

Recognising and supporting care relationships

A Department of Human Services policy framework



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Portfolio Services and Strategic Projects Division

Department of Human Services

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Ministers' foreword

Caring relationships between parents, children, partners and siblings are part of our common humanity. We generally take these relationships for granted. It is only when one party has a disability, a disabling short or long term condition (such as mental illness) or becomes frail that the naturally private relationship requires government recognition and support.


Recognising and supporting care relationships acknowledges that while government cannot legislate for love or friendship, it should and does provide supportive programs and services. These interventions need to be based on the explicit recognition that caring relationships within inclusive communities are essential to the health and wellbeing of all Victorians.

This policy framework builds on the many initiatives and innovations across the Department of Human Services that already recognise caring as a dynamic relationship between at least two people who both have individual needs and rights, rather than as a burden. The framework is designed to enhance and take forward an integrated approach that responds to the diverse and complex nature of care in contemporary society.

Taking care of one another is a core feature of building a fairer Victoria, and we are committed to ensuring that Victorians in caring relationships are appropriately acknowledged and supported.



Gavin Jennings MLC
Minister for Aged Care



Candy Broad MLC
Minister for Housing



Hon Sherryl Garbutt MP
Minister for Children
Minister for Community Services



Hon Bronwyn Pike MP
Minister for Health

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Introduction

The *Recognising and supporting care relationships* policy acknowledges that there is an important distinction between caring relationships based on personal and family connections and care provided by paid and/or regulated service providers.

Care provided by family and friends occurs in the context of an existing relationship. *Recognising and supporting care relationships* moves carer policy towards a **relationship-focused model**. It moves away from focusing on the needs of carers or the people being cared for and towards an integrated approach that looks at the dynamic interconnections between people in caring relationships.

Key stakeholders were consulted in the development of this policy and many of the issues they raised are reflected in this new framework¹ and in the action plans which have been developed in respect of older people, people with disabilities and disabling conditions, and people with mental illness. Detailed consultations with a broad range of stakeholders have already informed the action plans. The department's conversation with people in care relationships and their service providers will continue as this policy framework is implemented.

The purpose of this policy

This policy is a framework for the Department of Human Services in supporting the provision of informal care. It builds on and extends recent innovations in policy and program development across the department.² The document outlines a set of **overarching principles** that capture the most important elements of supporting caring relationships within a human services context.

Departmental program areas have encapsulated these principles and service innovations in the development of individual **action plans**, which form a suite of documents complementing this policy framework. The action plans cover:

- existing services that recognise and support the caring relationship
- innovative directions in conceptualising and focusing policy and program development based on mutually beneficial and supportive caring relationships
- where necessary, reframing existing service models to fit within the new policy context.

Carers, and the people they care for, often have different needs. Respondents emphasised the importance of acknowledging these differences—for example in age, gender, culture and life cycle stage—and the way they affect the caring relationship.

¹ Throughout this policy, participants in the community consultations are referred to as 'respondents'.

² The term 'informal care' is used in this policy to describe unpaid care of a person with an episodic or chronic illness, disability, mental illness, who is frail, aged, or at an end of life situation, with care provided by family, friends and/or neighbours. It is not intended to imply that the caring itself is casual or without structure. Rather, it is a term used to distinguish altruistic care from care provided within an institutional context, by agencies, and/or care paid for by a care recipient. The definition of 'carer' in this policy does not include formal or regulated care arrangements such as foster care and kinship care, where carers are assessed and approved within a statutory context to provide care for children unable to live with their parents.

It is also understood that care takes place in a variety of circumstances, including within families and across friendship networks, and sits within a broader social, economic and cultural context. To reflect these understandings this policy:

- directs attention to the needs of both the carer and the person receiving care
- seeks to avoid giving one party preference or privilege at the expense of the other or of the relationship
- acknowledges and responds to the different circumstances and contexts in which caring relationships exist
- recognises the diversity of care relations
- recognises ongoing shifts in relationships across the life course of both parties and understands that relationships have histories and are subject to dynamic change.

1. Caring in Australia - an historical perspective

Care provided by family members and friends for each other as part of a loving relationship underpins the **community care system**, which encourages people who need assistance to remain in their own homes or in the community wherever possible. Over the last two decades in Australia, the health, aged care, disability services and child welfare sectors have experienced significant structural change, shifting from institutional and residential models of care to a more broadly-based system that emphasises the principles of community care. These shifts are, in part, attributable to changing understandings and attitudes to disability, mental illness, ageing and the adverse consequences of large institutions within the community. As a result, the landscape of human services delivery and the expectations placed by family members on each other have changed significantly.

The 1960s and 1970s heralded increased international attention and community awareness of human rights for people with disabilities and mental illness.³ The application of a human rights perspective within the disability and mental health sectors led to a number of significant policy developments in Australia throughout the 1980s and 1990s. These include a suite of legislative and related mechanisms established to support the rights of people with a disability⁴ and people with a mental illness.⁵

Paralleling the campaigns for human rights by marginalised groups in the preceding decades, the 1990s saw the rise of **the carer movement** in Australia, which began to lobby Commonwealth and State governments to recognise the needs and rights of carers in policy and program delivery. The establishment of the Carers Association of Australia (now Carers Australia) in 1993 provided a formal voice on behalf of carers directly to government and to a range of support services and programs addressing the needs of carers. Since this time, other carer networks and organisations have been created and respondents were keen for this policy to support ongoing collaboration with such bodies.

3 The United Nations *Declaration on the Rights of the Mentally Disabled Persons 1971*, and the United Nations *Declaration on the Rights of Disabled Persons 1975* emphasised the inherent right to human dignity, the need to become as self-reliant as possible and to hasten the process of social integration and re-integration.

4 The *Guardianship and Administration Board Act 1986*, the *Disability Services Act 1986* (Cwth), the *Disability Discrimination Act 1993* (Cwth), and the *Equal Opportunity Act 1995*. The Office of the Public Advocate, the Ombudsman, the Privacy Commissioner and the Human Rights and Equal Opportunity Commission are able to hear and act upon complaints under their respective legislation on behalf of people with disabilities.

5 Provision for the guarantee and protection of rights and civil liberties of people with a mental health illness is central to the National Mental Health Policy. In Victoria, the process leading to the *Mental Health Amendment Act 1996* (Vic) began in 1992, when the National Mental Health Policy ('the policy') was endorsed by the ministers of all states, territories and the Commonwealth. Health Ministers agreed to enact legislation consistent with the United Nations *Principles for the Protection and for the Improvement of Mental Health Care* (1991), as well as the *National Mental Health Statement of Rights and Responsibilities* (1991). The policy was initiated as a response to the development of trends in mental health care in Western society supporting a community oriented approach to the recognition and treatment of mental illness.

In the early 1990s, the relatively new term of ‘carer’ was introduced to describe people providing unpaid care to spouses, partners, children, relatives and friends with a chronic illness, disability, mental illness, or older people requiring assistance. Previously, informal care-giving had been taken for granted as an activity undertaken by family and friends and was, more or less, invisible in policy terms. In the 1990s, carers had become a separate category with identified needs and rights directly attributable to their caring role. The Victorian Government launched the Victorian Strategy for Carers in 1996, which recognises the key role that families and carers play in the provision of support to people with a disability and chronic illness and to older people.

Sustained and effective advocacy on behalf of carers by the organised carer movement has resulted in carer issues achieving much greater visibility in both Commonwealth Government and State Government policy and programs. Most states and territories have either revised or introduced carer policies over the last four years and Western Australia is the first jurisdiction in Australia to give formal recognition to carers’ issues through stand alone legislation, in the form of the *Carers Recognition Act 2004*.

These developments provide a platform for a more comprehensive and contemporary framework for care policy. By recognising the intrinsic difference between caring relationships based on personal and familial connections and care purchased in the market, this policy can better address the distinct needs of people in informal care relationships. Further, it provides a context for engaging and addressing the potential tension between competing rights and needs of people within caring relationships. This shift in focus enables the interrelationship between services and supports for carers and those for people with disabilities, disabling health conditions or mental illness or those who are frail to be considered and their potential capacity for supporting the care relationship assessed.

2. Carers in Victoria

The *Survey of disability, ageing and carers* (ABS 2003) estimated that more than 100,000 Victorians (2.37 per cent of the Victorian population) were primary carers for people with disabilities or long-term conditions or older people. This figure grew to an estimated 690,000 (12 per cent) when those providing some care were included.

The survey provides the following picture of **primary carers in Victoria**:

- **69 per cent** were women
- **74 per cent** lived with the person they care for and 30.6 per cent of this group reported that they provided, on average, 40 hours or more of care each week
- **52 per cent** were aged 45 or over and **12 per cent** were aged 65 or over
- **3 per cent** were aged under 25
- **43 per cent** were employed, with **23 per cent** of those employed working part-time
- **49 per cent** reported that their principal source of income was a government pension or allowance
- more than **40 per cent** of Victorians were either born overseas or have at least one parent born overseas. During community consultations, respondents were keen to highlight the particular differences of diverse populations and that care policy needs to address systemic issues of access and equity.

3. The care policy context

A number of Australian jurisdictions are currently revising their carers' policy to address changing demographics (including an ageing population) and the move away from institutional care, wherever possible, as well as the concomitant growth in the community care sector.

Current Commonwealth, state and territory carers' policies have responded not only to a growth in the community care sector but also to the issues raised by carers' advocates and carers themselves. These include the 'burdens' potentially associated with caring, including negative effects on physical and emotional health, and stressors and restrictions placed on people by their care giving role. There is also growing concern that as carers age, or develop disabilities and illnesses, they are likely to find their capacity to care strained by their own health and wellbeing needs. In response to these issues, policy and support services have developed to respond to the needs of carers. Support services include counselling, information services and training programs available through state-based carers' associations and respite, home support and carer support funded through Home and Community Care (HACC) and other Department of Human Services programs.

3.1 Commonwealth

The Commonwealth Government recognises provision of informal care as grounds for the payment of income support through the Carer Payment and Carer Allowance. Carers may also be eligible for other categories of Centrelink payment, such as the Disability Support Pension. The Commonwealth also funds or co-funds a number of programs. These include the Carer Information and Support Program, the National Network of Commonwealth Carer Resource Centres and Commonwealth Carer Respite Centres, the HACC Program, the Early Stage Dementia Support and Respite Project and the Dementia Education and Support Program. The Commonwealth Government has also more recently committed resources to additional respite, support and information for young carers at risk of prematurely leaving school or vocational equivalent education, increasing respite provision for ageing carers of people with disabilities, and provision of respite for working carers.

3.2 States and territories

A number of specific new carer policies have been developed in Australia over the last several years. These range from policy statements and strategies to the introduction of legislation recognising the role of carers in the community. A summary of these policies is outlined in Appendix 1.

The common themes across most jurisdictions include the importance of recognition and support for the role carers play, together with dealing with the imbalance of supply and demand for high quality, responsive community care. Involving carers in planning policy and service delivery, at the individual and service system levels, is also identified as a key issue. Other themes include delivering culturally appropriate services for Aboriginal and Torres Strait Islander carers and carers from culturally and linguistically diverse backgrounds, and providing relevant information to support carers across the different stages of caring.

3.3 Victoria: Department of Human Services policies and programs supporting informal care giving

There are a number of specific initiatives funded under the Support for Carers Program (SCP) which provide flexible respite and support services. Respite can be provided during the day at home or outside the home on an activity, and overnight at home, in a worker's home or in residential respite. Support services for care relationships include information and advice, one-on-one support and counselling, and developing and maintaining carer support groups.

Other programs that directly benefit carers and the people they care for include Disability Services respite and many services provided under the HACC Program. Adult Mental Health Services can choose to employ a carer consultant using funds from the Mental Health Carer Support Program Brokerage Fund. Carer consultants provide information and referral to families and carers and work collaboratively with mental health staff in developing services that are responsive to the needs of families and carers.

Policy and program changes in a number of department-funded programs have emphasised greater attention to the needs of carers and the care relationship at key intervention points within general health, mental health, disability and community care programs. These include discharge planning and follow-up procedures in the acute and sub-acute sectors; introduction of carers' needs screening and assessment in HACC; the dementia care framework; palliative care framework; continuing care framework; and carer and care recipient participation policies for Primary Care Partnerships, mental health services and the Hospital Admission Risk Program (HARP). Respondents affirmed the value of this work.

Many of these changes are articulated in the suite of major policy documents released by Department of Human Services since 2002, which include recognition of the importance of informal care provision. These include the *Metropolitan Health Strategy* (Metropolitan Health and Aged Care Services - MHACS), *Improving care for older people: a policy for health services* (MHACS) *New directions for Victoria's mental health services* (MHACS), and the *State Disability Plan 2002-2012* (Disability Services).

Carers are acknowledged as critical to enabling people with care needs to remain at home, and are also identified as a specific needs group requiring access to support services and information. *Caring together: an action plan for carer involvement in Victorian public mental health services*, recently developed within the Mental Health Branch of the department and now released in an updated form, reaffirms the importance of effective and responsive partnerships between care recipients, carers and professionals.

The current focus on the specific needs and rights of carers as an identified needs group in government policy and services has been important in responding to many of the issues raised by carer advocacy organisations and carers themselves.

However, there are some issues and tensions that arise from this policy approach—particularly when the needs and rights of carers are treated in isolation from the person for whom they care. This is difficult territory as it goes to the heart of the relationship between the person providing care and the person receiving it.

4. New directions in care - towards a relationship-focused model

4.1 Why focus on relationships?

Demographic shifts

Demographic shifts in Victoria, including a steep increase in the state's older population, mean that the government and community agencies need to think differently about the planning and provision of informal care. The Australian Institute of Health and Welfare (AIHW: 2004) and the National Centre for Social and Economic Modelling (NATSEM: 2004) have undertaken research into possible scenarios for the future provision of informal care in Australia.

Factors identified by both AIHW and NATSEM as most likely to lead to a reduction in the provision of informal care include increasing rates of family breakdown, estrangement and/or geographical distance of parents from adult children, reduced family formation among young adults, the rise in lone person households, and increased women's labour force participation.

In its report, *Carers in Australia* (October 2004), the AIHW identifies a number of socio-demographic changes likely to impact on informal care in the community over the next decade, including:

- absolute growth in the numbers of people with a severe and profound restriction requiring care in the community
- higher numbers of adult offspring carers relative to the number of older people in need of care due to the progression of baby boomers to pre-retirement and early retirement stages of life
- increasing need for care from ex-household family members due to changing patterns of family formation and population ageing
- extended working lives, especially for women, which imply increased pressure on many carers at an emotionally vulnerable stage of life
- older, more dependent care recipients and older primary carers (by 2031 almost 1.5 million Victorians will be aged 65 and over compared to the current figure of approximately 625,000).

The AIHW suggests that the high growth in the number of people aged between 45-64 over the next ten years offers the potential of **increased** numbers of family carers for older people. Historically, primary carers in this age group have been mostly a spouse or partner (41 per cent) or a child (34 per cent) of the care recipient. The AIHW points out that future provision of informal care to people in this age group could be vulnerable to higher rates of relationship breakdown than has been evident in previous generations.

The report concludes that, contrary to the concerns and expectations of some commentators, the results of their projections indicate that a substantial reduction in the willingness of women to substitute time spent in unpaid caring for paid employment is unlikely to have a marked impact on the availability of carers over the next decade. What the report does point out is that the large proportion of female carers in the workforce highlights the need to consider issues around balancing work and care in the ongoing development of carer support programs.

Australian Bureau of Statistics (ABS) figures show a gender dimension to caring. Women are the majority of primary care givers across Australia (71 per cent) and in Victoria (69 per cent). These figures also indicate that a significant proportion of men are carers. Caring is often represented and therefore understood as women's work, performed as a labour of love for family, friends and neighbours. This suggests that women may be pressured into taking up the role of carer and that policies that encourage a growth in the community care sector may have a greater and more direct impact on women than men.⁶ Respondents suggested that targeted community education strategies could counter this gendered distribution of caring.

The impact of caring

There is a significant body of literature focusing on the impact that supporting people at home may have on carers. Research has identified that carers have distinct needs from those for whom they care because of the nature of their responsibilities and the activities in which they are involved. Issues identified include the physical, psychological and social losses associated with the care role, including high levels of stress, poor physical health, isolation, anxiety and depression, the difficulties associated with balancing paid work and caring, or career sacrifices (Schofield 1998, Braithwaite 1990). Health risks amongst carers include physical strain from lifting and restraining, which often results in back, knee and shoulder injuries, and ongoing fatigue and stress as a direct result of sleep interruption.

Two critical issues that emerge from these points are:

- the need to better support the familial and spousal relationships that have traditionally provided informal care, acknowledging the increasing pressures and opportunities of life (for example, expanded career opportunities for women)
- the need to acknowledge and nurture non-traditional relationships in the provision of informal care (for example, care provided by close friends versus children or a spouse).

4.2 Reconceptualising carer policy

A key issue for policy makers and service providers is how best to balance the needs and rights of both carers and care recipients, rather than simply considering individuals in isolation.

Moving to relationship-based policy responds to the fact that care is multidimensional and diverse and that caring occurs in a dynamic context between people of all ages and life stages. Put simply, care by definition involves the interconnection between the person who gives care and the person who receives care.

⁶ Studies demonstrate that, internationally, women provide the majority of care (see, for example, Hochschild 2000: 131).

Focusing on care relationships conceptualises care in a way that acknowledges the humanity, diversity and complexity of carers and the people for whom they care. While there are many different circumstances in which informal care is provided, the underlying thread is that care is provided in the context of relationships rather than financial transactions between people.

Because a care relationship comprises of people related by blood, obligation and/or affection, rather than contract, it can be understood as an **interdependent** relationship. It is not just about what one person does for another person, it almost always involves reciprocity. Recently, the Multicultural Disability Advocacy Association of NSW found that people with disabilities and their families place more value on interdependence over independence because interdependence ‘acknowledges that all human beings are social beings who rely on two-way relationships with each other’ (Gruhn 2005).

At the point of contact with the formal service system, the care relationship has:

- varying degrees of reciprocity
- a set of current dynamics
- a unique personal and family history (which can be positive or negative or mixed)
- a cultural context.

In her overview of the literature on sustaining care relationships, Sally Savage (2002) found that there is limited research available on the preferences of care recipients generally (p. 33). Savage points to the tension between the needs of carers and the interests of care recipients. In their examination of the construction of care in contemporary social policy, Henderson and Forbat (2002) identify the lack of consideration given to the **multidimensional aspects of care in policy**. While their work is primarily focused on policy developments in the UK context, there are some useful points that can be applied in Australia. Henderson and Forbat argue that research and policy that focus only on the perspective of the carer **or** care recipient are going to represent, at best, partial accounts of the relationship. They argue for the need to develop **multifaceted care policies** that recognise care both as a concept, and the importance of the relationship itself in how people construct meanings of their situation.

4.3 Diversity in care relationships

Many different factors have an impact on care relationships. The issues, needs and challenges faced by people within care relationships differ depending on the nature of the relationship, as well as the age, gender and health of both the carer and the person receiving care, the nature and severity of the condition or illness of the person being cared for, cultural expectations (highly relevant to a multicultural community such as Victoria), the resources available within the family unit or care network, and the capacity to access external support.

People have very different values, expectations and experiences of caring and being cared for. For some people, caring is an extremely positive experience, while for others it is stressful and difficult. Care relationships also change over time and involve different decision points and support needs depending on where people are at in the caring trajectory.

The AIHW's analysis of ABS data (AIHW 2004) indicates that there are two main reasons **why people undertake a caring role**, namely, a sense of being able to provide the best possible care and family obligation. Other reasons cited include no-one else to take on the caring role or no other alternatives. A report prepared for Carers Victoria on the beliefs and values about caring across six different ethnic groups in Victoria found that care is predominantly considered to be a family-based responsibility and that carers define themselves primarily by their relationships within the family (wife, son, daughter) and not as 'carers' (Cole & Gucciardo-Masci 2003).

The 1999 National Survey of Carer Health and Wellbeing identified two factors that contribute to a positive experience of caring for an elderly parent. These are **support of other family members** and having a sense that there is some **choice** in the decision to provide care. Respondents affirmed the importance of family members having the opportunity to choose, moderate or reject the caring role. Respondents also indicated that care recipients' right to receive the care they require is equally important.

Relationship history, including risks within the relationship, has also been identified in the literature as an important determinant on the impact and outcome of caring for both care providers and the person receiving care (Cahill 1999 in AIHW 2004). The notion of risk in this context refers to relationships that involve a history of conflict, tension, abuse or violence. Recognition needs to be given to the fact that **some care relationships are going to be difficult or even inappropriate** due to the relationship history. At a practical level, this might mean that health and community services professionals should not make assumptions about the appropriateness of family members providing care and that alternative options might need to be explored.

Understanding the condition or illness of the person being cared for has also been identified by respondents as extremely important for carers. If carers **understand the condition or illness** of the person they are caring for, they are less inclined to interpret behaviour as offensive or the product of their own inadequacy (AIHW 2004:25). The AIHW also found that depression in carers of people with a psychiatric disorder was mediated by the presence of a **carer confidante** (AIHW 2004: p.25).

4.4 Children and young people who provide care

Respondents expressed increasing concern about the situation of children and young people who provide care to parents, relatives or siblings. Research undertaken for Carers Australia, with funding from the Commonwealth Department of Family and Community Services (Carers Australia 2002) argues that there is a growing group of children and young people with caring responsibilities who have received little recognition or attention by the community and by policy makers, researchers and service providers. According to the research project there is an estimated 388,800 carers in Australia under the age of 26 and, of those, 18,800 are primary carers (the main provider of care and support to their family member or friend). The research project also found that:

- only 4 per cent of young primary carers are still at school, compared to 23 per cent of the general population
- 60 per cent of young primary carers are unemployed or not in the workforce, compared to 38 per cent of the general population.

The research findings indicated that young carers predominantly care for a mother with a physical disability or mental illness. Their care involves undertaking intimate care tasks, assisting with mobility and medication, providing emotional support, and completing housework or any other required tasks. The report highlighted the need for young carers to be included as a significant group within the wider framework of all carers and informal caring. It argues that the unique vulnerabilities of young carers, because of their age, distinguish them from other carers and need to be specifically addressed.

While recognising that there are issues specific to young people whose parents require assistance and care, it is important that consideration also be given to the broader context of reciprocity and mutuality in which such care is provided. Children and young people with a parent with a disability, chronic or mental illness are not necessarily by definition 'young carers', nor should it be assumed that their caring role in the family is necessarily onerous or damaging (Gays 2000). That is, we need to address what kind of supports a family unit might need to enable the parent to continue the parenting role and what supports young people might need when caring for a parent or family member.

5. Overarching principles for recognising and supporting care relationships

To support a policy focus on the **relationship** between the carer and the person receiving care, this framework identifies three overarching principles for program delivery, funding and service provision:

- **recognition and respect**
- **support**
- **participation.**

These principles, detailed below, capture the most important elements of supporting care relationships within a departmental context. They will guide the development of new initiatives and action plans across different program areas of the Department of Human Services into the future.

Recognition and respect of the carer as well as the person needing care.

- Recognition of, and respect for, the diversity of care relationships by health and community services professionals, including general practitioners and hospitals, as well as the general community.
- Recognition that care relationships are dynamic and can change over time.
- Recognition of relationship history, where appropriate.
- Recognition of the high degree of reciprocity and mutuality in care relationships.
- Recognition that key transition points in the relationship will differ depending on the needs of the person being cared for and the individual needs of the carer.
- Recognition of the need for, and legitimacy of, care outside the home in some circumstances.
- Recognition of the role of the carer as an important partner in assisting people to live in the community and to remain at home.
- Recognition of differences between carers and people receiving care.
- Respect for the expertise and knowledge of carers.
- Recognition that the duty of care of the state is greater for the more vulnerable party.

Support for both parties to the relationship as well as for the relationship itself.

- Development, implementation and evaluation of high quality, effective and practical supports to assist in sustaining the relationship between the parties in the relationship.
- Assistance to Victorians in navigating the health and community services system.
- Flexibility of support provision, particularly during the key transition points in the caring relationship and responsiveness to the different contexts and duration of caring relationships.
- Culturally and clinically appropriate and timely information for both the carer and the care recipient - for example, ensuring both parties understand the condition of the person requiring care and the range of services available.
- Regular review of relevant program policies, protocols and procedures to increase service providers' understanding of the caring relationship and encourage comprehensive support for both the care recipient and the carer within a relationship context.
- Good quality service provision which:
 - o provides practical assistance with care tasks
 - o promotes confidence that the needs of the care recipient are being met
 - o is regularly monitored, reviewed and evaluated.
- Encouragement of collaboration in service provision between government and community organisations.
- Improvement in the social construction of the care relationship through appropriate community education.
- Targeted support for vulnerable carers, particularly young carers.

Participation by both carers and people needing care.

- Participation, where appropriate, in care planning.
- Participation in planning, delivery and outcomes of health and community services.
- Participation in quality improvement and assurance processes.

6. Building on good work

Although *Recognising and supporting care relationships* reflects the first time the department has explicitly prioritised the care relationship on a whole-of-department basis, many initiatives that advance the new policy direction have already been developed and implemented. This section provides snapshots of some of these promising new directions.

Recognition of and respect for the carer as well as the person needing care.

In 2004, the Department of Human Services funded the Western Region Alcohol and Drug Centre Inc. and the South West Acquired Brain Injury Alcohol and Drug Advisory Committee to run a grief and loss program for Indigenous and non-Indigenous carers of people with an alcohol or substance acquired brain injury (ABI).

The project involves the production of a booklet, *Tears of hope*, which acknowledges the cultural diversity of Indigenous Australians. *Tears of Hope* focuses on the grief and loss issues associated when caring for someone who has an ABI through their substance abuse. The product includes an Indigenous-specific section highlighting relevant cultural issues. The booklet will be used to provide support to Indigenous people involved in care relationships centred on ABI.

Caring together: an action plan for carer involvement in Victorian public mental health services outlines a series of strategies for increasing carer involvement. One strategy highlights the importance of being responsive to the complexities of the caring role while recognising the possible areas of conflict with the consumer. Another recommends that ‘discussion occurs with the consumer about family and support networks’ and that ‘a record of relationship and contact details of the person who provides the most support/care’ is documented in the care recipient’s file.

The ***State Disability Plan 2002-2012*** outlines the direction and implementation of disability services and programs in Victoria. The State Plan reflects a partnership approach with people with a disability, parents, families and carers in reorienting and improving disability supports to respond to people’s needs at different stages in their lives. One of the key directions of the State Plan is the Individualised Planning and Support approach. This approach enables disability supports to be tailored to people’s individual needs, recognising the importance of early planning and support to achieve the best possible outcomes at all ages and stages of a person’s life. It also recognises the importance of working as equal partners with people with a disability and their carers to exercise choice in getting the support they need.

Since November 2003, more than 5,000 **Companion Cards** have been issued to eligible people with a disability, allowing their companion who assists them to access community activities and venues, to accompany them at no extra charge. This program is effective in encouraging and enabling people with a disability to participate in community activities.

The new **minimum data set for the Home and Community Care (HACC)** program reinforces the importance of the care relationship by ensuring that information about the carer and the person being cared are recorded on the same client record (with a separate record established where the carer receives HACC services due to their own frailty or disability). Over time, this will provide a much better picture for planning and policy development in relation to supports provided through the HACC program.

In 2006, *Care in your community*, developed jointly by the Metropolitan and Rural and Regional Health and Aged Care Services divisions of the department, will be released. *Care in your community* provides a ten-year vision for a modern, integrated and patient-centred health system, including the new policy focus on sustaining care relationships. Relevant principles include empowerment of people needing health care and their families and carers; a person and family centred approach to care, including awareness of the evolution of caring relationships; and key roles for care recipients and carers in an integrated area-based approach to planning.

During 2006-07, **Aged Care will initiate a research project** examining the barriers prohibiting carers and care recipients from accessing respite services that address their needs. The project provides an opportunity to study Commonwealth and State programs and consider how a focus on mutually beneficial and supportive relationships might positively support the provision of respite.

Support for the carer as well as for the person needing care.

In April 2005, the *Review and Redevelopment of Support for Children with a Disability and their Families* recommended the adoption of family-centred support approaches by Disability Services workers.

The **Child Centred Family Focused Project** will develop a framework for all disability workers that incorporates family-focused principles. This framework will recognise the value of the care giving relationship and support the whole family, not just the child or person with a disability. While reforms are occurring with regard to service provision for children with disabilities and their families, the new emphasis on relationships will be expanded to include services for adults with disabilities and their supporting relationships.

In 2005, the Victorian Government and the Commonwealth Government entered into a bilateral agreement to provide respite support for families where ageing parents are supporting people with a disability. The **Ageing Carers Respite Initiative** focuses on providing flexible and individualised respite planning and support for ageing carers and the person with a disability.

Under the government's new disability legislation, disability service providers will be monitored for compliance with the **revised Victorian Standards for Disability Services**. The Victorian Standards for Disability Services will:

- be human rights based and apply across the range of human services
- reflect a 'person directed' approach to planning
- recognise the role of the community and generic services in achieving participation, integration and community inclusion
- focus on lifestyle options and choices, wellbeing, community inclusion and quality of life.

Since 1996, six **mental health carer resource/support workers** have been located in metropolitan and rural Victorian carer services. These workers have a direct service, community development and advocacy role with carers of people with mental illness. Through a combination of direct referral and linkages to health and community services for carers, and the use of health promotion, education and information sharing, the needs of carers are understood and responded to.

The State Government recently funded Carers Victoria through the My Connected Community (mc2) initiative to establish online carer communities - **Connected Carers Project Bringing carers together - online**. These 'virtual' communities make it easier for carers to access support and information and encourage discussion and social networking with peers.

The Mental Health Branch has developed ***Families and mental health: a parenting resource kit*** for distribution to families where a parent has a mental illness. The kit, which is given to families on entry to clinical mental health services, includes useful information to assist with parenting and accessing community resources. It also includes stories from people who share their own life experiences.

Signposts for building better behaviour, a training package, provides support for carers (commonly but not exclusively parents) of children with difficult behaviours, especially children with intellectual disabilities. The training package increases carers' ability to provide care by expanding their understanding of the challenging behaviours exhibited by the children in their care (the target cohort is 3-15 year olds). By better equipping carers to manage their children's behaviours, *Signposts* operates as an early intervention strategy to prevent deterioration in care relationships by providing skills and support before the care situation reaches crisis point. Since *Signposts* training started in 2005, around 300 facilitators have been trained and they have, in turn, trained 3,000 families.

Since 1996, the Carer Respite Centre (Southern Region) has been funded with a **carer resource worker** (mental health). The worker's key role is community development and advocacy for carers with generalist and mental health services across the Southern Region. An initiative of the position on the Mornington Peninsula reflects collaboration between local clinical mental health services, psychiatric disability support services and carers in the planning, development and operation of a carer council. The position was central in the coordination of all the stakeholders. The carer council now exists as a body of carers who are available to participate in service planning, education and training and advocacy.

The Disability **Individualised Support and Choice Program** takes a person-centred approach, and involves working with people with a disability, their parents, families and carers to plan the supports required for their choice of lifestyle.

There are a number of initiatives and actions outlined in the implementation plan for the **State Disability Plan 2002-2012** to support parents, families and carers. Under Priority Strategy One: Reorient Disability Supports, the Disability Program is committed to:

- ensuring that the Individualised Support and Choice Program process also considers the needs of carers by providing appropriate referrals and support for carers
- the establishment of 'Disability Online' as an electronic means of providing access to information, support provider contact details, fact sheets and calendars of events
- managing national research reviewing current responses to meeting the support needs of people with a disability and the effectiveness of strategies to support families
- ensuring that the need for proactive support for ageing parents and carers is identified and addressed as part of intake, vacancy management and other processes for accessing support. This includes support to plan for the future of their adult child with a disability in relation to housing and support, finance, maintenance of friendship networks, and the transition from parental care.

Mental Health Branch funds a range of supports including carer consultants, resource kits, family sensitive training for services, a funded carer academic position and projects to advance knowledge about how best to respond to carers' needs. For example, in recognising the particular impacts on young people of parental mental illness, the Mental Health Branch, in partnership with VicHealth and beyondblue (the depression initiative), has invested in the pilot PATS (Paying Attention to Self) project for adolescents. This project has advanced our knowledge about how services can better support young carers who have a parent with a mental illness. The learnings from the pilot are being made available to all services and are being used to inform policy directions centrally.

Carers Victoria operates a **Young Carers Network** and delivers professional education to increase recognition of young carers and encourage additional peer support opportunities for young carers. In addition, various philanthropic trusts and the department have recently funded Carers Victoria to develop an exciting range of resources for young carers, service providers and schools, including a CD ROM, a wallet sized card with key information, a video/DVD featuring five young carers, and two brochures, one targeted at health professionals and one for school staff.

Pathways to the Future 2006 and Beyond Dementia Framework for Victoria and the dementia **Implementation Plan 2006-08** were launched by the Minister for Aged Care in April 2006. The framework and implementation plan highlight the importance of supporting the care relationship, throughout the pathway of dementia, whether at home, in respite or in residential care.

Participation by both carers and people needing care.

Caring together: an action plan for carer involvement in Victorian public mental health services includes a series of strategies for increasing carer involvement. One strategy outlines the importance of developing and regularly reviewing and updating carer plans to accommodate changes in care relationships.

Carers are recognised as an important part of the person-centred care approach to the acute and sub-acute care of older Victorians outlined in the Victorian Government's policy *Improving care for older people: a policy for health services* (Continuing Care Section, Programs Branch, MHACS). A key aim of the policy is to make sure older people are being cared for in the appropriate setting for their individual situation, and to empower them and the people who care for them to be involved in decision making. Carers are recognised as active participants, where appropriate, in the care planning process for the older person undergoing treatment.

In revising the **Service Coordination Tool Templates** (SCTTs), which are a key plank of the Primary Care Partnerships Strategy, representation from carers groups has resulted in significant improvement in the templates' capacity to capture information about carers and the sustainability of the carer relationship. Additional work is planned to examine whether the templates can be further improved to support identification of carers needs, including consideration of whether a separate carers profile template is required. If developed, the carers profile will be implemented in the next update of the SCTTs planned for 2008.

The **Primary Health Consumer, Carer and Community Advisory Committee** ensures ongoing consultation with both carers and care recipients in the way state-funded primary health services are designed, planned and delivered. The committee is comprised of representatives from all regions across the state.

The **Ministerial Advisory Committee on Mental Health** (MACMH) includes an ongoing Consumer and Carer Subcommittee with service, care recipient and carer representatives. The group's work plan includes the identification of mechanisms to drive the implementation and evaluation of care recipient and carer action plans, ongoing provision of advice on key work of the MACMH and the Mental Health Branch, and the identification of future priorities for carer and care recipient participation for presentation to the Minister.

Doing it with us not for us - participation in your health service system 2006-09: Victorian consumers, carers and the community working together with their health services and the Department of Human Services policy recognises that participation is valued as:

- an aid to improve health outcomes and the quality of health care
- a mechanism to ensure accountability
- an important democratic right.

The policy recognises the roles carers have within their relationships with care recipients and promotes the involvement of carers in decision making across the levels of the health system. Examples of carer participation are given throughout the policy, many of these coming from care recipient-carer health support group members.

Dementia care in hospitals (2005) published key findings and ideas from the evaluation of four projects on dementia-friendly care in acute hospitals. The publication has a section on ideas for supporting care relationships, including suggestions on communicating with people with dementia and their carers, assisting carers to provide feedback, and what happens after being discharged from hospital.

Appendix 1: Carer policies in other states and territories

Western Australia

The *Carers Recognition Act 2004* formally recognises carers as partners in the provision of care for people who are frail, chronically ill or have a disability. The stated aim of the WA legislation is to improve the culture of service providers by involving and partnering with carers in the delivery of care.

ACT

The ACT Government's *Caring for carers policy* (December 2003) outlines that carers should have choices, receive support to make decisions about the caring role, and have their own needs recognised by human services. The policy also recognises that people receiving care should not be solely dependent on the resources and goodwill of their immediate family or social network. Rather, a range of supports provided by the community should also be available to offer choice and assistance to achieve a quality of life that is in accordance with community standards.

South Australia

South Australia is developing a whole-of-government carers policy. A consultation paper, prepared by the SA Carers Ministerial Advisory Committee was released on 20 October 2004. Feedback from carers, service providers, advocacy organisations and government departments will inform the development of South Australia's carers policy.

Queensland

Queensland's *Carer Recognition Policy* (October 2003) sets out eight key principles, including acknowledging, respecting and supporting the contribution made by carers, ensuring information is provided to carers on their rights when dealing with government agencies, and acknowledging carers as individuals with their own needs. Operational guidelines outline ten specific commitments in relation to carers, including establishing procedures where care recipients can identify their carer to Government agencies, recognising carers and their range of needs as a specific group, and including them in service delivery planning and development at the individual and system level.

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