

# Carers of People with Disabilities: Current issues and future trends

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The Carers monograph is one of a series of papers prepared as background information for stakeholders who are participating in the development of future directions for people with disabilities, their families and carers in Western Australia. The monograph explores the unique issues experienced by carers of people with disabilities, usually family members, and identifies priority issues to be addressed over the next 15-20 years.

## 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<sup>1</sup>.

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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<sup>1</sup> 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<sup>2</sup>. 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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<sup>2</sup> 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 2000's 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 or 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 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 than 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; and 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 increase 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 support 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 the 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 a right.

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