:122).

Caring is a long-term commitment for many people. Care is typically provided over a much longer period to a child with disabilities, often extending to many decades. Recent research found that over a quarter of carers provided care to a person with disabilities or an aged person for between 10 and 24 years (NATSEM, 2006).

The Commission's Accommodation Blueprint Steering Committee (2003, P. 26) noted an ongoing concern about the growing number of aged carers looking after their sons and daughters at home. The committee's final report recommended targeting accommodation support funding under the Commission's Combined Application Process to support each year at least 10 people with disabilities living at home with carers aged 70 and over, in addition to those individuals (regardless of age) assessed as being in most urgent need (recommendation 20). Although the Blueprint report targets for older carers have been exceeded, there remain a number of older carers whose needs can not be met.

Young carers

Young people may have responsibilities for a parent or parents, and also siblings and other relatives. Young carers may have limited possibilities to experience the usual social activities and friendships of childhood/young adulthood. They may miss school; be marginalised and isolated, experience anxiety, low self esteem and poor health, and face reduced workforce opportunities due to their caring responsibilities (for instance Creative LINKS and Associates, July 2003:22-23). The Senate inquiry into poverty noted that many young carers are in a sole parent household and may face a precarious financial situation (Commonwealth of Australia 2004:387).

The Disability Services Commission has provided project funding to Carers WA over the past four years for activities including the establishment of a young carers' network, providing holiday respite and producing information for service providers.

Cultural factors – CALD and Aboriginal backgrounds

Specific cultural factors may affect the experiences of carers from CALD backgrounds and of Aboriginal people. For example, there may be difficulties with the English language; there may be differing cultural beliefs regarding the type of personal care that can be provided, and by whom; there may be varying levels of knowledge and understanding about available services; a reluctance to use services and supports; care may be shared among several people; and there may be mistrust of service providers (Creative LINKS and Associates, August 2003:26-27; Commonwealth of Australia, February 2007; Commonwealth of Australia, November 2007:96-7).

Rural and remote issues

Consultations conducted by Carers WA in 1999 found that carers living in rural and remote locations face many issues including travelling long distances to access services; additional costs for services; a lack of knowledge, skills and awareness among service providers; physical isolation; and strong cultural ties and obligations (Creative LINKS and Associates, 2003:18). While there have been subsequent developments in rural and remote areas in Western Australia, many difficulties remain.

In recent national studies, participants from rural and remote areas noted the disadvantages they faced and the need for a greater range of services (for instance TOCC, 2007:33; Commonwealth of Australia, February 2007; Commonwealth of Australia, November 2007:97).

Carer health and wellbeing

It is well recognised that carers frequently experience poor health. National research conducted by the Carers Association of Australia in 1999 found that the physical, mental and emotional health and wellbeing of most carers in Australia is poorer than the general population (Carers Association of Australia, 2000:3). Local studies in the early 2000s underscore the health and wellbeing challenges faced by Western Australian carers (Creative LINKS and Associates, August 2003:16-17).

More recently, national research found that over half of all carers (59 per cent) experienced a decline in physical health and two-thirds felt that their mental and emotional health was affected. Carers experienced stress, disturbed sleep and physical injuries, for instance due to lifting (NATSEM (2006). The unrelenting and intense nature of the role for carers of children with severe disabilities was highlighted in a 2007 review of carer payment (child). The review report also noted the life and death nature of the care provided (Commonwealth of Australia, November 2007:25).

A survey of some 30,000 carers conducted by Deakin University for the Australian Unity Wellbeing Index found that carers have the lowest collective wellbeing index of any demographic group the researchers had encountered. The study showed that carers are likely to be moderately depressed, female carers have lower wellbeing than male carers, and sole parents are the most disadvantaged carers, by household composition (Cummins et al, 2007:4-16). Challenges to carer wellbeing include a greater vulnerability to pain, and a greater likelihood than normal to experience chronic pain, be carrying an injury, and not to be receiving treatment for a significant medical or psychological condition that is extremely damaging to wellbeing, mainly due to lack of time of cost (Cummins et al, 2007:23-24).

Poverty and the cost of caring

Carers play a very significant role in society, yet they are among the poorest and most disadvantaged groups in society (Creative LINKS and Associates, July 2003:16). Carers have a lower workforce participation rate than people with no caring responsibilities. Many are reliant on pensions and those who are in the paid workforce frequently face pressures in maintaining their jobs.

Research shows that many carers experience poverty and almost all carers face financial challenges. For example, the report of the Senate inquiry into poverty noted that four carer subgroups - young carers, single parents, ageing carers and low income earners – are likely to face financial difficulties (Commonwealth of Australia, 2004:387). Caring involves additional costs that affect the carer's health and wellbeing. The National Centre for Social and Economic Modelling recently found that carers are, on average, $5,600 worse off each year that non-carers. A government pension is the main income source for almost 40 per cent of carers (NATSEM 2006).

A recent review of the carer payment (child) noted the additional costs of disability as a major theme arising from consultations. Many carers of children with disabilities pay equipment costs and modifications out of their own pockets, experiencing hardship as a result. The review report recommended that the Government review overall costs of caring for children with disabilities (Commonwealth of Australia, November 2007).

Complex and multiple care responsibilities

Carers of people with complex needs face particular challenges. The person receiving care may have multiple disabilities and health conditions; have a mental illness or substance abuse problem in addition to a severe disability; or may be ventilator-dependant or require tube feeds. A person may require specialised 24-hour care and/or supervision, which places very high demands and responsibilities on the carer.

Many carers have multiple caring responsibilities, for instance providing care for both a child with disabilities and a spouse or ageing parent (Commonwealth of Australia, February 2007:120-121). The Australian Institute of Health and Welfare notes that many parents of younger children with a disability report a need for more support (AIHW 2007:169). The recent Commonwealth Government review of Carer payment (child) highlights the stresses on carers of children with disabilities. People with disabilities may themselves be providing support to others (AIHW 2007:169). Carers' needs may be exacerbated by a combination of factors including cultural issues, health problems, poverty, housing stress, isolated location, poor education and so on.

Workforce participation

The literature reveals that carers of working age have a substantially lower workforce participation rate than the general population. Carers who are in or trying to enter the workforce face many challenges, including difficulties in balancing work and caring responsibilities; managing the stress of caring while trying to continue working; arranging alternative or respite care (for instance DOCEP 2001).

Recent research in Australia conducted by the Taskforce on Care Costs found that although public rhetoric acknowledges the need to help carers balance work and caring responsibilities, tangible support is insufficient and ineffective – as evident in both public policy and workplace policy and practices. There is a mismatch between rhetoric and reality. Among the findings are that carers feel undervalued, experience difficulty balancing their work and caring responsibilities, feel that support services are inadequate and fractured between different levels of government and between government departments, and financial supports are insufficient. The report noted that carers are an under-utilised workforce resource and many work below their skill level due to their need for greater flexibility to accommodate their caring responsibilities (TOCC, 2007: 4-5).

Carer supply and labour market pressures

Australia is currently experiencing dual pressures – to increase labour supply as well as carer supply, and these pressures are likely to increase (AIHW 2007:5-7). The Taskforce on Care Costs report (TOCC, 2007:11-13) notes demographic trends that contribute to Australia's current work/care pressures including:

- a declining total fertility rate over the long term, denoting a lower birth rate and lower proportion of young people entering the workforce;
- increased life expectancy;
- increased proportion of older Australians;
- higher proportion of females with higher qualifications than males (with implications for caring as most care is currently performed by women);
- increased labour force participation by females and decreased participation by males; and
- a projected increased in participation for people aged 44 to 64.

Unmet demand and access to services

Despite positive national and State legislation, increasing resources and innovative policy and program initiatives, many carers battle to have their needs met. There remain gaps between policy and practice (Creative LINKS and Associates, July 2003:25-32).

The recent Senate Inquiry into the funding and operation of the CSTDA noted that family members carry the main responsibility for meeting the needs of people with disabilities, providing unpaid care and assistance on a regular and sustained basis (Commonwealth of Australia, February 2007:119). The evidence to the inquiry illustrates that carers continue to experience huge stress. The need for adequate services and supports for carers and the individuals for whom they care remains unmet in many instances.

There is a level of unmet need among older carers and a significant level of 'hidden caring', in that a large number of older carers are not accessing CSTDA services. Disability Services Ministers have agreed that a priority for the next CSTDA is to make older carers a priority for all disability services under the CSTDA.

The Government is progressing this work under its commitment to move funding for older carers from the previous government's Disability Assistance Package into the CSTDA.

The higher level of resources available for disability services and supports, the better the outcome for everyone – people with disabilities, their carers, governments and the community in general. The very high level of unmet demand across all disability services, but particularly in respite care and accommodation support, is well documented (for instance Commonwealth of Australia, February 2007:82-84; AIHW 2007:6; 192-3).

Not only are specialised disability services in deficit, but access to other essential services - for instance housing and transport - is a constant struggle for many carers. Housing in particular is essential to health and wellbeing, yet the cost of housing places a major burden on many low and moderate income households (AIHW 2007:209).

c) Future projections

Several factors combine to reinforce the need for prompt action to develop additional measures and strategies to support current and future carers. These include:

- the ageing of the population;
- the increased longevity of people with disabilities;
- an increasing desire for independent living in the community;
- the increasing incidence of disability with age; and
- the fact that more women are entering the workforce.

These trends will see an increasing proportion of employees with carer responsibilities, and a need for workplaces to be more flexible and adaptable to workers' care responsibilities (DOCEP 2001:5-6; Carers NSW 2005; AIHW 2007). There will also be a shortage of people to provide care to their family members and others, with resultant strong increases in demand on the formal service systems.

Evidence of financial disadvantage leading to carer poverty, along with low levels of health and wellbeing, has been well-documented - in Western Australia, nationally and internationally. Recent studies provide no indication of improving indicators of carer wellbeing, despite public policy measures targeting carers.

4. SUMMARY AND CONCLUSION

Carers are an essential contributor to community wellbeing, providing the majority of support to people with disabilities and older people in need. The importance of carer recognition and participation, and the need for a partnership approach between carers and service systems, have been widely documented and have continuing relevance. Important components include choice, value and respect, support and information, open dialogue, and - perhaps paramount – adequate resourcing.

The implications of not adequately addressing carer needs are both social and economic. Low levels of carer health and wellbeing are a particular concern. More needs to be done to alleviate poverty – not only in the short term but also the longer term. This will entail a change in thinking and innovative policy making at the national level, for instance introduction of a national superannuation scheme for carers. Measures to support carers in the workforce need to be strengthened. Low and declining levels of carer income and wellbeing will contribute to the reduced availability of carers and lead to increased demand pressures on formal disability services, which are already demonstrably unable to meet the needs.

There is an urgent need for increased commitment to carers and coordinated action from all levels of government. This includes the need for a long-term vision and a sustained planning effort to ensure that carers' needs are being adequately met. The United Kingdom's newly-established Standing Commission on Carers may offer a useful model in this regard. The Commission aims to make carers central to policy-making as equal partners. The terms of reference include a program of work on the long-term challenges that will affect carers (Dept. of Health UK; TOCC 2007:20-21). The British Government recently introduced a ten-year strategy to support carers, with new initiatives resourced at over £255 million (Department of Health, UK, 2008).

A system where people with disabilities and their carers can receive the supports they require as of right – as in Sweden – would do much to alleviate present stresses on carers. Swedish disability policy starts from the principle of universal equality and equal rights. There is legislation that makes it financially possible for persons with severe disabilities to live independently and receive the personal assistance they need - for 24 hours a day if required (Socialstyrelsen, 2006; AFDO September 2007). A recent Australian conference presentation on flexible housing options is reported as noting that Swedish people with disabilities, families and government administrators all stated that there are adequate resources to meet basic needs of people with disabilities, including for housing, community life and a holiday (AFDO September 2007).

In the shorter term there is a need for concerted action to address the many issues around poverty, health and wellbeing, workforce participation and access to services. There is value in looking towards philosophies and models operating elsewhere and, in the longer term, working towards achieving a situation where all people who require intensive support from society, including people with disabilities and their carers, can have their needs met as of right.

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ATTACHMENT 2

Note – The following information is included as received, apart from minor editorial changes. The words stand alone as a powerful message about the experiences of Aboriginal carers in a remote setting. The consultation process in itself is a strong example of the power and benefits of direct consultation with the people of most concern – in this case, Aboriginal people with disabilities and their carers.

Fitzroy Valley Advocacy Group

Better Care for our Carers Workshop

FITZROY VALLEY ADVOCACY GROUP TO HAVE YOUR SAY ABOUT BETTER SUPPORT FOR CARERS

Prelude

As part of the Government's House of Representatives Standing Committee inquiry into Better Support for Carers, the Fitzroy Valley Advocacy Group provided the opportunity for Carers, people with disabilities and community members from Fitzroy Crossing and remote surrounding communities to attend a workshop to give input. Considerable focus was given to issues that impact and influence services and support for Better Care for Carers in the Fitzroy Valley.

The Fitzroy Valley Advocacy Group was formed in 2003. The aim of the Advocacy Group was to identify and address local issues that impacted on people with disabilities, their carers and families and to give a *'collective voice' to* respond to these issues.

This advocacy group is unique in the fact this it is the only one in Western Australia that is representative of Aboriginal people with disabilities and their Carers.

The workshop was held on Tuesday June 10th 2008 from 10.30 to 12.30 and lunch was provided at the Fitzroy Crossing HACC Centre.

Demographics

Fitzroy Valley

The Fitzroy Valley is located in the Kimberly region of Western Australia and covers approximately 52,000 sq km which makes it similar in size to Tasmania. Fitzroy Crossing is the region's only town and provides very limited retail, government and other services for people living in town and has approximately

40 surrounding Aboriginal communities, some of which are up to four hours drive from Fitzroy Crossing on gravel 4wd roads. The nearest towns are Broome (four hours drive), Derby (three hours drive) and Halls Creek (four hours drive). There are 4 Aboriginal language groups in the Valley with English being the second or third language for the majority of the people.

Representation & Methodology

Advice and information to attend the Better Support for Carers workshop was by:

- mail out;
- word of mouth;
- hand deliver flyers;
- advertised over the local radio;
- generic email to service providers; and
- flyers placed in prominent notice board positions in the community.

A total of 15 people attended. A cross-section of participants included Carers, people with disabilities and community members who engaged in discussions. While some people lived in Fitzroy Crossing, other people who attended lived in the more remote communities in the Fitzroy Valley.

Initial overview and welcome was introduced by Rhonda (Yarmintali) Murphy. Workshop participants were then divided into four small groups. Topics discussed were broken into the following subjects:

- Health;
- Aids & Equipment;
- Education;
- Housing;
- Transport;
- Good things;
- Remote area issues; and
- Cultural.

Acknowledgments

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- Rhonda (Yarmintali) Murphy from Yarmintali Consultancy.
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- Selina Middleton from the West Kimberley Family Support Association.
- Deb Craigie from the Disability Services Commission, Fitzroy Crossing and Halls Creek.

ISSUES

Health

There are some good medical services in the Valley.

A male Carer suggested that it was difficult to access health services – this was primarily due to cultural protocols.

Limited consistency with health service staff due to high staff turnover which makes it hard because Carers have to tell their story over and over again.

Carers' health – important to have equipment to assist with caring, lifting etc and relevant information.

Limited / nil trained support workers to provide respite or in home services.

Carers need to have opportunity to build trust with support and medical services as it impacts on them and the families not wanting to use the service if the trust is not there.

Have to leave the Valley to access certain allied and specialist services. This results in leaving valuable family supports behind and creates isolation and stress. Added to this are the cultural and language barriers faced by Aboriginal people being away from home.

If Carers are sick and family supports are away, who then provides the care for the person with the disability?

Carers would like to have training in manual handling and first aid, and information to access resources services and supports.

Carers get tired – who cares for the Carer? – limited respite options locally and regionally.

Often Carers not only care for the person with disability but also care for elders, grandchildren and other extended family – have multiple care responsibilities.

Some carers have health issues themselves and find it hard to cope.

Community does not about and understand the issues of being a Carer.

Aboriginal organisations need to develop a better understanding so they can be responsive to the needs of Carers and people with disabilities.

Aids & Equipment

Aids – lack of equipment. Equipment and aids generally come from another town and Perth so there is a lengthy wait time. If staff leave, it could get forgotten about altogether.

Families do not receive consistency with visits from allied health and specialist services due to high staff turnover and staff vacancies.

It is difficult to access and to have installed ramps, railings etc.

Limited accessible footpaths – some footpaths in poor state and non accessible.

Education

Lack of support workers in the class room results in children with disabilities missing out on their education.

People with disabilities have little or no access to adult education – educational scope is limited to staffing levels and also the need for support workers to assist.

Housing

Limited adequate housing that meets the needs.

People in the Valley are dependent on government funding for housing.

Housing resources do not meet the needs of the people with disabilities.

Repairs and modifications are virtually non existent and take a long time to do.

Limited tradespersons to carry out repairs and modifications.

Overcrowding – impacts on social, environmental and mental health well being.

Nil / limited disabled access.

Consultation needs to happen before housing is built to ensure needs are met.

All houses in the community need to built for access and inclusion; need to talk about the design before building.

Extended family share the care subsequently housing should reflect this need.

No new land released for housing limited / nil housing stock.

Housing stock needs to be replaced as very old.

No hot water.

No fencing – no enclosures for security.

Transport

Majority of the carers and families in the Valley are on income support / Centrelink and unemployment is high - subsequently do not have access to / or own a vehicle.

For example, of the 15 people who attended today's meeting only one person had their own vehicle.

No public transport system. The local taxi service does not provide a wheelchair accessible vehicle and taxi fares are costly i.e. to travel 15 kilometres one way will cost $40.00.

There are only three wheelchair accessible vehicles in the whole of the Fitzroy Valley - which belong to the local HACC service. HACC is not funded to provide a seven day a week transport service and resources are limited to Monday to Friday only.

On remote Aboriginal communities there is very limited access to transport because communities are not resourced to have communal vehicles.

Carers become isolated because they cannot access transport services which prevents them and people with disabilities from accessing support service and social activities.

Good things

People with disabilities are included and are respected in the community.

Extended family provide care and support for the Carers and people with disabilities. Without this care and support, the risk of being institutionalised for people with disability would be significant.

Fitzroy Valley Advocacy Group is a positive outcome initiated by the Carers who live in the Valley which gives strength and a strong collective voice to address and advocate on the issues that impact on Carers.

Remote Area Issues

Carers face extremely high costs for basic living expenses.

Carers pension is inadequate because of the high cost of living in remote areas.

The cost of food and living in remote areas generally exceeds carers' income support.

Communities are isolated due to flooding in the wet season and this restricts families' access to services and support.

Due to extreme heat, air conditioning is a requirement for those with a disability – however due to the cost of electricity, the air conditioner and installation, families on low incomes are not able to afford or access.

Extreme high temperatures significantly elevate the electricity bills for air conditioning (for those who have air conditioning).

Cultural

Due to limited respite options, services and supports, many Carers miss out on and are unable to practice and participate in their cultural obligations: i.e. funerals, sorry business, native title meetings and women's and men's business.

Cultural protocols often determine who can or cannot provide respite, services and support: i.e. a sister cannot provide personal care for a male family member, and people from different skin groups may not be able to mix with another skin groups.

Meetings with families are often influenced by cultural protocols i.e. mother-in-law is not permitted to speak to her son-in-law.

Cultural protocols influence respite options and service provision.

GOVERNMENT OF WESTERN AUSTRALIA

DISABILITY SERVICES COMMISSION
making a difference

You are invited to attend

FITZROY VALLEY ADVOCACY GROUP TO HAVE YOU'RE SAY ABOUT BETTER SUPPORT FOR CARERS

Be part of the Government's House of Representatives Standing Committee inquiry into better support for Carers.

Tuesday June 10th 2008
Start at 10.30 to 12.30
Lunch Provided
HACC Centre Fitzroy Crossing

If you care for someone with a disability this is your opportunity to have your say - we need to hear from you!

For more information contact:
Phone: Ivy Till – Fitzroy Crossing HACC – 9193 0079
Phone: Deb Craigie – Fitzroy Crossing DSC – 9191 5079
Phone: Yarmintali (Rhonda) Murphy - 9203 9226

Proudly supported by the Fitzroy Valley Advocacy Group