



**Consolidating support for caring families\* for the future  
Actions for the Victorian government**

**Carers Victoria**

**Pre-budget submission 2014–2015**

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\* Wherever the term 'caring families' is used within this document, it is intended to be inclusive of all the parties in care relationships; people requiring support and assistance and their family, friends and others who offer informal unpaid care.



### About Carers Victoria

Carers Victoria is the state-wide peak organisation representing those who provide unpaid care. We represent more than 700,000 family carers across Victoria – people caring for a person with a disability, mental illness, chronic health issue or with an age-related condition. The people being cared for could be a parent, child, spouse, grandparent or a friend.

Carers Victoria is a member of the National Network of Carers Associations, as well as the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership based organisation. Our members primarily consist of family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

This pre-budget submission was prepared by Carers Victoria's policy team.

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## List of Recommendations

1. That the Victorian Government invest capital resources towards the development of infrastructure for an online Carer Portal through Carers Victoria to empower caring families to exercise increasing choice and control.
2. That the Victorian government invest in an ongoing way in resources and training programs to assist families to develop skills and capacity in supported decision making.
3. That the Victorian government makes a priority investment in specialist transition and succession planning programs for older parents of people with a lifelong disability.
4. That the Victorian government negotiate with the Commonwealth to pilot a Victorian program of integrated specialist Carer Support Centres.
5. That the Victorian government increase investment in professional and provider skills development and practice change programs to ensure caring family responsive programs and services.
6. That the Victorian allocates Support for Carers Program funds to an improved, comprehensive independent and regionally based individual and systemic family advocacy system.
7. That the Victorian government ensure that HACC service system resourcing funds directed to Victorian policy, research and advocacy activities continue after the transition to the Commonwealth Home Support Program
8. In relation to the Shergold report and Services Connect initiative, that the Victorian Government :
  - 8.1. develops approaches to service delivery that are both person centred and family focussed, even when there may be multiple members of the family in direct need of support for example a person with a disability and a young carer
  - 8.2. ensures that a focus on the 'most troubled families' does not entail a loss of early intervention and prevention approaches
9. In relation to Victoria's Vulnerable Children: Our Shared Responsibility, that the Victorian Government:
  - 9.1. invests in the Cummins' report's recommendations about achieving earlier intervention and prevention
  - 9.2. makes changes to legislation to ensure that adult specialist services, for example disability and mental health, identify children within families
  - 9.3. invests in adult specialist services and workforce initiatives so that they can respond appropriately to changes in legislation and policy. An example is new expectations of Psychiatric Disability Rehabilitation and Support (PDRSS) services that they will be required to identify children in families of a person with a mental illness and make appropriate assessments and referrals in relation to their needs. Leadership, training and tools will need to be available to ensure that this work is done appropriately and effectively by a workforce largely unfamiliar with working with children.
  - 9.4. considers carefully the implications of conceptualising young people in families with a person with a disability as being 'vulnerable' within future service system reforms . To not include them may ensure that they, and their needs, continue to be largely hidden. To include them as a cohort may run the risk of making assumptions about the needs and experiences of a very diverse group and their other family members/parents. More work is needed to develop and refine appropriate definitions, screening tools and resulting actions in this area
10. That the Victorian government funds an action research project providing whole of family support to young people in families with a person with a mental illness. 'Unfinished Business' provides reference to a similar UK project that has been evaluated that may provide some guidance to program design.

11. That the Victorian government plan for the housing needs of the current and projected Victorian population of people with a disability, possibly in collaboration with the National Disability Insurance Agency (NDIA).
12. That the Victorian government explore new ways to improve access to stable, affordable housing for people with a disability. A range of initiatives will be necessary to provide choice. These should include:
  - 12.1. Providing an additional 'high need housing payment' with which tenants with a disability can approach social housing providers, as proposed in the Henry Taxation Review 2010.
  - 12.2. Setting clearer targets for Housing Associations to provide housing for people with a disability and/or mental illness.
  - 12.3. Stamp duty concessions to improve the housing mobility of people with a disability. There is evidence that adults with an intellectual disability in particular have very low rates of housing mobility, affecting the housing choices of the whole family.
  - 12.4. Lobbying for changes that improve targeting of Commonwealth Rental Assistance and link it more closely to market rents.
  - 12.5. Consider making changes to influence and encourage longer private rental tenures. Lack of certainty of tenure for people with a disability is a key concern for many.
  - 12.6. Lobby for continuation of Commonwealth contributions to the National Rental Affordability Scheme (NRAS) and expand state co-contributions. It is currently difficult to evaluate access to the NRAS by people with a disability. Opportunities to collect data and target people with a disability should be sought. Additional incentives for landlords to provide rental housing to people with a disability may be necessary.
  - 12.7. Carefully consider the scaling up of mixed equity schemes. Planning and analysis (see Recommendation 11) is likely to show that there is a significant population of people with a disability (and their families) who have a small source of capital. This may be sufficient to exclude them from access to social housing but be insufficient to allow them to purchase a home, given that incomes of people with a disability are often low. There may be significant cost-benefits for the government in providing assistance in the form of equity to allow home purchase. Any government initiative in this area should form a part of a broader disability housing strategy that considers fairness of access to housing assistance between different cohorts of people with a disability.
13. That the Victorian government continue to increase investment in out of school hours and vacation care for adolescents and adults with a disability. This is necessary both as an interim measure as the NDIS rolls out and as a continued investment for those people who may not be eligible for the NDIS.
14. That the Victorian government lobby the National Disability Insurance Agency to be inclusive of family members and facilitate workforce participation of carers. Every opportunity should be taken, when there is no conflict with the wishes of the family member with a disability, for disability support hours to coincide with a carer's current or desired employment hours. The NDIA should be encouraged to collect data about changes to carer workforce participation as both an individual outcome and an aggregate system design measure.
15. That the Victorian government monitor and supplement employment support for carers, particularly those that have been locked out of the workforce for long periods.

## 1. Introduction

The Victorian Government has a strong record in leading the way with regard to:

Carer recognition and support

- Funding of the Victorian Support for Carers Program
- Initiating the Victorian Carer Card
- Proclaiming the Victorian Carers Recognition Act.

Disability and Mental Health reform

- The development of individualised care packages and innovative services.
- The inclusion of no disadvantage clauses in the National Disability Insurance Scheme (NDIS)
- Protection of the safeguarding role of the Disability Services Commissioner
- Reform to community mental health support services for people with a psychiatric disability.

Aged Care reform

- Advocating with the Commonwealth government for the inclusion of a national approach to wellness and reablement in the Commonwealth Home Support Program
- Retaining the benefits of the Victorian system in the transfer of the Victorian Home and Community Care Program to the Commonwealth in July 2015.

Government leadership is also evident in other key reforms identified in the Shergold Report<sup>1</sup> including:

- Services Connect
- Victorian Homelessness Action Plan
- Action Plan to Address Violence against Women and their Children
- Victoria's Vulnerable Children's Strategy
- Reducing the alcohol and drug toll: Victoria's plan 2013–2017, and New Directions for Alcohol and Drug Treatment services: A roadmap
- Victorian Aboriginal Affairs Framework 2013–2018, and
- Youth partnerships.

The depth and breadth of the various reform agendas hold much promise to deliver reconfigured, more integrated and consolidated services that improve quality and minimise transaction costs for service users.

At the same time, an intense period of reform, including proposed transfers of major program responsibilities between Federal and State levels of government, presents the risk of negative unintended consequences for proven and valued support services for carers. This risk for carers arises where these existing services are financed as subsidiary components of disability, health aged care and family programs, rather than from their own dedicated funding stream. Frequent, ongoing consultation with carers and their representatives during the reform process will help to mitigate this risk.

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<sup>1</sup> Shergold, P (2013), Service Sector Reform, a roadmap for community and human services reform: Final report.

In this context, Carers Victoria appreciates the opportunity to provide input to the Victorian Government's pre-budget deliberations. Our submission outlines priority reforms which are needed to enable the Victorian government to achieve the following broad social policy goals:

- Ensure that caring for people is economically and socially sustainable in Victoria.
- Minimise the costs of caring to people's social, civic and employment participation; their health and wellbeing and financial security.
- Address the risks of population ageing and the predicted reduced supply of informal care (Percival and Kelly 2004)
- Maintain the critical economic role of informal care in both complementing and supplementing the health, mental health, aged care, disability and family welfare systems.

## 2. Caring families and friends

### 2.1 Carer roles

Carers provide unpaid care and support to a family member or friend needing assistance with a disability, mental illness, chronic health issue or age-related condition.

Carer roles are diverse and can encompass any combination of the following skills and functions:

- Monitoring and recording
- Interpreting and exercising judgement
- Making informed decisions
- Taking appropriate actions
- Making adjustments and modifications
- Accessing resources for the person receiving care and for self
- Working together with the person receiving care
- Negotiating and advocating within the care system, and
- Providing hands-on care.

(Adapted from Schumacher, K., Stewart, B., Archbold, P., Dodd, M., Dibble, S. (2000), 'Family caregiving skill: development of the concept', *Research in Nursing & Health*)

### 2.2 Carer profile

Each caring situation is different. Carers come from all walks of life and all cultures. They vary in age across the full lifecycle. They may be spouses, partners, parents, sons or daughters, siblings, friends, nieces or nephews or neighbours. *Many people identify themselves in terms of these family relationships and may not identify themselves as 'carers'.*

According to the Survey of Disability, Ageing and Carers, there are some 773,400 informal carers in Victoria (or 13.6% of the total population), 217,800 (3.8%) of whom are 'primary carers'.<sup>2</sup> The 'primary carer' is defined as the carer within the household who provides the majority of ongoing care to the person requiring assistance.

The caring role is not evenly balanced across gender lines. Australia-wide, of the 769,800 'primary carers'; 536,700 or 70 per cent are female and 233,100 or 30 per

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<sup>2</sup> Australian Bureau of Statistics (ABS), Survey of Disability Ageing and Carers (SDAC) 2013, Table 36-1&2.

cent are male.<sup>3</sup> The same ABS (2013) survey estimated that there were 74,800 primary carers under the age of 15 years Australia wide, while there were an additional 231,200 informal carers between the ages of 15 and 25 years.

### **2.3 The future trends in caring**

Demographic studies have predicted that the number of people needing informal care will steadily increase, primarily because of the rapid ageing of the Australian population.

It is estimated that the numbers of older persons with a severe or profound disability in Australia will increase by 160 per cent between 2001 and 2031.<sup>4</sup>

The number of people available to provide informal care is also expected to increase. Crucially, however, the number of people available for informal caring will increase at a markedly lower rate than that the number of people requiring care. Over the same period 2001 to 2031 the number of available carers is projected to increase by only 57 per cent.<sup>5</sup>

This decrease in the 'carer ratio' is again driven by population ageing, as well as other social factors such as: fewer numbers of children per family; increased family breakdown and mobility; more people living alone and increased workforce participation by women.

The decrease in the informal care ratio presents an urgent policy challenge and reinforces the need to invest judiciously in the development and support of informal carers to retain their ability and capacity for social care.

### **2.4 Economic value of caring**

According to a report prepared for Carers Australia by Access Economics, informal carers within the community provided 1.32 billion hours of care in Australia in 2010.<sup>6</sup>

When calculating the replacement cost to society if all current informal community care was delivered through formal care systems, Access Economics conservatively estimated this figure to be \$40.9 billion per year. This is equivalent to 60 per cent of the health and community sector budget for that year or 3.2 per cent of annual Gross Domestic Product (GDP).<sup>7</sup>

### **2.5 Carer needs**

While the situations of individual carers and families are diverse, there is now a strong and growing body of evidence in the literature indicating that particular health, social and economic problems disproportionately affect the unpaid caring population in comparison to the general population.

Issues experienced by carers include:

- comparatively poorer physical health (e.g. chronic illnesses, including cardiovascular conditions, diabetes, asthma and muscular-skeletal conditions)
- poorer mental health (e.g. higher rates of stress, anxiety and depression),

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<sup>3</sup> ABS 2013 SDAC, Table 33, 1.

<sup>4</sup> Percival, R & Kelly, S 2004, *Who's going to care? Informal care and an ageing population: report prepared for Carers Australia by the National Centre for Social and Economic modelling*, NATSEM, Canberra.

<sup>5</sup> Ibid.

<sup>6</sup> Access Economics (2010), *The economic value of informal care in 2010*, Carers Australia

<sup>7</sup> Ibid.

- severe financial disadvantage (lower household incomes, lower employment participation and higher household expenditures related to the illness or disability in the family)
- poorer social connection and greater exclusion from a range of normal life opportunities and activities.<sup>8</sup>

This evidence underlines the vulnerability and disadvantage of family carers as a segment within society. It highlights the compelling need to assist caring families to maintain their well-being, to achieve more meaningful social and economic participation and to continue to remain effective in their essential role in the health, aged care, disability and family welfare service systems.

### 3. Core Business for the future:

#### **Enabling caring families to be informed and effective with opportunities for a 'good life'**

Families remain the basic units of our society. They can be resilient and productive, even when faced with significant caring responsibilities. But, as shown by the evidence in the research literature, resilience cannot always be sufficient to overcome significant disadvantage. Most caring families will at some time need structured support, or ongoing investment - if they are to remain well, participate in and enjoy life's social and economic opportunities and maintain their vital economic contribution.

Carer Victoria's emergent best practice model to support carers and to strengthen their vital function of informal caring is based upon recognising *the totality of care relationships within the family or family-like group*. The model addresses the wholeness, interrelatedness and complexity of families and their immediate environments.

Some of the themes of this emergent practice model include:

- assessment and intervention processes which are person-centred and with a strong family focus
- an emphasis on information provision, connectedness and support to empower families to achieve their own goals
- a strengths-based and capacity-building approach, enhancing the natural adaptive abilities of families
- linkage to mutual help and self-help activities and resources
- linkage to mainstream service systems in the community- always with a preference for (cost-effective) prevention and early intervention
- specialist service provision, including emotional, financial and practical assistance, respite care, individual and systemic advocacy
- promoting mutually positive family solutions while protecting basic individual rights of family members, and
- encouraging the equitable sharing of care within the family, across genders and between the informal and formal care system.

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<sup>8</sup> (Australian Institute of Family Studies: Commonwealth Government 2008, The Nature and Impact of caring for Family Members with a Disability in Australia; Cummins, R. A., et al. The wellbeing of Australians: Carer health and wellbeing, Deakin University, Carers Australia and Australian Unity Melbourne 2007; NATSEM Draft Report: Lifetime health and economic burden of care giving, Canberra September 2008, Survey of Disability, Ageing and Carers, ABS 2013).

Into the future, enabling caring families to be informed and, effective with opportunities for a 'good life' is core business for Government, service provider agencies and the wider community. It is not only a vitally important part of social policy but also one which generates major economic savings for the taxpayer.

#### **4. About the recommendations**

Carers Victoria consults widely and on an ongoing basis about the full range of issues affecting caring families. It carefully analyses data collected in relation to the short and longer term needs of this group.

In the context of this 2014-2015 State Government Pre-Budget Submission, Carers Victoria has taken the decision to document a concise summary of priority recommendations and concerns, rather than canvass the exhaustive list of the carer issues, which it has dealt with in its research and publication work. Carers Victoria appreciates that Government, like all bodies, operates in an environment of competing demands and finite resources.

For this reason, ***Carer Victoria has specified what it believes are the most cost-effective solutions to the most pressing issues for caring families.***

In preparing this submission Carers Victoria has considered the recommendations of the Victorian Auditor General's report on the audit of Carer Support Programs in 2012 namely:

That the Department of Health and the Department of Human Services:<sup>9</sup>

- identify and address gaps in the promotion of carer supports to improve carer awareness of services
- require consistent carer identification and needs assessment
- improve administration and monitoring of carer brokerage funds
- monitor and report on timeliness of access to carer supports, and
- develop outcome measures for carer supports and monitor outcomes.

Carers Victoria has built on these foundations with further recommendations that invest in building the capacity of caring families and designing a support system for the future. Consequently recommendations include the need for a whole of government approach to:

- allocation of responsibilities for government departments beyond the Department of Health and the Department of Human Services, and
- planning intergovernmental work in the transfer of responsibilities between the Victorian and Commonwealth government.

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<sup>9</sup> Victorian Auditor-General's Office (2012), Carer Support Programs.

## 4.1 Recommendations

Many of the following recommendations can be largely cost neutral if the Victorian Government chooses to redirect some Support for Carers Program resources into the investments outlined.

### 4.1.2 Recommendations about building the capacity of caring families

Caring families have widely variable understandings of the change process and what will be required of them within the reformed service systems.

Improved access to specialist carer supports and services must be accompanied by investment in capacity building and mutual support programs for caring families. Investment to date has focused on building the capacity of the provider sector for transition to individualised funding and increased consumer choice and control. While Victorian government funding for the Confident Connected Carers project in the Barwon NDIS launch site is very welcome, there also needs to be greater ongoing investment in initiatives to build the knowledge and skills of consumers and families. Market research<sup>10</sup> conducted by Carers Victoria indicates that an approach combining traditional face to face support with the opportunities available online is welcomed by carers. These would combine on line and interactive information and learning with facilitated workshops and opportunities for mutual support and collaboration.

#### Recommendation 1:

That the Victorian Government invest capital resources towards the development of infrastructure for an online Carer Portal through Carers Victoria to empower caring families to exercise increasing choice and control.

Carers Victoria has continued to advocate for family-focussed responses to the recommendations of the Victorian Law Reform Commission's report on Guardianship.<sup>11</sup> Currently informal family representation of people with a disability is insufficient to provide protection to the person with a disability or to the family carer representing them to public and financial institutions. It is essential that mechanisms are put in place for VCAT to take into account both the views of the person with a disability, and of the plans of significant involved people, to make informed orders for:

- supported decision making and co-decision making – giving voice to people with limited capacity
- substitute decision making as required, and
- succession documents as a means of effective advanced planning.

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<sup>10</sup> Carers Victoria's market research, together with research by other organisations indicates the importance for most carers of access to reliable and accessible information, including information at key lifecycle transition points and at critical events such as changes in the health and wellbeing of the person with a disability, or a family carer. (Quantum Market Research 2012) Information needs change over time, particularly for parents of people with a disability, where new lifecycle milestones demand new services and new responses.

Key learning areas wanted by carers include knowing where to go for help (45%); understanding services and entitlements for the person being cared for (40%); coping strategies (40%); emotional support (38%); finding the right people to help (38%); understanding the condition and its pathway (35%); behaviour and conflict management (29%) (Quantum 2012) In addition, 79 per cent of the Carers interviewed by Quantum wanted an on line learning format, with 45 per cent wanting a website with downloadable information and 31 per cent wanting interactive web access.

<sup>11</sup> Victorian Law Reform Commission (2011), Guardianship Final Report.

A mechanism which allows people who access supported and co-decision makers to nominate future financial and personal supporters is also essential.

Carers Victoria is working with Latrobe University and SCOPE on a research project to explore supported decision-making. This project, with funding from the Legal Services Board of Victoria, aims to:

- map good processes and key dilemmas in being supported and supporting people with cognitive disabilities in decision making
- develop a set of guidelines that provides considerations to inform practice when supporting someone in his or her decision making, and
- test the performance of the resultant multimedia resource in real-world scenarios.

### **Recommendation 2:**

That the Victorian government invest in an ongoing way in resources and training programs to assist families to develop skills and capacity in supported decision making.

Victoria is facing an imminent crisis of people with a decision making disability who live with ageing parents. Many parents have no future plans in place for their son or daughter and are not registered on the Victorian Disability Support Register (DSR). While the NDIS is committed to improving the support available for the sons and daughters of ageing parents, the limited roll out of the trial sites increases family anxiety. Ageing parents and other family members may struggle with their own disability, illness and mortality. They are often unable to find the future supports that are needed for their adult child. They will become increasingly desperate for accommodation and other support services for their family member as their own capacity diminishes.

There is an urgent need in Victoria for investment in services to support the transition of people with a disability to care outside the family home. Victoria has an opportunity to lead the way by developing a specialist carer support program of support with:

- family counselling, mediation and life planning
- legal and financial planning
- housing
- disability support staff
- social support, and
- coordination of formal and informal support.

### **Recommendation 3:**

That the Victorian government makes a priority investment in specialist transition and succession planning programs for older parents of people with a lifelong disability.

#### **4.1.3 Recommendations about building the capacity of the service system**

The Productivity Commission reports on Disability Care and Support and Caring for Older Australians both recommended the establishment of Carer Support Centres

nationally.<sup>12</sup> The Commonwealth government has committed \$11M over five years in addition to the funding currently allocated to Commonwealth Respite and Carelink Centres.

The new centres would provide:

- education and training
- counselling
- peer support, and
- access to emergency respite care.

The centres are also intended to provide support to carers in order to reduce their need for emergency respite. The centres would provide support services to ‘all carers’ regardless of the specific condition the person receiving care. Importantly, they could also support carers who choose not to receive support through the aged care, disability or mental health systems, or indeed are unable to do so because their family member does not wish to.

The Victorian government is well positioned to advocate with the Commonwealth government to build on the holistic models of carer support that have been developed in Victoria through the Support for Carers Program. This approach is consistent with the agreement between the Victorian and Commonwealth governments to retain the benefits of the Victorian system in the transfer of HACC and in the no-disadvantage clauses in the NDIS.

National and international evidence<sup>13</sup> demonstrates that multi-component interventions provide more effective carer support than single interventions such as information provision or respite care.<sup>14</sup> Victorian Support for Carers Program funds would support broadening the scope of specialist carer support centres in the following areas:

- family capacity building in mutual support and self help
- system navigation and effective connection to the disability, mental health and aged care systems
- advocacy
- demonstration of family focused models of support
- service system capacity building, workforce development and dissemination of good practice, and
- support for caring families of people who are not eligible for the NDIS.

#### **Recommendation 4:**

That the Victorian government negotiate with the Commonwealth to pilot a Victorian program of integrated specialist Carer Support Centres.

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<sup>12</sup> Productivity Commission (2011). *Disability care and support*, report no. 54, Canberra, Productivity Commission (2011). *Caring for Older Australians*, report no. 53, Canberra.

<sup>13</sup> Parker G, Arksey H and Harden M, Meta-review of international evidence on interventions to support carers. July 2010 Working Paper No.DH 2394 Social Policy Research Unit, University of York.

<sup>14</sup> Eagar, K., Owen, A., Williams, K., Westera, A., Marosszeky, N., England, R., & Morris, D. (2007). *Effective caring: A synthesis of the international evidence on carer needs and interventions*. Vol. 1: The report. Wollongong, NSW: CHSD, University of Wollongong.

Sector reforms that promote use of individualised budgets and consumer directed care require ongoing investment in workforce development and professional and vocational training programs. Workforce and sector development strategies must also skill the sector for effective partnership and collaboration with caring families. Family focused practices in disability, mental health and aged care can more cost effectively use limited resources in a tight fiscal environment. They can reduce the transactions by both professionals and families that are currently required in accessing and coordinating care and supports, increasing system efficiency and productivity. Embedding family focused practices will importantly build on recognising and supporting care relationship principles contained in the Carers Recognition Act.

Strategies to build workforce and sector capacity include:

- evidence based research and consultation with caring families concerning best practices, planning and service models that support sustainable informal care
- input into the development and delivery of accredited prevocational and professional training programs, and
- job redesign to improve direct care staff satisfaction and retention.

#### **Recommendation 5:**

That the Victorian government increase investment in professional and provider skills development and practice change programs to ensure caring family responsive programs and services.

#### **4.1.4 Recommendations about strengthening the safeguards in Victoria for caring families**

The significant degree of service system reform currently underway also points to a need for investment in individual family advocacy for those caring families at risk of being left out or left behind in the change process. These may be caring families who require additional support with service system navigation or those who are especially disadvantaged within the service system.

To date, investment by the Commonwealth and Victorian governments in advocacy have been:

- Primarily directed to individual rather than family centred advocacy in the aged, disability and mental health sectors.
- Tied to sector funding programs rather ensuring the development of joined up services and addressing advocacy issues in both mainstream and specialist adult support services.

Increased Victorian government investment is absolutely necessary to identify and address individual and systemic advocacy issues with a view to fair resolution and increasing caring family empowerment. Data derived from individual family advocacy issues would support systemic advocacy for needed change to policy and practice.<sup>15</sup>

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<sup>15</sup> Individual Advocacy and Caring Families discussion paper, Carers Victoria, 2011.

### **Recommendation 6:**

That the Victorian allocates Support for Carers Program funds to an improved, comprehensive independent and regionally based individual and systemic family advocacy system.

The Victorian Government's HACC service system resourcing currently underpins much of the core research, policy and systemic advocacy activity for the caring families within the State. The future of systemic advocacy function, literally the voice for the caring community, remains highly uncertain with the proposed transfers of program responsibilities in community aged care between Commonwealth and State levels.

Carers Victoria's ongoing systemic advocacy and evidence based research via consultations, surveys and research is needed to address the emerging issues and experiences of caring families. It also has the potential to ensure independent monitoring of service delivery and practices in the aged, disability, and psychiatric disability systems. The systematic collection and maintenance of caring family feedback data makes an important contribution to Victorian and national system design and development. Particularly important from a consumer perspective, may be the monitoring of market failures, market risks and market costs in an environment of fundamental and unprecedented systems change.

Investment in a strengthened system of research and project development would play a key role in applied research and development of innovative solutions. Such investment would aid in exerting influence with markets, government and providers and in the development and trialling of new service models and improved practices with caring families.

The preservation and protection of systemic family advocacy functions is essential to ensure both the individual needs and a collective voice of caring families are better represented, especially during this time of significant sector change and reform.

### **Recommendation 7:**

That the Victorian government ensure that HACC service system resourcing funds directed to Victorian policy, research and advocacy activities continue after the transition to the Commonwealth Home Support Program.

#### **4.1.5 Recommendations about improving service system responses to young people in families with a person with a disability**

Carers Victoria recently released a discussion paper titled 'Unfinished Business: Public policy and children in families with a person with a disability or mental illness'.<sup>16</sup> The paper argues that there is a need for a debate and rethink about how we should conceptualise and respond to 'young carers'. The contention is that we currently lack a clear set of policy goals that can be shared by the community sector.

<sup>16</sup> <http://www.carersvictoria.org.au/file-assets/unfinished-business/>

The extent and range of disadvantage faced by many young people with caring responsibilities are undisputed within the research literature. The paper emphasises that although many of these problems are strongly *correlated* with young carers, they are not always *caused* by their caring role per se. Sophisticated policy analysis is required to determine appropriate policy and programmatic responses which safeguard future generations of young people with caring responsibilities.

Our discussion paper identifies that providing specialist support for young carers is only one component of the much broader response needed to improve outcomes for young people. Systemic changes involving adult specialist, mainstream and child and family services are required if negative impacts associated with caring are to be prevented. There is a high degree of consensus amongst academic, disability, mental health and child welfare experts interviewed for the project about the need for:

- improved identification of and engagement by the service system with young people in families with a person with a disability, their parents and family members.
- family focussed approaches that can manage and respond to interdependent and separate needs within families
- an increased focus on supporting family functioning and parenting relationships
- improvements to supports for the person with a disability to allow more meaningful choices about the balance of formal and informal care within families.

The timing of this debate within Victoria is fortuitous. There are a number of government reforms that have begun or are proposed that can be seen as consistent with making the systemic improvements we need. However, without a defined intention to improve interventions for children in families with a person with a disability, there is a risk that these opportunities could be missed. Here are some recommendations for the Victorian government derived from the discussion paper:

### **Recommendation 8:**

In relation to the Shergold report<sup>17</sup> and Services Connect initiative,<sup>18</sup> Carers Victoria recommends that the Victorian Government:

- 8.1. develops approaches to service delivery that are both person centred and family focussed, even when there may be multiple members of the family in direct need of support for example a person with a disability and a young carer
- 8.2. ensures that a focus on the 'most troubled families' does not entail a loss of early intervention and prevention approaches

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<sup>17</sup> Shergold, P (2013), Service Sector Reform, a roadmap for community and human services reform: Final report.

<sup>18</sup> Victorian Government, Department of Human Services (2011): The Case for Change.

### Recommendation 9:

In relation to Victoria's Vulnerable Children: Our Shared Responsibility,<sup>19</sup> Carers Victoria recommends that the Victorian Government:

- 9.1. invests in the Cummins' report's recommendations about achieving earlier intervention and prevention<sup>20</sup>
- 9.2. makes changes to legislation to ensure that adult specialist services, for example disability and mental health, identify children within families<sup>21</sup>
- 9.3. invests in adult specialist services and workforce initiatives so that they can respond appropriately to changes in legislation and policy. An example is new expectations of Psychiatric Disability Rehabilitation and Support (PDRSS) services that they will be required to identify children in families of a person with a mental illness and make appropriate assessments and referrals in relation to their needs.<sup>22</sup> Leadership, training and tools will need to be available to ensure that this work is done appropriately and effectively by a workforce largely unfamiliar with working with children
- 9.4. considers carefully the implications of conceptualising young people in families with a person with a disability as being 'vulnerable' within future service system reforms.<sup>23</sup> To not include them may ensure that they, and their needs, continue to be largely hidden. To include them as a cohort may run the risk of making assumptions about the needs and experiences of a very diverse group and their other family members/parents. More work is needed to develop and refine appropriate definitions, screening tools and resulting actions in this area.

### Recommendation 10:

Carers Victoria also recommends that the Victorian government funds an action research project providing whole of family support to young people in families with a person with a mental illness. 'Unfinished Business' provides reference to a similar UK project that has been evaluated that may provide some guidance to program design.<sup>24</sup>

A Victorian action research project should measure multiple outcomes for children and their family members and include collection of information that contributes to cost-benefit analysis.

Action research would provide invaluable information about how mainstream and specialist services might interface with an NDIS, develop co-ordination strategies, identify workforce and practice issues and identify and respond to service gaps.

<sup>19</sup> Victorian Government (2013), Victoria's Vulnerable Children: our Shared Responsibility.

<sup>20</sup> Cummins, P., Scott, D., Scales B. (2012), Report of the Protecting Victoria's Vulnerable Children Inquiry, Department of Premier and Cabinet, Victorian Government

<sup>21</sup> Ibid.

<sup>22</sup> Victorian Government (2013) Reforming community support services for people with a mental illness: Reform framework for Psychiatric Disability Rehabilitation and Support Services

<sup>23</sup> Cummins, P., Scott, D., Scales B. (2012), Report of the Protecting Victoria's Vulnerable Children Inquiry, Department of Premier and Cabinet, Victorian Government.

<sup>24</sup> Ronicle, J. and Kendall, S. (2010), Improving support for young carers – family focused approaches, York Consulting, for Department of Education, UK.

#### 4.1.6 Recommendations about housing for people with a disability and/or mental illness

Access to affordable and suitable housing and support for people with a disability or mental illness continues to be a primary concern for many caring families. Previous Carers Victoria submissions and pre-budget bids have made specific recommendations to the Victorian government about addressing these issues<sup>25</sup>. Many of these are still valid.

The introduction of an NDIS holds the promise that eligible people with a disability<sup>26</sup> will receive ongoing support for the duration of their lives. For some this will mean that, for the first time, the constraint on receiving adequate housing and support will predominantly be determined by their access to housing.<sup>27</sup> Given the shortage of affordable housing, there is a very real risk that people with a disability will be able to exercise choice and control over the support they receive but will be unable to make choices about where, with whom and in which type of accommodation they live .

The Productivity Commission's report into Disability Care and Support stated that an NDIS would not provide housing to all eligible participants of the scheme.<sup>28</sup> It suggested that those assessed with the most profound disabilities would be provided with supported accommodation and the scheme would provide a 'user cost of capital' to encourage providers to invest in accommodation for people with a disability.

Carers Victoria has previously advocated that housing for people with a disability should be separate from provision of support. An NDIS cannot provide housing for all participants and achieve financial viability. There is also a strong case that some services for people with a disability should remain outside of an NDIS: a scheme meeting all the needs of a person with a disability, whether disability related or not, could create a form of segregation.<sup>29</sup>

An intention to provide housing assistance to people with a disability raises difficult social policy targeting questions. Should level of disability be a guide or should provision be based upon housing need - or some combination of both? How should personal or family assets be taken into account? In addition, how should policy decisions about preferred mechanisms for the delivery of assistance be made; through private ownership, rental schemes or social housing?

The future role of the State in relation to housing may be uncertain. The Australian Parliament Senate has announced it is conducting a Parliamentary Inquiry into affordable housing. The Commission of Audit may also make new recommendations about state and commonwealth responsibilities in relation to investment and service provision.

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<sup>25</sup> Carers Victoria (2010), Submission into the Inquiry into the Adequacy and Future Directions of Public Housing; Carers Victoria (2010), Community living for the 21<sup>st</sup> century: A blueprint for caring families, Carers Victoria's Pre budget submission 2010-2011; Carers Victoria (2012), A Brighter Future for Victorian Caring Families; Carers Victoria's Pre budget submission 2012-2013.

<sup>26</sup> Includes people with a psychosocial disability due to mental illness.

<sup>27</sup> Joseph Connellan presentation to NDS forum.

<sup>28</sup> Productivity Commission (2011). *Disability care and support*, report no. 54, Canberra.

<sup>29</sup> Bigby, C., & Fyffe, C. (2013), Making mainstream services accessible and responsive to people with intellectual disability: What is the equivalent of lifts and Labradors? Proceedings of the Seventh Roundtable on Intellectual Disability Policy, Bundoora: Living with Disability Research Group, Faculty of Health Sciences, LaTrobe University .

Carers Victoria urges the Victorian government to remain heavily involved in providing housing assistance to people with a disability in order to grow supply and have influence over service design. There are several actions the State can consider now:

**Recommendation 11:**

That the Victorian government plan for the housing needs of the current and projected Victorian population of people with a disability, possibly in collaboration with the National Disability Insurance Agency (NDIA).

**Recommendation 12:**

That the Victorian Government explores new ways to improve access to stable affordable housing for people with a disability. A range of initiatives will be necessary to provide choice. These should include:

- 12.1. Providing an additional 'high need housing payment' with which tenants with a disability can approach social housing providers, as proposed in the Henry Taxation Review 2010.<sup>30</sup>
- 12.2. Setting clearer targets for Housing Associations to provide housing for people with a disability and/or mental illness.
- 12.3. Stamp duty concessions to improve the housing mobility of people with a disability. There is evidence that adults with an intellectual disability in particular have very low rates of housing mobility, affecting the housing choices of the whole family.<sup>31</sup>
- 12.4. Lobbying for changes that improve targeting of Commonwealth Rental Assistance and link this more closely to market rents.<sup>32</sup>
- 12.5. Consider making changes to influence and encourage longer private rental tenures. Lack of certainty of tenure for people with a disability is a key concern for many.
- 12.6. Lobby for continuation of Commonwealth contributions to the National Rental Affordability Scheme (NRAS) and expand state co-contributions. It is currently difficult to evaluate access to the NRAS by people with a disability. Opportunities to collect data and target people with a disability should be sought. Additional incentives for landlords to provide rental housing to people with a disability may be necessary.

<sup>30</sup> Australia's Future Tax System Recommendation 105.

<sup>31</sup> Beer, A. and Faulkner, D (2009) The housing careers of people with a disability and carers of people with a disability, AHURI Research Paper.

<sup>32</sup> Australia's Future Tax System (2010) Recommendations 102 and 103.

12.7. Carefully consider the scaling up of mixed equity schemes. Planning and analysis (see Recommendation 11) is likely to show that there is a significant population of people with a disability (and their families) who have a small source of capital. This may be sufficient to exclude them from access to social housing but be insufficient to allow them to purchase a home, given that incomes of people with a disability are often low. There may be significant cost-benefits for the government in providing assistance in the form of equity to allow home purchase. Any government initiative in this area should form part of a broader disability housing strategy that considers fairness of access to housing assistance between different cohorts of people with a disability.

#### 4.1.7 Recommendations about carers and employment

In general, carers have significantly lower rates of workforce participation than other Australians of workforce age.<sup>33</sup> Carers are more likely to work part time, be in casual work, reduce their hours and work in roles with reduced levels of responsibility in order to balance paid work with their caring responsibilities. The resultant lower income levels, combined with additional costs associated with caring and the likelihood that the person they care for also receives a low income, increases household financial hardship.

Most vulnerable are those who have been caring at high intensity for long durations with limited sharing of the care with other informal and/or formal care. For this group, the consequences of being locked out of the workforce can include long term poverty, social isolation and poor physical and mental health.<sup>34</sup>

Research evidence and previous analysis has shown that some carers will need all of the following in order to balance paid work with their care responsibilities:

- Alternative care that is:
  - Affordable
  - High quality
  - Co-ordinated with paid work hours<sup>35</sup>
- Workplace supports and modifications
  - Legislation to support requests for flexible work arrangements<sup>36</sup>
  - Anti-discrimination legislation<sup>37</sup>
- Income support that encourages and supports carers to train, return to the workforce and allows sharing of care between family members
- Training and employment support for those wishing to return to the workforce, particularly after extended periods of caring.

Of particular concern is a cohort of carers who cease caring because their family member is deceased or has moved into long term residential care. For this group, grief and loss, lack of engagement with the workforce and long term financial hardship (including low or no superannuation) can combine to create multiple

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<sup>33</sup> Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) 2009.

<sup>34</sup> Edwards, B, Higgins, DJ, Gray, M, Zmijewski, N, & Kingston, M 2008, 'The nature and impact of caring for family members with a disability in Australia', *Research report*, no. 16, 2008, Australian Institute of Family Studies (AIFS), Melbourne.

<sup>35</sup> See Carers Victoria (2010), *Ways to work: Employment support for carers of adolescents and adults with an intellectual disability*.

<sup>36</sup> See Fair Work Act 2009, National Employment Standards.

<sup>37</sup> See Equal Opportunity Amendment (family responsibilities) Act 2008 (Vic).

disadvantages and barriers. Specialised and carefully targeted supports may be necessary.

The Productivity Commission's work highlighted that the financial viability and justification of an NDIS is in part predicated upon the return of carers (as well as people with a disability) to paid employment ( or increasing their hours), with resulting reductions in the income support bill and increases in taxation revenue.<sup>38</sup> In addition, all family members are set to benefit from increased carer workforce participation. However, without co-ordination and family involvement in the NDIS planning process, there is a risk that additional resources could be provided for the person with a disability without any resulting return to the workforce by carers.

Carers Victoria acknowledges that many of these areas are a Commonwealth responsibility. Here are some areas that Carers Victoria believes the Victorian government can have a role in:

**Recommendation 13:**

Continuing to increase investment in out of school hours and vacation care for adolescents and adults with a disability. This is necessary both as an interim measure as the NDIS rolls out and as a continued investment for those people who may not be eligible for the NDIS.

**Recommendation 14:**

Lobbying the National Disability Insurance Agency to be inclusive of family members and facilitate workforce participation of carers. Every opportunity should be taken, when there is no conflict with the wishes of the family member with a disability, for disability support hours to coincide with a carer's current or desired employment hours. The NDIA should be encouraged to collect data about changes to carer workforce participation as both an individual outcome and an aggregate system design measure.

**Recommendation 15:**

Monitoring and supplementing employment support for carers, particularly those that have been locked out of the workforce for long periods.

**5. Concluding comment**

As the organisation solely representing carers in Victoria, we look forward to frequent and ongoing consultation between the carer support sector and the Victorian government during a period of major reform, reconfiguration and transfer of responsibilities between the Commonwealth and State governments.

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<sup>38</sup> Productivity Commission (2011). *Disability care and support*, report no. 54, Canberra.