

Disability Services Carer Action Plan

Recognising and supporting care relationships



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Department of Human Services

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Ministers' foreword

I am pleased to present the *Disability Services Carer Action Plan: Recognising and supporting care relationships* – an action plan to support and enhance the care relationships between informal carers and children and adults with a disability.

Parents, families and other informal carers play a vital role in the lives of people with disabilities. It's not only about the physical care and support, but also about the relationships that are maintained between the carer and the person with the disability. These relationships develop and deepen the lives of everyone who is a part of them. It is something that can never be replicated in more formal services, however good those services might be.

Being a carer, of course, can be hard work. There can be a lot of challenges, a lot of hurdles, a lot of setbacks. But when carers receive support and recognition it can also be an immensely positive and affirming role.

That is why the Victorian Government is providing a growing range of supports to carers and to people with disabilities who are in caring relationships.

This Action Plan outlines some of what we are planning to do in the future. It is based on the principles of recognition, respect, support and participation. These are simple but profound principles that lie at the core of the government's approach to supporting carers of people with disabilities.

A community is greatly enriched when it fosters and supports caring relationships. Carers and caring relationships help communities to become more inclusive and better places for everyone.

I commend the Disability Services Carer Action Plan to you.



Hon Sherryl Garbutt MP
Minister for Children
Minister for Community Services

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Introduction

The Disability Services carer action plan builds on the Department of Human Services policy framework *Recognising and Supporting Care Relationships*.

Disability Services has developed this action plan to:

- outline the policy context that directs attention to the recognition and support of the caring relationship
- identify existing services that recognise and support the caring relationship
- describe innovative program and service developments that support and enhance mutually beneficial caring relationships
- outline future directions for policy and program development to more adequately reflect a relationship-focused model of caring.

Both *Recognising and supporting care relationships* and this action plan focus on 'informal care', which is the unpaid care and support provided by family, friends or community networks, rather than the care provided by paid and/or regulated service providers.

This action plan for disability services relates to the informal support and care provided by parents, partners, children, siblings, grandparents, friends or community members to children, young people and adults with a wide range of lifetime and acquired disabilities, including intellectual disability, physical disability, sensory disability, acquired brain injury, neurological impairment or any combination of these.

Each caring relationship is unique, reflecting the age, gender, cultural background, life stage and social and economic circumstances of the carer and the aspirations, needs, issues and life stage of the person with a disability. Caring relationships will change over time as circumstances change for both the carer and the person with a disability.

Over time and as circumstances change, the interface between the informal care provided by family and friends and the support and care provided by the formal service sector may change. At various times in the life of a caring relationship, the balance between informal and formal care and support may alter as one or the other form of care is predominant.

Within the disability services sector, the aim is to maintain strong, supportive informal care relationships even when formal support services have the predominant role in day to day care.

Background

The departmental policy framework

Recognising and supporting care relationships is the policy framework for the Department of Human Services to direct its work in supporting informal care.

The policy focuses on the relationship between the carer and the person receiving care and seeks to:

- direct attention to the needs of both the carer and the person receiving care and to avoid privileging one party at the expense of the other or the relationship
- acknowledge and respond to the different circumstances and contexts in which caring relationships take place
- recognise shifts in relationships across the life course.

The policy describes three principles that capture the most important elements of supporting care relationships in the departmental context, namely:

- recognition and respect of the carer as well as the person needing care
- support for the parties to the caring relationship and for the relationship itself
- participation by both carers and people needing care.

These principles are intended to guide policy and program development and service delivery within the Department of Human Services and the agencies it funds.

The policy will be implemented through the development of action plans by relevant Department of Human Services programs areas, based on the policy and its principles and directions.

Disability Services policy framework

The *Victorian State Disability Plan 2002–2012* (State Disability Plan) outlines the government's vision for the future and establishes the policy directions and priorities for this ten-year period. It builds on the government's commitment to partnership, inclusion and participation.

The State Disability Plan seeks to put in place strategies that will value families, carers and volunteers for the contribution they make towards meeting the support needs of children and adults with a disability and provide earlier and more responsive supports to meet individual and family and carer needs.

In particular, the State Disability Plan has as its first priority strategy, a commitment to 'reorienting disability supports'. The Individualised Planning and Support (IP&S) approach enables disability supports to be more flexible and to work with people with a disability and their families and carers as partners to respond to individual needs and aspirations.

Priority strategy two relates to ‘developing strong foundations for disability supports’. In part this entails the development of a quality improvement strategy to monitor and continually improve the quality of support for people with a disability. One of the measures of quality improvement is the satisfaction (or otherwise) of people with a disability and their families and carers and the involvement of people with a disability and their families in planning, monitoring and reviewing disability supports.

Priority strategy three is to ‘promote and protect people’s rights’ and focuses on ensuring that support providers and the Victorian community as a whole respect, promote and safeguard the rights of people with a disability.

Priority strategy four relates to ‘strengthening local communities’ so that communities across Victoria are more welcoming, more accessible and more inclusive of people with a disability and those who care for them. This strategy seeks to promote communities that value people for the contribution they make and value and support families and carers.

Over the past three years, the Victorian Government has completed a comprehensive review of the *Intellectually Disabled Persons’ Services Act 1986* and the *Disability Services Act 1991*, culminating in the new *Disability Act 2006*, which will come into effect on 1 July 2007.

The *Disability Act 2006* establishes a whole-of-government approach to enable people with a disability to actively participate in community life. The Act creates a strong foundation for the provision and regulation of high quality supports for people with a disability and to safeguard and strengthen the rights of people accessing these supports.

The Act recognises the importance of partnership with families and carers, requiring disability services to:

- consider and respect the role of families and other persons who are significant in the life of a person with a disability
- acknowledge the important role families have in assisting their family member to realise their individual physical, social, emotional and intellectual capacities
- where possible, strengthen and build capacity of families who are supporting someone with a disability.

The planning sections of the new Act also recognise the importance of the role of families and carers. The Act states that planning should:

- where relevant, consider and respect the role of family and other persons who are significant in the life of the person with a disability
- where possible, strengthen and build capacity within families to support children with a disability.

The experience of caring

There are many Victorians who provide care for a person with a disability. Several research projects have been undertaken to identify the impact of caring for a person with a disability, including *What carers value – review of carer literature and practice* (Department of Human Services, 2004), *Review and redevelopment of support for children with a disability and their families* (Department of Human Services, 2005) and *Older carers of adults with intellectual disability, characteristics and service provision issues* (Bigby and Ozanne, 1999).

The research reviewed in these reports points to the impact of caring for a person with a disability. Difficulties identified were impacts on carer health and finances due to carers' capacity to work. Positive experiences of caring have also been highlighted, such as the strong family relationships and feelings of satisfaction and achievement.

What carers value also describes a number of factors that enhance the caring experience. These are:

- recognition and valuing of unpaid family and informal care
- recognition that carers are both providers of care and individuals with their own needs
- recognition of carers as care partners
- support for carers and consumers to participate in service planning and delivery.

Guiding principles

The three overarching principles identified in the Department of Human Services policy framework to guide program development, funding and service delivery are:

- recognition and respect
- support
- participation.

These principles are important for all departmental program areas that support care relationships and have particular relevance for Disability Services, for Department of Human Services regionally and for funded service providers.

Recognition and respect

Recognition and respect of the carer as well as the person needing care means that disability service planners and providers will respect and value a carer as a partner in the care of the individual. They will respect the knowledge and expertise of carers and recognise that care relationships change over time, have a high degree of mutuality, and have key transition points when particular support may be required. This additional support may entail care outside the home.

Support

Support for both parties in the relationship as well as for the relationship itself entails:

- development, implementation and evaluation of high quality, effective, practical and individually tailored supports to assist in sustaining the relationship
- easy access to information and assistance to navigate the service system
- culturally and clinically appropriate and timely information for both the carer and the person with a disability
- regular reviews of program policies, protocols and procedures to increase service providers understanding and support for the care relationship
- community education to increase community recognition and support for care relationships
- targeted support for vulnerable carers.

Participation

Participation in care and support planning, in service planning and delivery, in establishing and measuring service outcomes and in quality improvement processes by both carers and people with a disability are important for supporting care relationships.

Quality outcomes

The State Disability Plan promotes the active participation of people with a disability in planning, monitoring and reviewing disability supports. The Quality Framework for Disability Services, including the Victorian Standards for Disability Services, is being reviewed to support disability support providers to put the principles of the State Disability Plan into practice. A revised quality framework is being developed, piloted and implemented from 2006. An independent monitoring mechanism will be implemented from 2009.

Recognising and respecting care relationships provides a number of principles for the support of carers that will make the Quality Framework for Disability Services relevant to carers.

Future policy actions

- Develop a **carer participation plan** to provide a framework to assist program developers and services providers in engaging with families and carers.
- Develop quality outcomes for carers for inclusion in the *Quality framework for disability services* and the *Victorian standards for disability services*;
- Assist government departments to develop **disability action plans** that reflect recognition, respect and partnerships with families and carers.
- In developing the implementation plan for the *Disability Act 2006*, ensure the recognition and respect for carers issues and views.
- Review existing policies and information provided by the Department of Human Services and accessed by families and carers, to ensure it provides practical information to empower families and carers to be active and informed partners in care and support planning.

Programs and services that recognise and support the care relationship

Disability Services has a number of programs and services that, through their goals or outcomes, recognise and support the person with a disability and their carer. These programs provide a variety of supports to assist the carer in maintaining their caring role and the person with a disability to live within their community.

Individual support

A significant investment in the Individualised Planning and Support (IP&S) approach has provided a wider range of flexible individual supports for people with a disability, their families and carers. This approach involves working in partnership with individuals, their families and carers to plan for and implement supports tailored to their needs, interests and priorities using a person-directed and family-focused planning approach. Individual supports may assist the person with a disability to remain in their family home, maximise their independence and participate in community activities and facilities. Individual support recognises the needs of the person with a disability and their informal networks and supports the ongoing care relationship.

Aids and equipment

The aids and equipment program provides information about, and access to, a range of appropriate aids and equipment. The program is targeted to people with a permanent or long-term disability, people with a chronic illness and the frail aged. The supports provided through this program are based on an individual's particular needs and the provision of aids and equipment that will enable them to live more independently and assist their carers in their caring role.

Respite

Respite aims to achieve a balanced approach to the provision of support by responding to the diverse needs of families, carers and people with a disability by:

- supporting and maintaining the primary care giving relationship while providing a positive experience for the person with a disability
- providing short or time limited breaks
- providing information and improving access.

Specialist services

Behaviour intervention services provide client-focused advice, assessment, intervention and consultation for individuals, families and carers to address an individual's challenging behaviours. Two goals of these interventions are to support an ongoing care relationship and to assist the individual with a disability to maximise their independence and engagement with the community and their informal care network.

Community participation and inclusion

A number of programs aim to support the participation of people with disabilities and their families and carers in the life of their community through strengthening the capacity of the community to be inclusive and through improving access.

- **MetroAccess** and **RuralAccess** aim to strengthen the capacity of local communities to be more inclusive and welcoming of people with disabilities. MetroAccess and Rural Access provide an area-based community building strategy, targeting people with disabilities in local communities across Victoria.
- **Community Options** aims to provide flexible support options in response to individual needs as they change over time and to key transitions for the individual and their family.
- **Day Programs** provide high quality programs that address individual needs and enhance independence, abilities, community participation and quality of life. A secondary goal is to support informal care by giving priority to people whose support arrangements are in jeopardy due to the age, health and/or capacity to provide ongoing care of the carer.

Planning and coordination

Case Management assists people with a disability to maximise their opportunities and independence through collaboration with a person with a disability and their family or carer in planning and accessing appropriate support and services. Case management is a partnership between service providers, people with a disability and families and carers.

Information and advocacy

Information services aim to provide people with a disability, their families, carers and service providers with up-to-date, accessible, independent, objective information to support self-management and individual choices. The centrepiece of disability information provision is Disability Online. Funded services are also supported to provide accessible, up-to-date information and to participate in Disability Online.

In addition to these programs and the services they support, some other statewide initiatives have been implemented over the past couple of years to support families and carers.

Signposts for building better behaviour is a training package that provides support for carers (commonly but not exclusively parents) of children with difficult behaviours, especially children with intellectual disabilities. The training package aims to increase 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). Since training started in 2005, around 300 facilitators have been trained and they have, in turn, trained 3,000 families.

The Companion Card, established in November 2003, enables people with a disability who require the assistance of a companion to access community activities and venues. More than 13,000 cards have been issued to eligible people with a disability, allowing their companion to attend a variety of events and use services, including public transport, at no charge.

Future program actions

- Broaden the implementation of the IP&S approach consistent with the *Victorian State Disability Plan 2002-12*.
- Review current training strategies for staff on working with parents, families and carers and develop a staff development package focusing on working in partnership with families and carers.
- Implement the Disability Support Register to better target resources and support to families and carers.
- Review and document examples of good practice in working in partnership with parents, families and carers, including those with additional needs (young carers, Indigenous carers, carers with a disability and carers from culturally and linguistically diverse backgrounds).
- Review Disability Accommodation Services practice instructions to reflect the principles of *Recognising and supporting care relationships*.

Policy developments and innovations that enhance caring relationships

Recognition of the importance of informal support and the value of working in partnership with families and carers is a critical part of Disability Services' current policy development and program improvement agenda. A number of regions are trialling new and innovative approaches to disability support that reflect partnerships with families and carers.

Some significant components of the current policy and program agenda are outlined below.

Program developments

Disability Services has established a carer portfolio to strengthen the involvement and recognition of carers by establishing consistent links with carer organisations and to act as a resource to policy and program staff. This portfolio will have a major role in supporting the implementation of this action plan.

IP&S is the key strategy through which disability supports are being reoriented to meet the diverse and individual needs of people with disabilities and their families and carers and to support informal care arrangements.

During 2006–07, 170 additional Support and Choice packages will be allocated throughout the state using an IP&S approach. The priorities for further development are a continued focus on individual needs, earlier planning and support to achieve the best possible outcomes at all ages and stages of a person's life, engaging the informal care network and working as equal partners with people with a disability and their carers. During this year, ongoing review will occur to ensure that the program fulfils its intentions of providing flexible responsive supports to individuals, families and carers.

In April 2005, the *Review and redevelopment of support for children with a disability and their families* (Department of Human Services, 2005) recommended the adoption of family-centred support approaches by workers working with children with a disability and their families within Disability Services. This work has now commenced through the Child Centred Family Focused Project. This project will develop a framework for all disability workers incorporating family-focused principles that recognise the value of the care giving relationship and support for the whole family, not just the child or person with a disability.

Work is underway to develop proactive support for ageing parents and carers through information, support to plan for the future and increased respite funding. Planning support may include issues relating to housing, finance, maintenance of friendships and the transition from parental care to independent living.

The Victorian Government allocated additional funding in 2005–06 for additional respite for carers of people with a disability. This provided support for families and carers of people with a disability to maintain caring arrangements.

The revised Quality Framework for Disability Services and the Victorian Standards for Disability Services will assist disability support providers to become more accountable to people with a disability, carers and government, through the monitoring of services against areas of importance to carers and people with a disability.

The *Disability Act 2006* establishes a whole-of-government approach to enabling people with a disability to participate in community life. During 2006, disability action plans have been developed in all government departments.

Disability Services worked with these departments to assist them to develop plans that reflect recognition, respect and partnership with families and carers.

The *Disability Act 2006* also places considerable emphasis on building strong complaint systems. The Act affirms the right to make a complaint about the provision of disability services and ensures that service providers are open to user feedback as part of quality assurance mechanisms. The Act also establishes an Independent Disability Services Commissioner to conciliate and investigate complaints in relation to disability services. In implementing this part of the Act, attention will be given to ensuring that family and carer input is respected and that their complaints are valued as an important contribution to quality improvement.

Regional innovation

Just as new directions and change are brought about through policy and program development, regional innovation in service development is an important contributor to change through informing program development and providing leadership among regional colleagues.

There are a number of areas where regions are demonstrating leadership in service development that recognises and supports families and carers and reflects partnership approaches.

The final report of the *Review and redevelopment of support for children with a disability and their families* (Department of Human Services, 2005) contains examples of good practice in supporting children with a disability, including working with families as partners and individually tailoring supports to meet the needs of family members as well as the child or young person with a disability.

Through the ageing carer respite growth funding, regions are supporting partnership approaches with ageing carers to address immediate issues and to engage in long-term planning for the future care of their family member with a disability. Southern and Eastern metropolitan regions are piloting Circles of Support as a means of working closely with ageing carers and their adult children with a disability to plan for the future. A Circle of Support is an informal care network that comes together on a regular basis to support the ageing carer and the adult child with a disability.

In the Gippsland Region, some respite growth funds and respite targets have been allocated to an Aboriginal Cooperative to allow them to develop culturally appropriate respite responses to assist ageing carers. Through this approach, the community becomes part of the informal care network as locally and culturally approaches are developed to meet individual needs.

In the Loddon Mallee Region, through the RuralAccess program, an extensive range of workshops have been held to assist parents and families of children and young people with a disability to understand the needs of their children with and without a disability, to build family capacity and resilience through education, information and to establish partnership with professionals. The RuralAccess program operates in all rural regions where similar activities are occurring.

Summary of actions for policy and program development

Directions for policy and program development

System level		
Activity	Strategies to recognise and support carers	Measuring progress
Develop a carer participation plan to provide a framework to assist program developers and service providers in engaging with families and carers.	<ul style="list-style-type: none"> Consult with carers to develop a framework for the participation of carers in service planning, delivery and reviews. Develop a Disability Services carers charter. 	<p>Published carer participation plan.</p> <p>Carer representation on project group.</p>
Develop quality outcomes for carers for inclusion in the Quality framework for disability services and the Victorian standards for disability services	<ul style="list-style-type: none"> Develop indicators incorporating carer outcomes for specific funded activities. Develop evidence. indicators against the Victorian standards for disability services. Develop best practice guides. Incorporate principles of active participation of people with a disability and family members and carers into the framework. 	<p>Outcomes carers focus group convened and input provided.</p> <p>Draft outcomes and self assessment tools tested and evaluated in and the Department of Human Services Eastern Metropolitan Region and Gippsland Region by March 2007.</p> <p>Carer participation in training for 2006 pilot</p>
Assist government departments to develop disability action plans that reflect recognition, respect and partnership with families and carers	<ul style="list-style-type: none"> Disability action plans reflect a whole-of-government approach to recognising and respecting families and carers. 	<p>Provide and promote the department framework, <i>Recognising and supporting care relationships</i>, to government departments.</p> <p>Provide and promote the Disability Services <i>Carer Participation Plan</i> once developed.</p>
In developing the implementation plan for the <i>Disability Act 2006</i> , ensure recognition and respect for carer issues and views.	<ul style="list-style-type: none"> Consult with carer representatives 	<p>Carer consultation undertaken by Implementation Team</p>
Review existing policies and information provided by the department and accessed by families and carers, to ensure it provides practical information to empower families and carers to be active and informed partners in care and support planning.	<ul style="list-style-type: none"> Include within the review of any policy or document consultation with carers. Disability Online – review accessibility and information in consultation with carer organisations. Work with advocacy agencies to identify opportunities to make information regarding post-school options more accessible for parents of young people leaving school. 	<p>Number of reviewed documents and polices which include carer participation and recognition.</p> <p>Disability Online updated to reflect the needs of carers.</p>

Program level		
Activity	Strategies to recognise and support carers	Measuring progress
<p>Broaden the implementation of the Individualised Planning and Support (IP&S) approach consistent with the <i>Victorian State Disability Plan 2002-2012</i></p>	<ul style="list-style-type: none"> • Develop a communication strategy which includes strategies to support the participation of families and carers in individualised planning. • Review and refine existing communication materials. These will address information needs of families and carers regarding <i>Support and Choice</i> (S&C) • Develop a learning and development strategy for facilitators aimed at ensuring consistent and quality facilitation, with quality plans that reflect the IP&S approach. These will include a focus on role/support of carers. • Implement ageing carers respite growth funding to include an IP&S approach and develop new initiatives to support informal care based on the needs of the parent, family and the person with a disability. 	<p>Development of communication strategy.</p> <p>Learning and development strategy developed in consultation with carers.</p> <p>Number of staff provided with professional training in working with families and carers.</p> <p>Carer feedback through Respite Carer Survey.</p>
<p>Review current training strategies for staff and prepare a staff development package focusing on working in partnership with families and carers.</p>	<ul style="list-style-type: none"> • Develop a professional training program for Futures for Young Adults (FFYA) and S&C planners including negotiation skills and working with families. • Develop the child-centred family-focused practice framework and associated training package. • Learning and development activities regarding IP&S include a focus on family sensitive/centred practice. 	<p>Learning and development program developed in consultation with carers.</p> <p>Number of staff provided with professional training in working with families and carers.</p>
<p>Implementation of Disability Support Register (DSR)</p>	<ul style="list-style-type: none"> • Better targeting of resources and support to families and carers. 	<p>Inclusion of demographic groupings on the DSR.</p>

Program level (con't)		
Activity	Strategies to recognise and support carers	Measuring progress
Review and document examples of good practice in working in partnership with parents, families and carers, including those with additional needs (young carers, Indigenous carers, carers with a disability and CALD carers).	<ul style="list-style-type: none"> • Recognise programs, policies and practices that support carers. • Recognise unique needs and diversity of programs for carers from a CALD, Indigenous or disability background. 	Examples of good practice disseminated.
Review of Disability Accommodation Services (DAS) practice instructions	<p>Practice instructions reflect the principles of:</p> <ul style="list-style-type: none"> • recognition and respect for informal care relationships even when formal support services have the predominant role in day to day care • support for parents, families and carers to continue the informal care relationship in partnership with the formal care providers • participation of parents, families and carers in planning and support with DAS. 	Carer feedback on revised practice instructions sought.

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