A Brighter Future for
Victorian Caring Families

Carers Victoria’s
Pre-budget Submission 2012-2013

November 2011
About Carers Victoria

Carers Victoria is the state-wide peak organisation representing those who provide care. We represent more than 700,000 family carers across Victoria – people caring for ageing parents, children with disabilities, and spouses with mental illness or chronic health issues.

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 submission was prepared by Carers Victoria’s Policy Team

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List of Recommendations

1. **Getting Victoria ready for an NDIS and NIIS (See section 1 – 1.25)**

*Carers Victoria recommends:*

That the Victorian government continues its work to contribute to reforms in disability care and support by:

- Advocating for a broad national mapping of existing disability and psychiatric disability family respite and support programs; their eligibility policies, funding sources and levels and their services delivery capacity.
- Advocating concerning the development of a framework for the design of future carer respite and support programs within or alongside an NDIS. This should consider eligibility assessment tools, access pathways, support entitlement and efficient models of services delivery.

That the Victorian Government strengthens its investment into individual advocacy support programs for families of people with a disability or psychiatric disability. Phased in recurrent investment in an individual advocacy program over 4 years is required.

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*About data capture, Carers Victoria recommends that the Victorian Government:*

- Invest in and oversee the development of a register of ageing parent carers in Victoria.
- Invest in a data collection and consultation process about the needs and circumstances of Victorian participants in NDA employment services and their families. This should include their current and projected housing and support needs.
- Invest in a project to consult with and collect data about the needs, circumstances and preferences of older parents of people with significant psychiatric disabilities. Nationally there has been no significant applied research in this area. Such a project would ensure the provision of informed advice to the Victorian government and a National Disability Insurance Scheme concerning the current and future needs of this cohort.
About National Injury Insurance Carers Victoria recommends:

- That the development of a federated National Injury Insurance Scheme includes the assessment of family support needs, and allocation of support entitlements for high needs families. Family inclusive quality standards and outcome monitoring processes are also required.

About Guardianship and Administration, Carers Victoria recommends:

- That the new Guardianship and Administration Act supports parents being able to nominate those responsible for the care of their son or daughter with a disability after the death or illness of the parent.²

- The development of a suite of educational materials and resources for families and services providers to support the new Guardianship and Administration Act. Funding of an interagency stakeholder working group to initially develop tools and resources requires a non recurrent commitment of $1 Million.

- Fundamental reforms to VCAT proceedings to ensure that they are welcoming of and accessible to, adults with impaired capacity who need support to communicate their wishes and preferences, and to the families who support them.

2. Matters of the Utmost urgency

2.1 Investment in Housing and Support for Ageing Parents. (See section 2.1)

Carers Victoria recommends:

- That the Victorian Government makes a priority investment into the development of three coordinated regional transition and succession programs for older parents of people with a lifelong disability. These will commence operation in 2012.
### Housing for people with a mental illness or disability

(See section 2.2)

**Carers Victoria recommends:**

- That the Victorian Government maintains the momentum generated by the Nation Building funding by providing sustained and planned investment in social housing.
- That the Victorian Government continues its commitment to funding the National Rental Affordability Scheme while improving the scheme’s targeting to those on very low incomes.
- That the Victorian Government take every possible opportunity to support reforms to Commonwealth Rent Assistance such as those outlined in the Henry Taxation Review.
- That the Housing Choices Mixed Equity Housing Program be funded to expand by providing 30 dwellings over the next 3 years.
- That the Victorian government provides clearly targeted funding for social housing for people with a disability and/or a mental illness based on population needs.
- That the Victorian Government audits the extent of access of people with a disability or mental illness to public housing. This should extend to include community housing.
- That the Victorian Government lobbies for 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.
- That the Victorian Government set clearer targets for Housing Associations for providing housing for people with a disability an/or mental illness.
3. **Young people with caring responsibilities** *(See section 3)*

**Carers Victoria recommends:**

- That the Victorian Government establishes and resources an interagency steering committee on young people with care responsibilities to shape and drive systemic improvements. Membership should include representation from education, employment support, health, youth, disability, mental health, drug and alcohol, and family support services from Victorian and Commonwealth governments in addition to carer representation.

- That the Victorian Government funds the roll out of the successful Families of Parents with a Mental Illness program (FaPMI) across all Victorian regions. It demonstrates that a systemic, family and child focused service can be designed and developed to respond to the needs of all family members in the existing mental health service system including young people and their parents.

- That the Victorian Government carefully considers the findings and insights of the recent evaluation report of FaPMI with a view to the translation of elements to other parts of the service system such as the disability and family support sectors. Some caution should be used in recognition that different sectors have their own unique challenges, characteristics and cultures.

4. **Carers and employment** *(See section 4)*

**Carers Victoria recommends**

- That the Victorian Government conducts an evaluation of the Victorian Equal Opportunities (Family Amendment) Act 2008. This should investigate the impacts of the amendment including the extent to which it has been used, by whom, in what circumstances, and the range of short and long term outcomes for employees and employers.

- That further funding is provided to develop and implement out of centre hours and vacation respite services for families who care for an adult with a disability. Pilot sites should be selected according to demonstrated demographic need.

- That the Victorian Government establish a new structure to drive improvements to supporting caring families and employers to balance paid employment and caring responsibilities.
5. **Carers of people with mental illness** *(See section 5)*

**Carers Victoria recommends:**
- That the Victorian government proactively maps and projects the overlap of the possible NDIS population of people with a psychiatric disability and the current PDRSS population.
- That the Secure and Extended Care Unit Diversion and Substitution and Intensive Home Based Outreach Services initiatives are extended and expanded, with greater attention afforded to access to housing for program participants.
- That the Victorian government increases the momentum of the roll out of Prevention and Recovery Care services to ensure that all Victorians have access to needed services.
- That the Victorian Government provides resources for a comprehensive consultation with people with a mental illness and their carers about the implications and preferences for a fused guardianship-mental health act.
- That the Victorian government increases its investment in mental health carer advocacy support.

6. **Early childhood intervention services** *(See section 6)*

**Carers Victoria recommends:**
That over the next 4 years the Victorian Government invests in:
- 1000 Early Childhood Intervention services at $ 7 million and
- 500 Kindergarten Inclusion support packages @ $5 Million

7. **Pay equity for the disability and welfare sectors** *(See section 7)*
- That the Victorian Government commits funding to ensure pay equity for those working in the disability and welfare sectors.
The needs of many caring families in Victoria remain unaddressed

Carers Victoria’s pre budget bid and election platform 2010 -11\(^1\) made the case that, in spite of a sound rationale, the implementation of community living policies had failed to keep abreast with the needs of people with a disability and/or a mental illness and their families. There has been a lack of sustained investment. We noted that the acute shortage of accommodation and support for people with a disability and/or mental illness was a priority for caring families. Advocacy on this issue continued through Carers Victoria’s election campaign.

Two years on, this issue remains the paramount concern of caring families. Much of Carers Victoria’s pre budget submission for 2010 -11 is still current. As acknowledged in the Coalition’s election platform, investment over recent years has been incremental at best. Our pre budget bid for 2012-3 aims to reinforce, update and build on Carers Victoria’s advocacy for improved support for people with a disability and their caring families particularly the need for accommodation and support for people with a disability and/or a mental illness.

Our last budget submission noted that the problems experienced by people with a disability and their caring families were becoming more acute. Demand for support was likely to significantly increase. This was a consequence of complex interactions between:

- Demographic change, including the ageing of people with a disability and their families and the increased longevity of people with most types of disability.
- Social change in particular around the roles and expectations of women who undertake the majority of informal care and
- Economic factors such as the link between care giving and economic disadvantage particularly for women. They have not had access to appropriate support to allow their workforce participation. We noted the decrease in housing affordability and the potential impact of this on people with a disability and on their families. An increased supply of community and public housing provision would be necessary.

In particular our submission noted increased evidence of the negative impact that care giving may have on carer health (physical and mental) and well being.

\(^1\) Carers Victoria (2009) Community living for the twenty first century; a blue print for caring families
Unmet need for a variety of services and supports for people with a disability and their families was discussed, as well as the economic and social costs of crisis driven and rationed services.

Changes to the policy environment

The last 2 years have seen some highly significant developments in political and policy reform.

Firstly, the Victorian Coalition Government released election platforms\(^2\) which challenged the previous government’s performance in the social policy arena. They also committed to some improvements and investments for people with a disability and their families. This included a reinvigorated focus on the needs of caring families in housing, support and respite and a broad based approach to investment in the mental health sector.

Secondly, there is an environment of highly significant national reforms. The Productivity Commission\(^3\) recently released its final reports on the Care of Older Australians, and its report on Disability Care and Support. The latter recommended a National Long Term Disability Insurance Scheme (NDIS) and a federated and harmonized no fault National Injury Insurance Scheme (NIIS). The National Disability Insurance Scheme and the National Injury Insurance Scheme have received bi-partisan support at the Commonwealth Government level as well as enthusiastic support and commitment from the State Government. Carers Victoria believes that reforms to these service systems have the potential to transform the lives of people with a disability, and also their families.

Looking to the future

As a consequence of the agreement of the Council of Australian Governments on National Health, Hospitals and Aged Care Reforms\(^5\), aged care investment will continue to be funded at the Commonwealth Government level. On the other hand, a National Disability Insurance Scheme and a federated National Injury Insurance Scheme will have profound ramifications for the funding and governance of disability, mental health and mainstream services which are currently the responsibility of the Victorian Government. The implications of the proposed disability reforms are far reaching; this pre budget submission includes an exploration of the reform contexts and the opportunities and risks they provide.

\(^2\) The Victorian Liberal Nationals Coalition plan for Community Services (2010), the Victorian Liberal Nationals Coalition plan for Carers (2010) and the Victorian Liberal Nationals Coalition plan for Mental Health (2010)


\(^5\) Council of Australian Governments (2011) National Hospitals Health and Aged Care Reforms
In particular, this document will provide a detailed analysis of how the Productivity Commission’s report into Disability Care and Support might be furthered in a Victorian context. It will highlight the role the state government can play in bridging a shift from state to commonwealth control and in contributing to the development of new and successful schemes for delivery of services.

The Victorian Liberal/ National Government needs to:

• Build the capacity of the disability service system to ensure that Victoria is NDIS ready.
• Respond to the needs of caring families that are too urgent to wait until an NDIS is trialed and implemented. This includes proposals to meet the urgent concerns of ageing parent carers and people with a disability or significant mental illness.
• Invest in services to complement an NDIS and provide coverage of those areas not directly addressed by the proposed scheme.

The Coalition Government’s pre election platform included some of the necessary commitments to address these systemic needs.

1. Getting Victoria ready for a National Disability Insurance Scheme and a National Injury Insurance Scheme

1.1 Government commitments to date

The Victorian Liberal/ National Coalition Government has taken a significant role in advocating for fundamental change in the disability and carer support system through its policy platforms for the 2010 state Election. These acknowledge:

• That services for people with a disability and their families are under resourced and fragmented, especially regarding access to housing and support, and respite access.
• The needs of families for support with ‘whole of life’ planning for the future.
• Concern about the poor levels of health, and wellbeing of family carers and their higher rates of disability and chronic illness.
• Concern about long and meaningless waiting lists for services where demand continues to massively outstrip supply.
• The need for improved intra and inter departmental planning.
The Victorian Coalition Government has committed to drive major long term disability reform through the establishment of a National Disability Insurance Scheme (NDIS) and a harmonised National Injury Insurance Scheme.

A commitment to the NDIS was included in the Coalition Plan for Community Services 2010.

✓ A Victorian NDIS Taskforce was established and resourced in 2011.
✓ A commitment was made to pilot an NDIS in Victoria.
✓ National Disability Services Victoria has been funded to develop a comprehensive 5 year transition plan for the Disability Services System in Victoria.
✓ KPMG has been contracted to work on a client pathway for access to future disability services⁶.
✓ Minister Wooldridge will participate on the Select Council of Treasurer’s and Disability Services Ministers to drive reform of Disability Care and Support including accelerating and finalising the development of:
  o common eligibility assessment tools
  o national services quality standards
  o a national workforce strategy
  o legislation, funding and governance arrangements for an NDIS and NIIS.

✓ Funding for growth in innovative housing and support services and respite services were committed in the 2011-2 Victorian Budget and are currently open for expressions of interest, in coordination with the Commonwealth Supported Accommodation Innovation Fund⁷.

1.2 Future investment needed to get Victoria ‘NDIS ready’.

Government actions that are urgently required include:

1.2.1 Analysis and planning concerning access to respite and family support services.

The Productivity Commission Report on Disability Care and Support pays insufficient attention to exploring the adequacy, complexity, fragmentation and cost effectiveness of the current services delivery system which supports caring families. This includes the Home and Community Care Program, state funded Specialist Disability Services, state funded Support for Carers Programs, the National Respite for Carers Programs and the National Mental Health Respite Program.

⁶ KPMG (2011) A new vision for the client experience of disability services (in process)
⁷ Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), website.
In addition there are inconsistent recommendations about carer support services between the two Productivity Commission reports on Disability Care and Support and the Care of Older Australians. Potential cost offsets for the NDIS from existing Commonwealth, State and Territory carer respite and support programs are unexplored.

**Carers Victoria recommends** that the Victorian Government continues its work to contribute to reforms in disability care and support by:

- Advocating for a broad national mapping of existing disability and psychiatric disability family respite and support programs; their eligibility policies, funding sources and levels and their services delivery capacity.
- Advocating concerning the development of a framework for the design of future carer respite and support programs within or alongside an NDIS. This should consider eligibility assessment tools, access pathways, support entitlement and efficient models of services delivery.

1.2.2 Exploring means for improved inclusion of family support into a harmonised National Injury Insurance Scheme

Currently national injury insurance schemes within Australia and New Zealand are largely person centred rather than person centred and family focused. They have a limited focus on family support needs even though informal family care is often the backbone of support provided to people who acquire a disability. In the future, the design of national no fault injury insurance schemes must address the needs of caring family members - for information, respite, in home support or assistance, emotional support and counselling. This will require work to assess the need and eligibility of caring families, the development of systems for support entitlements for some families, and processes to incorporate the needs of caring family members in quality standards, quality assurance processes and in monitoring the outcomes of service interventions.

**Carers Victoria recommends** that the development of a federated National Injury Insurance Scheme includes the assessment of family support needs, and allocation of support entitlements for high needs families. Family inclusive quality standards and outcome monitoring processes are also required.
1.2.3. Ensuring the development of adequate independent individual and systemic advocacy programs for caring families alongside an NDIS.

The Productivity Commission report on Disability Care and Support recommends that individual and systemic advocacy programs are funded separately to an NDIS. Advocacy programs funded under the National Disability Agreement or via the states and territories should be retained alongside NDIS. This shows inadequate awareness that caring families also need systemic and individual advocacy. Commonwealth funded disability advocacy agencies in general do not address the advocacy needs of families. Individual and systemic advocacy for people with a disability and for their families are highly rationed and inadequately funded.

Families feel frustrated that while they provide vast majority of care and accommodation for vulnerable Victorians they have no funded advocates to support their issues with and access to services.

The empowerment model of individualised funding proposed by the Productivity Commission should be accompanied by individual and systemic advocacy to ensure a collective voice for people with a disability and their families. Empowering individuals and families to have choice as consumers of services is only one component of progressing towards empowerment as full citizens. There is also a need for people with a disability or psychiatric disability and their families to have a collective voice in relation to the NDIS, the NIIS and mainstream services providers. They need opportunities to provide feedback to Ministers and Governments concerning the adequacy, accessibility, affordability and quality of both specialist disability and mainstream services. Without ‘voice’, the promotion of ‘choice’ can result in an unintended dilution of power or even an undermining of collective gains. This means sustainable financial support to ensure the development of systemic and individual advocacy by statewide peak bodies both in the disability and mental health sectors.

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Carers Victoria recommends:

That the Victorian Government strengthens its investment into individual advocacy support programs for families of people with a disability or psychiatric disability. Phased in recurrent investment in an individual advocacy program over 4 years is required.

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1.2.4 Guardianship, administration and representation of people with decision making disabilities.

The Productivity Commission report on Disability Care and Support acknowledges that ‘where a person is unable to make their own decisions, court appointed family members or guardians should be appointed to assist them with decision making, taking into account the wishes of the person with a disability’. This is seen as enabling families to act as the agent of the person with a disability in the management of self directed funding. The economic environment in which services are provided in Australia is increasingly risk averse. Institutions, such as banks and power companies, increasingly want to do business with a legally appointed administrator. However the Guardianship and Administration Act 1986 established guardianship and administration as protective rather than enabling mechanisms.

Parents experience many difficulties in relation to the representation of and management of the affairs of their offspring. Their authority is often challenged; access to court appointment as a Guardian is extremely difficult, and the appointment of family members as Administrators is difficult and can be an onerous obligation when assets are small. There is as yet no mechanism to allow advance appointments of family members as guardians or administrators prior to parent death or incapacity. The decision about ongoing representation is made by VCAT with some regard to wishes expressed in the parent’s Will. This provides insufficient reassurance to people with a disability or to their families that the future is secure.

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1 Carers Victoria notes the underfunding of individual family advocacy in the mental health sector (Note ARAFEMI(2011) Someone to walk alongside us) and the under resourced system of Carer Consultants in the clinical and PDRSS sector. There is no significant Victorian advocacy service for families of adults with a disability.


The Victorian Coalition Government made a commitment in its election platform to:

- Strengthen the role of family members in caring for persons not capable of managing their own affairs, for example, by creating a presumption in favour of appointment of an appropriate family member or members rather than the Public Advocate and/or State Trustees.
- Support family members being able to nominate those responsible for care of their children with disabilities after the family member’s death.

The Victorian Law Reform Commission (VLRC) will present its Final Report on Reform of the Guardianship Act to the Attorney General on 23 December 2011. Our participation in the review process gives us confidence that the VLRC will recommend that the new Act strengthen the recognition of family members who have provided lifetime care and support to adults who have never had capacity. Key to this will be the provision of principles and a legal framework to ensure appropriate family representation mechanisms including supported and co decision making.

Consistent with the view of the Government Carers Victoria strongly recommends that the new Guardianship and Administration Act supports parents being able to nominate those responsible for the care of their son or daughter with a disability after the death or illness of the parent.

The successful introduction of supported decision making in Victoria will hinge upon the development of improved practices of partnership between families, friends and services providers. It requires a culture that is both person centred and family focused and which recognises and respects the reality of interdependence between people with a decision making disability and their families. Education and resources for people with a disability, their families and services providers will be required concerning the practices of supported and co decision making as well as substitute decision making. These may draw on the work of Scope, the South Australian Public Advocate and other practice experts. A new practice manual for caring families and friends should replace Securing their Future.

The development education programs and resources for people with a disability, their families and services providers will need to be followed in future years by significant ongoing funding to support building practice capacity in the sector.

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12 Office of the Public Advocate (SA) 2011 Developing a Model of Practice: Supported Decision making.
13 Office of the Public Advocate (Vic) and Victorian Legal Aid (2010) Securing their Future
Carers Victoria recommends:

- That the new Guardianship and Administration Act supports parents being able to nominate those responsible for the care of their son or daughter with a disability immediately after the death or illness of the parent.²
- The development of a suite of educational materials and resources for families and services providers to support the new Guardianship and Administration Act. Funding of an interagency working group to initially develop tools and resources requires a non-recurrent commitment of $1 Million.
- Fundamental reforms to VCAT proceedings to ensure that they are welcoming of and accessible to, adults with impaired capacity who need support to communicate their wishes and preferences, and to the families who support them.

1.2.5 Improved data capture about people with a disability and their families.

Carers Victoria has argued strongly in past years for the Victorian Government to develop a comprehensive disability and mental health housing strategy¹. This requires the development and resourcing of systems to collect comprehensive data to inform policy and planning in relation to housing and support needs. The NDIS will aim to progressively collect and improve longitudinal population data concerning people with a disability and their families. In the interim the Victorian Government can ensure the collection of improved data about unmet, under met and projected need for housing and support services for people with intellectual, physical, sensory or psychiatric disability who have significantly reduced functioning. It should include data concerning the capacity of families to contribute housing capital and to contribute to ongoing psychosocial support. Action by the Victorian Government can include:

- Raising sector awareness about the importance of improved data collection for future planning through generating improved data for the Victorian NDA Minimum Data Set.
- The development of a register of ageing parent carers and their offspring, including data about the family’s current and projected housing and support needs, family structure, health and well being, financial circumstances and access to support services. This needs to be accompanied by outreach services and regular monitoring of the care situation which can quickly change. It is anticipated that the number of ageing parents of people with an intellectual or significant
psychiatric disability who reach crisis point will accelerate in coming years; the cohort will be
given priority in a NDIS\textsuperscript{14}.

- Extending data collection about family needs and circumstances to include National Disability
  Agreement funded open and supported employment services. These services are currently not
  required to collect information on informal or primary care or living arrangements. However
  participants’ number close to 30\% of NDA funded services users in Victoria\textsuperscript{15}. While it is likely
  that a minority of participants in employment services live alone or in cared accommodation\textsuperscript{16},
  the majority are likely to continue to live with their family. Because the median age of users of
  employment services is 38 years\textsuperscript{17} it is likely that some caring families may be elderly. Family
  needs, circumstances and preferences for the future care and support of participants are
  unknown. Many may need access to housing and support and opportunities for community
  participation.

Most current users of NDA funded open and supported employment are likely to be eligible for care and
support through an NDIS. Examination of available data\textsuperscript{18} indicates that 54\% of people accessing NDA
employment services (open and supported) need assistance with Activities of Daily Living; and 29.2\%
require support with Activities of Independent Living (AIDL) or activities of Working, Education or
Community living (AWEC). The largest group have a psychiatric disability. Only 16\% of current
participants in employment programs did not report a need for assistance in major life areas.

\begin{quote}
\textbf{Carers Victoria recommends} that the Victorian Government:

- Invest in and oversee the development of a register of ageing parent carers in Victoria.
- Invest in a data collection and consultation process about the needs and circumstances of
  Victorian participants in NDA employment services and their families. This should include their
  current and projected housing and support needs.
- Invest in a project to consult with and collect data about the needs, circumstances and
  preferences of older parents of people with significant psychiatric disabilities. Nationally there
  has been no significant applied research in this area. Such a project would ensure the provision
  of informed advice to the Victorian government and a National Disability Insurance Scheme
  concerning the current and future needs of this cohort.
\end{quote}

\textsuperscript{14} Productivity Commission (2011) Disability Care and Support, recommendation 7.7
\textsuperscript{15} Productivity Commission (2011) Report on Government Services (2009-10) Table 2.5
\textsuperscript{17} AIHW (2011) Report on NDA MDS 2009-10 Table 3.7
2. Matters of the utmost urgency

2.1 Investment in housing and support for ageing parents

The highest priority for investment by the Victorian Government is in ‘planning, choosing and implementing a positive future: transition and succession planning for older parents and their son or daughter.’\(^{19}\) A bottom-up, pre-emptive model is needed to empower people with a disability and their families to plan together for the future when parents can no longer care.

Many ageing parents find futures planning a complex, difficult and multifaceted task. While a number of excellent programs exist in Australia\(^19\) in general they are not comprehensive in their scope and not inclusive of all the planning and support components that may be required. In particular existing ‘futures’ programs lack access to resources to enable families to plan and implement housing and support arrangements for the person with a disability outside the family home. Futures’ planning is constrained by the current crisis driven approach to the allocation of housing and support resources. It is largely reactive, not proactive.

Succession and transition planning requires interconnected and coordinated components.

- Support with psychosocial planning for the future. This includes supporting broad family discussions of future needs and roles; decision making about preferred future housing and support arrangements (where and with whom the person with a disability may choose to live); exploring how this may be achieved; planning ongoing social and emotional support and emergency care planning.
- Support with Legal and Financial planning, including Wills and estate planning; special disability or family trusts; testamentary trusts; family agreements, contracts for family property management; and planning ongoing representation arrangements for the person with a disability.
- ‘Transition ready’ people with a disability and their families need access to local social housing properties and/or a pool of housing capital for spot purchase, pre-construction purchase; and mixed equity purchase, managed through a Community Housing Organisation. Choice concerning where, in what sort of housing and with whom a person with a disability may live cannot be constrained by the need to register on the Disability Support Register. In addition, families in a position to do so may make a direct housing purchase or contribution to a mixed equity arrangement for their offspring.

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\(^{19}\) Senate Community Affairs References Committee (2011) Disability and Ageing: lifelong planning for a better future.
• Guaranteed synchronised access to a pool of recurrent funds for staff support for individual, couple or other shared housing arrangements. These may include staff supported living arrangements, sleep over support, drop in support and assistance, living nearby support, lead tenant and home share arrangements, based on assessed individual needs. This component would be managed by a disability support services provider.

• Explicit arrangements for combining formal and informal care and for ensuring social support.

Government investment in this initiative will require the development or consolidation of partnerships between providers at a regional/ local level, the appointment of skilled program coordinators and the development and training of part time disability sensitive legal consultants, locally based in Community Legal Centres. Detailed planning processes between the Disability Services Branch and partner organisations would finalise a project brief, and determine reporting and accountability requirements. It is noted that the development of pre-emptive housing and support arrangements on the basis of choice must not be constrained by the crisis driven Disability Support Register mechanism.

Families who are ‘transition ready’ would be offered active and empowering support with the transition of their son or daughter to alternative care. The project would progressively support these families to plan, develop, implement and support transitions into care outside the family home. Principles of person and family centred care, consumer and family choice, empowerment and supported planning processes would govern program operation.

Currently the number of parents aged over 65 who are primary carers still living with their son or daughter with a disability in Victoria is estimated to be 3,200. A further estimated 1,025 continue to care for and about their son or daughter who lives elsewhere. There has been a significant growth in the numbers of ageing parents between SDAC 2003 and 2009. Their characteristics include low household income, extended periods of care giving and a significant percentage of parents who have disabilities themselves. Little public data is available about their marital status (although the number of sole older parents increases with age) or their access to formal and informal support. Grounded knowledge suggests that many are single and care alone.

A significant proportion of older parents will need access to a range of different models of formal housing and support arrangements for their son or daughter, from outreach support to 24 hour care. The current gap between demand and supply of supported accommodation options and individual

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support packages means for the majority, choice will not be available and crisis solutions will be necessary.

**Carers Victoria recommends:**

That the Victorian Government makes a priority investment into the development of three coordinated regional transition and succession planning programs for older parents of people with a lifelong disability. These should commence operation in 2012.

**Total estimated costs**

<table>
<thead>
<tr>
<th>Item</th>
<th>2012-3</th>
<th>2013-4</th>
<th>2014-5</th>
<th>2015-6</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing Capital (60 places @ $500,000)</td>
<td>$10 million</td>
<td>$10 million</td>
<td>$10 million</td>
<td>$10 million</td>
<td>$30 million</td>
</tr>
<tr>
<td>Home modifications</td>
<td>$0.12m</td>
<td>$0.12m</td>
<td>$0.15m</td>
<td>$0.39m</td>
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</tr>
<tr>
<td>ISP’s - housing support (30 places/year)</td>
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<td>$1.988m</td>
<td>$2.997m</td>
<td>$5.984m</td>
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</tr>
<tr>
<td>Legal practitioner/ support with futures planning – salary and operating costs 15 hours/ week in 3 regions</td>
<td>$0.20m</td>
<td>$0.20m</td>
<td>$0.20m</td>
<td>$0.80m</td>
<td></td>
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<tr>
<td>Back up consultation and training for legal practitioners</td>
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<td>$0.05m</td>
<td>$0.05m</td>
<td>$0.05m</td>
<td>$0.20m</td>
</tr>
<tr>
<td>Program coordination</td>
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<td>$0.36m</td>
<td>$0.36m</td>
<td>$0.37m</td>
<td>$1.48 m</td>
</tr>
<tr>
<td>Totals</td>
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<td>$11.729</td>
<td>$12.718m</td>
<td>$13.767m</td>
<td>$38.854m</td>
</tr>
</tbody>
</table>

Outcomes will include:

- The planning, development and implementation of individually tailored community housing and support arrangements, based on choice, for up to 80 people with a disability and their ageing parents.
- Clarifying arrangements for the ongoing representation and support of the person with a disability who moves to community housing.
- The provision of improved, coordinated futures planning support for 100 additional families, leading to increased satisfaction and reduced anxiety among people with a disability and their families.
- The development and promotion of practice guidelines on futures and transition planning.
- Increased family and community awareness of possible housing and support options.
2.2 Complementing an NDIS: Investment in Housing

2.2.1 Housing for people with a mental illness and/or a disability

The Productivity Commission’s Report into Disability Care and Support acknowledges the importance of suitable accommodation for people with a disability. The report quotes Carers Australia’s submission that “Lack of access to suitable, stable and affordable housing consistently ranks as one of the biggest challenges for people with a disability”.

Access to affordable housing also rates as one of the biggest challenges or risks to the proposed National Disability Insurance Scheme’s success. The scheme aims to ensure through sustainable funding for lifelong care and support, that people with a disability achieve improved social, community and workforce participation. At the same time, it is well documented that poor housing undermines the possibility of people with a disability (including psychiatric disability) achieving these outcomes.

The Productivity Commission draws a distinction between those people with a disability who require specialist supported accommodation and those who can, and should, access mainstream housing. This distinction reflects the current one in which supported accommodation is provided through the National Disability Agreement (NDA) and mainstream social housing is provided through the National Affordable Housing Agreement (NAHA), or private rental (with the possible eligibility for Commonwealth Rental Assistance), or private ownership. However, the Productivity Commission proposes that NDIS supported accommodation packages would factor in the cost of capital as a way of ensuring that needed facilities are built.

Carers Victoria makes a number of key points concerning housing access which are highly relevant to the Victorian Government:

Although the demand for supported accommodation will increase after the introduction of an NDIS, many eligible people in Tier 3 of the scheme will continue to need mainstream housing as will many of those in Tiers 1 and 2. If the scheme is successful in empowering people with a disability with increased choices about their lives, more people will aspire to housing and living independently of their families. This will result in an increased but currently unquantified demand for affordable and suitable housing.

Increased demand will also be impacted by demographic, social and economic trends. As the population ages, the incidence of disability increases. People with a disability often experience multiple challenges.

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disadvantages when seeking appropriate housing. They have much lower incomes than the general population due to lower rates of workforce participation or employment in jobs offering lower wages\textsuperscript{21}. These circumstances may continue for long or indefinite periods. As a result, people with a disability are greatly over represented in the lowest income quintile, as are carers\textsuperscript{22}.

The most commonly quoted barriers to housing for people with a disability are issues of physical access. However, lack of access because of inaffordability is very profound and affects a large proportion of the population of people with a disability. They have been disproportionately affected by progressive increases in the price of housing and the increased rationing of social housing both in relation to rental or purchase.

Housing affordability also impacts on caring families. A landmark report by AHURI demonstrated that in past decades families affected by disability had prioritised the purchase of housing in order to safeguard the future of their family member\textsuperscript{23}. The shortage of affordable housing combined with lower rates of workforce participation by carers means that housing purchase has become increasingly difficult for them to attain. Younger cohorts of family carers now have lower levels of home ownership than other Australians of the same age.

\subsection*{2.2.2 Housing supply problems for people with a disability or a mental illness.}

As documented by the Australian Housing Supply Council\textsuperscript{24}, there is a projected gap of 308,000 dwellings between demand and supply in Australia over the five years to 2014. The extent of this problem makes housing an issue affecting many different population groups with different needs.

Research done by AHURI\textsuperscript{25} has shown that housing shortages affect those in the lower income quintiles most severely. There is a 211,000 shortfall of private rental dwellings that are affordable to people from the bottom quintile. This problem is exacerbated by the fact that 73,000 potentially affordable dwellings for this cohort are taken by people from higher income quintiles.

When economic drivers are combined with community discrimination, the housing market comprehensively and systematically fails people with a disability or a mental illness.

\textsuperscript{22} Australian Bureau of Statistics (ABS) 2009, Survey of Disability, Ageing and Carers
\textsuperscript{24} National Housing Supply Council (2010), 2\textsuperscript{nd} State of Supply Report
\textsuperscript{25} Wulff et al (2011), How great is the shortage of affordable housing in Australia’s private rental market? AHURI Research and Policy Bulletin Issue 144
These barriers will continue even when the disability support system is reformed if current policy remains in place. People with a disability will be left vulnerable to inappropriate accommodation such as rooming houses and caravan parks or will be forced to stay in the family home into adulthood in spite of wanting to live independently.

2.2.3 How big is the problem?

Carers Victoria’s last pre budget bid emphasised the necessity to collect data about the present and projected housing need for people with a disability and/or a mental illness on a population basis. This aimed for informed long term planning and housing investment by the Victorian Government.

The current instruments in use to measure housing demand such as public housing waiting lists and the Disability Support Register are unable to identify the broad and heterogeneous range of housing needs and preferences of people with a disability and their caring families. People with a disability and/or a mental illness need housing assistance through a range of housing and support models and tenure types. Current data is unable to identify key issues such as the levels of income and assets of those needing housing assistance. The previous studies undertaken to do this have produced inconsistent findings\textsuperscript{26} 27.

2.2.4 Improving the access of people with a disability to housing

The economic and social imperatives for addressing housing supply issues in Victoria are inescapable.

The Victorian Government has the opportunity to influence the housing market and its affordability through its Stamp Duty and Land Tax settings. Although this level of housing economics is clearly beyond the expertise and remit of Carers Victoria, we are aware that modeling and analysis done by Gavin Wood of RMIT and AHURI has resulted in a set of detailed recommendations on this subject\textsuperscript{28}.

People with a disability and/or a mental health problem who have negligible assets and income, and have families who cannot subsidise their housing, require scaled up investment in social housing. This is needed both now and as a necessary companion to a future National Disability Insurance Scheme. The Commonwealth Government’s recent investment in social housing through the Nation Building Program and Jobs plan has been spent. It is hoped that the Commonwealth will continue to invest significantly in social housing.

\textsuperscript{26} Allen Consulting Group (2008) Development of a Model(s) for families and Individuals
\textsuperscript{27} Pinnegar et al (2008), Innovative financing for home ownership: the potential for shared equity initiatives in Australia, AHURI
\textsuperscript{28} Wood, G. (2011) Improving Housing Affordability through Tax reform
However, the additional Commonwealth funding required to set up an NDIS may result in an expectation that social housing growth for people with a disability is funded by state governments. Because of the scale and impact of the shortage of housing and support and the usual lag in investing, planning and building bricks and mortar, Carers Victoria urges the Victorian Government to address these issues immediately.

**Carers Victoria recommends:**

That the Victorian Government maintains the momentum generated by the Nation Building funding by providing sustained and planned investment in social housing.

Housing problems extend to access issues as well as supply. Support for access to housing by people with a disability and/or mental illness is needed across the whole range of tenure types.

These include:

**2.2.4.1 Private rental**

- The Government’s investment in housing and support for people with a mental illness through Mental Illness Fellowship’s Opening Doors project is welcomed. Its evaluation should include exploring broad systemic issues to provide information about the long term financial viability of the scheme and its potential for future scaling up. The scheme is most likely to succeed if the program participants achieve employment in jobs which can cover the cost of private rental. People with prolonged psychiatric disability can recover, given housing and support, but are likely to work part time. Thus the monitoring of the rationale and practices of resident selection for the program will be important. In addition, consideration of factors between geographical area’s and average market rents will be needed. It may be that this scheme will be most successful in the long term in geographical areas of lower market rents and for housing people with less severe and protracted psychiatric disability.

- The National Rental Affordability Scheme (NRAS), a State-Commonwealth funding collaboration designed to reimburse landlords in return for providing housing with below market rents, has great potential to assist people with a disability and their caring families. However, available data limits the extent to which their access to it can be monitored. Comparative data about the extent to which benefits have been gained by people with a disability or mental illness with the lowest incomes is unavailable. A recently updated research project by Wulff et al recommended that NRAS should continue to be expanded but increasingly targeted to those on lowest incomes.\(^{25}\)
The Commonwealth Rent Assistance (CRA) program provides a supplement to assist individuals with their rental costs. Currently, the amount of CRA provided is uniform across the country regardless of the considerable geographical variations in rent prices that exist. Furthermore, CRA is insufficient to allow people on very low incomes to afford suitable housing in the private rental market. There is broad consensus amongst advocates, governments and economists that changes are needed to the design, quantum and targeting of the program.

**Carers Victoria recommends:**
That the Victorian Government continues its commitment to the funding of the National Rental Affordability Scheme while improving the scheme’s targeting to those on very low incomes.

**Carers Victoria recommends:**
That the Victorian Government take every possible opportunity to support reforms to Commonwealth Rent Assistance such as those outlined in the Henry Taxation Review.¹

### 2.2.4.2 Home ownership

- The Victorian Government can consider stamp duty concessions on new home purchases by families of people with a disability particularly parents who need to purchase a new home because of separation from a partner (an all too common experience of families with a child with a disability). They are ineligible for stamp duty concessions. There is inequity between carers who are reliant on income security payments and aged care pensioners and self funded retirees.

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¹ Australia’s Future Tax System (2010)

Recommendation 102: The maximum rate of Rent Assistance should be increased to assist renters to afford an adequate standard of dwelling. To ensure that Rent Assistance can be maintained at an adequate level over time, the rent maximum should be indexed by movements in national rents, which could be measured by an index of rents paid by income support recipients.

Recommendation 103: To better target an increase in the maximum rate, Rent Assistance should be part of the income support system, with eligibility based on rent paid and the income support means test, rather than on eligibility for another payment (for example, Family Assistance).
Mixed equity housing schemes have untapped potential for caring families. A current scheme, delivered through Housing Choices Australia, allows people with a disability and/or a mental illness to access stable and affordable housing even if they have over $30,000 in assets. The only alternative housing option for them is often private rental because their assets are either too great and exclude them from subsidised housing or too small to allow private ownership. This mixed equity model also provides greater choice, tenancy support and management and liaises closely with support agencies, all of which are of great importance to people with a disability and their families. Although reliable data is again scarce, it is probable that there would be sufficient demand if the program was expanded.

Carers Victoria recommends:
That the Housing Choices Mixed Equity Housing Program be funded to expand by providing a minimum of 30 dwellings over the next 3 years.

2.2.4.3 Social housing (public and community housing)

Many people with a disability and/or mental illness will need social housing because they lack income and assets and need long term security of tenure. For the most vulnerable, transitional housing models are unrealistic and ineffective.

The Nation Building and Jobs Plan provided a much needed injection to the social housing sector, but the extent of allocation of new properties to people with a disability and/or a mental illness is unclear. A complex combination of Commonwealth targeting policies, discrepancies between Commonwealth and State definitions of disability, conflicting housing policy aims and business imperatives for Housing Associations meant that although some people with a disability and/or mental illness have undoubtedly benefited, this occurred through compromise and good will rather than clear policy direction.

Carers Victoria notes the targeted and allocated funding for housing for people with a disability and people with a mental illness undertaken by the Western Australian Liberal/National Coalition government29. This should be a key component of a new Victorian Housing Strategy.

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29 Western Australia 2011-12 Budget Papers, p.702
Carers Victoria recommends:

- That the Victorian Government provides clearly targeted funding for social housing for people with a disability and/or a mental illness based on population needs.
- That the Victorian Government audits the extent of access of people with a disability or mental illness to public housing as highlighted in the Coalition’s election platform.\(^2\) This should extend to include community housing.

The Victorian Auditor General’s report on Access to Social Housing\(^{30}\) highlighted that the provision of housing for people with a disability and/or mental illness can create financial viability issues for community housing providers. This applies particularly if potential tenants are single and on a statutory income.

Carers Victoria recommends:

- That the Victorian Government provides, or lobbies for 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\(^{31}\)
- The Victorian Government should set clearer targets for Housing Associations to provide housing for people with a disability and/or mental illness.

It was mentioned earlier in this section that success of a new NDIS could be threatened by a lack of housing to accompany the support of people with a disability. For this reason, there is a need to reconsider eligibility criteria and access processes for housing assistance programs such as public and community housing. They need to harmonise with the new scheme and allow those people with a disability to live independently in the community if they wish. This would involve the adopting of common definitions and assessments of disability and broadening eligibility criteria.

3. Young people with caring responsibilities

Studies show that young people under the age of 25 years who have caring responsibilities have poorer education, workforce participation, social participation, health and wellbeing than their age peers who do not have caring responsibilities.

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\(^{30}\) Victorian Auditor-General (2010) Access to Social Housing

\(^{31}\) Australian Treasury (2010), Australian Future Tax System. Recommendation 105
In 2010, Carers Victoria made a presentation to the Victorian Inter-Departmental Committee for Youth about the needs of young people with caring responsibilities. It argued that the negative impacts of caring for young people can only be meaningfully addressed through the use of a systemic approach. Although the Commonwealth Government funds a dedicated Young Carer Respite Program through FaHCSIA, the small scale of the program and its position in the service system mean that its systemic impact is constrained.

There are an estimated 73,500 young people in Victoria who have caring responsibilities. This figure is a large underestimate; because of survey methodology and the strong tendency for young people not to identify with the carer terminology, many young people with caring responsibilities remain “hidden” from research. Recent work conducted by the Social Policy Research Centre (SPRC) developed a proxy identification method and discovered that if all potential young carers were included, figures would almost double. This would mean that there are as many as 150,000 young people with caring responsibilities in Victoria.

Young people with caring responsibilities are also often hidden in the service system for a number of complex reasons. They may mistrust service providers, experience stigma or shame, not know about services, have normalized their caring role or be anxious about intervention into their family because of fears about child protection. A recent report produced by Carers Victoria, the Centre for Multicultural Youth and the Ethnic Communities Council found that young people with caring responsibilities who are from migrant or refugee backgrounds may be even more likely to be hidden from services.

Evidence suggests that young people who live in families who do not receive support from formal services are in turn the least likely to seek help. These hidden young carers may well be those with the greatest caring responsibilities and associated negative impacts. Young people with parents with a mental illness or drug and alcohol problem may encounter particular problems because of the stigmatised nature of their parent’s condition. This may increase their need for support.

The FaHCSIA Young Carer Respite Program is funded at about $8million a year nationally. This means that it can only support a fraction of the possible population of young carers and is extremely rationed. The program is not ideally positioned to work with hidden young carers because the services are located within Commonwealth funded Carer Respite Services. They are largely separate from state delivered services for people with a disability, mental illness or drug and alcohol dependence who

34 Carers Victoria, Centre for Multicultural Youth, Ethnic Communities’ Council of Victoria (2011). Refugee and Migrant Young people with Caring Responsibilities: What do we know? Background paper and sector consultation report
rarely identify the needs of young people with caring responsibilities. Young people who identify with the term “young carer” are those who access the service. They are also those who are most likely to already receive family and formal supports.

Improvements in the broader service system are needed to better identify young people with caring responsibilities who need support and assistance. This means enhancing the capacity of education, health, mental health, disability, drug and alcohol, youth and family services to identify and respond to young people with care responsibilities rather than placing the burden of identification and help seeking on young people themselves.

A National Disability Insurance Scheme would improve opportunities and outcomes for some young people with care responsibilities by providing the support and care that their family member needs. A family focused approach to services is necessary. Assessment tools and the skills and attitude of assessors need to “consider what reasonably and willingly be provided by unpaid family carers” (Recommendation 7.2)

Systemic reforms to improve the interfaces between state funded services are necessary whether an NDIS occurs or not.

**Carers Victoria recommends:**

- That the Victorian Government establishes and resources an interagency steering committee on young people with care responsibilities to shape and drive systemic improvements. Membership should include representation from education, employment support, health, youth, disability, mental health, drug and alcohol, and family support services from Victorian and Commonwealth governments in addition to carer representation.
- That the Victorian Government funds the roll out of the successful Families of Parents with a Mental Illness program (FaPMI) across all Victorian regions. It demonstrates that a systemic, family and child focused service can be designed and developed to respond to the needs of all family members in the existing mental health service system including young people and their parents.
- That the Victorian Government carefully considers the findings and insights of the recent evaluation report of FaPMI with a view to the translation of elements to other parts of the service system such as the disability and family support sectors. Some caution should be used in recognition that different sectors have their own unique challenges, characteristics and cultures.
4. Carers and employment

Carers experience different patterns and levels of workforce participation than the general population. They are less likely to work full time, are over represented in the bottom quintiles of income and more likely to experience financial hardship. Some carers take on paid work at a lower level of responsibility or skill to accommodate their caregiving. They may sacrifice their careers. Others feel unable to continue any paid employment at all.

Paid employment not only provides financial benefits for the family, but also social and community participation and a “respite effect”. The costs of not participating in the workforce are borne by carers themselves and their family members. They also impact significantly on the economy. The Productivity Commission’s most recent report included modeling which showed that, even if only a small proportion of carers were able to re enter the workforce or increase their hours of paid work, this would result in an increase of $1.5 billion per annum to the Gross National Product.

The tenuous attachment of some carers to the workforce is sensitive to several different factors, which in turn cut across different levels of government and their departments. This makes policy development in this area complex.

A well developed body of evidence shows that carers need the following:

- Workplace supports: employment support, training, legislation to support flexible work conditions and employer education
- An income support system that supports smooth transitions in and out of the workforce and encourages the balancing of caring and paid employment
- Access to alternative care arrangements

For many carers, all three of these domains are essential. Like the legs of a stool, if one component is unavailable, then meaningful workforce participation cannot occur.

37 Taskforce on Care Costs (2007): The hidden face of care: combining work and caring responsibilities for the aged and people with a disability, Taskforce on Care Costs (TOCC),
38 Productivity Commission (2011) Disability Care and Support, Final Inquiry Report, Pages 966-970
It is recognised that the area of workplace supports sits largely with the Commonwealth. Employment support and training services are largely administered through DEEWR. States and territories may contribute and it was noted that the Victorian Returning to Earning Grants for carers was allowed to slip away.

Carers need the right to request flexible work. This is ensured for some under the banner of the Fair Work Act and its National Employment Standards but is insufficiently inclusive. The Victorian Equal Opportunities (Family Amendment) Act 2008 also has its part to play. Both pieces of legislation need to be followed with detailed evaluation to determine their take up, employer responses and impacts on people with caring responsibilities.

**Carers Victoria recommends:**
That the Victorian Government conducts an evaluation of the Victorian Equal Opportunities (Family Amendment) Act 2008. This should investigate the impacts of the amendment including the extent to which it has been used, by whom, in what circumstances, and the range of short and long term outcomes for employees and employers.

Income support is largely a Commonwealth responsibility. Carers Victoria will continue to work closely with Carers Australia and other national partners to advocate in this domain. Recent discussions about tax transfer payment reform have provided some opportunities here. It is in the area of providing alternative care that the Victorian government has the most opportunity to make a real difference. A study conducted by Carers Victoria in 2010, “Ways to Work” emphasised the needs of parents of adults with decision making disabilities for support to ensure their workforce participation. Currently, many parents of adults with a disability would like to re-enter paid employment, but cannot because care services for their family member do not provide enough hours of care in the working day to make this a realistic proposition. The problem of juggling care and employment hours becomes even more acute when day programs are closed during vacation periods. The Victorian Government’s election promise to develop out of home school holiday respite models is most welcome, as is the respite care funding pool. However, the former is inequitably confined to providing services for children and young people with a disability rather than adults. The latter is too broad to ensure that the employment needs of families with an adult with decision making disability are comprehensively addressed.

**Carers Victoria recommends** that further funding is provided to develop and implement out of centre hours and vacation respite services for families who care for an adult with a disability. Pilot sites should be selected according to demonstrated demographic need.

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Successful applications should demonstrate innovation so that:

- Funded programs meet the needs of both the adults with a disability and their family member(s). This can be done by ensuring that programs provide choice of meaningful activities and have a clear focus on individual community participation and recreation goals. The possibility of increasing the institutionalisation of people with a disability who attend day programs and centre based out of hours respite can be averted by designing programs which have transitional markers between the day program and the out of hours or vacation program.
- Adults with a disability and their families have a clear choice of whether to attend respite care in a place based program or in their own home.
- New programs are clearly designed to support the workforce participation of family carers during usual business hours but are not exclusive to employed carers.
- Programs are affordable. Similar to the cost sensitivities of parents of young children, family members of adults with a disability will be discouraged from participating if the cost of care erodes the financial benefits of paid work too greatly.

Innovative approaches would need to take into account current (and predicted) industrial awards and agreements for support staff. This need not be a barrier to providing suitable quality and duration of care, as evidenced by out of school hours and child care programs. This issue, however, can be expected to have implications for program budgets and costs.

The policy context of encouraging the workforce participation of family carers warrants a co-ordinated approach involving employers, employee and carer representatives, legislators and policy makers. The Victorian Liberal Nationals Coalition election platform for carers made the very positive recommendation that the Working Families Council should include representation by carers to use ‘a good opportunity to put the issue of carers returning to and retaining paid employment at the forefront of the policy agenda’\(^2\). The election plan also refers to the UK’s “Employers for Carers” initiative in which employers were supported to realise the significant business benefits of providing flexible workplaces for carers. In spite of Victorian and national legislation, there is much more to be done to respond to the opportunities in this area.

Carers Victoria notes that the Working Families Council has ceased to meet, and urges the Victorian Government to create a new structure with which to progress these issues.
Carers Victoria recommends:
That the Victorian Government establish a new structure to drive improvements to supporting caring families and employers to balance paid employment and caring responsibilities.

5. Carers of people with a mental illness

The Victorian Liberals Nationals Coalition produced a well considered election platform on mental health services. Its stated approach of investing in mental health services across the whole system and the life course is a worthy one².

Carers Victoria encourages the Victorian Government to continue the roll out of its proposed mental health investments. It must also maintain the momentum and goodwill built up with the sector and the community through the consultation process of the previous government’s Victorian Mental Health Reform Strategy.

Carers Victoria considers that the priorities for the Coalition government in its deliberations about the 2012-13 budget include work on mapping and modeling of the proposed NDIS and current Psychiatric Disability Rehabilitation Support Services (PDRSS). Currently, it is unclear as to the extent of overlap and gaps between eligible populations of the two. Mapping will have important ramifications for the future state funding of NDIS ineligible people with a psychiatric disability. Co-ordination between clinical, NDIS and state funded psychosocial support services will be a critical issue.

Carers Victoria recommends:
That the Victorian Government proactively map and projects the potential overlap of the possible NDIS population of people with a psychiatric disability and the current PDRSS population.

The continuation and growth of the Secure and Extended Care Unit (SECU) Diversion and Substitution programs and Intensive Home Based Outreach Services (IHBOS) programs are critical. The recently released Department of Health/ Nous progress report¹ noted that these programs are meeting their objectives, and echo the findings of the Social Policy Research Centre’s report into the Integrated Rehabilitation and Recovery Care (IRRC) Program³. These programs, if expanded have the potential to fill long term gaps in the service system continuum for

¹ Department of Health/Nous (2011) Evaluation of Selected Adult Mental Health Reform Initiatives, Progress Report 1
people with a mental illness and their families. Both reports noted that these initiatives have been constrained in their effectiveness by a lack of access to suitable housing.

The expressed purpose of these services is to solve service system problems. In the longer term, there are further opportunities in adopting person centred and family focused approaches. In these, early intervention and prevention objectives can be achieved through less intrusive approaches and less reliance by the system on involuntary treatment orders.

Continued investment in these services can be seen as building the capacity of the service system to provide expertise and choice to people with a psychiatric disability when a NDIS is rolled out.

**Carers Victoria recommends:**

- That the Victorian Government extend and expand the Secure and Extended Care Unit Diversion and Substitution and Intensive Home Based Outreach Services initiatives.
- That greater attention is afforded to access to housing for participants of these programs. This will require funding, protocols and accords in collaboration with the Office of Housing.

People with a mental illness and their families highly regard Prevention and Recovery Care services (PaRCs) recognising and valuing their psychosocial and recovery focused approach. For many families, PaRCs provide the most appropriate and effective form of “respite effect” when their family member is unwell. Carers Victoria urges the government to continue to roll out the program to every region in the state using state monies in addition to sub-acute funding through the National Health and Hospital reforms. The proportion of the program’s step up component must be monitored carefully in the face of continued service pressures to use the services for step down support because it is this that holds further untapped potential to avoid traumatic and crisis driven acute interventions. In terms of a possible NDIS, developmental work will need to be done to meet the logistic and market demands of a hybrid model in which the clinical mental health component is funded through the health system and the psychosocial component is delivered through an individually funded market driven sector.

**Carers Victoria recommends:**

That the Victorian Government increases the momentum of the roll out of Prevention and Recovery Care services to ensure that all Victorians have access to needed services.
Carers Victoria has been heavily involved in the reviews of the Victorian Mental Health Act (1986) and the Guardianship and Administration Act (1986), as have many individual carers and other organizations. In spite of the profound implications of any changes to the Mental Health Act, the intention to review the act in the light of the Victorian Charter of Human Rights was well received. It is recognized that any serious changes will also have budget implications.

Carers Victoria recommends that a more substantial model of mental health commission is adopted than that proposed in the exposure draft. Funding will also be needed to ensure that a new act results in meaningfully supported decision making. The review of the Guardianship and Administration Act needs to ensure that a consultation process establishes consumer and carer views of a fusion model of the guardianship and mental health acts. Although Carers Victoria is supportive of a fusion model in principle, the real world implications for people with a mental illness and their families have not yet been extensively examined.

Carers Victoria recommends:
That the Victorian Government provides resources for a comprehensive consultation with people with a mental illness and their carers about the implications and preferences for a fused guardianship-mental health act.

6. Early childhood intervention

Carers Victoria is aware that children with a disability or developmental delay and their families can experience long waiting times for access to early intervention programs, and difficulties with access to preschool educational opportunities or integrated child care. Timely access to early childhood intervention and inclusive early childhood education can enhance child development, help children reach their potential and prevent the development of secondary problems. They can ensure that children get the best possible start.

The individualised early childhood intervention funding offered through FaHCSIA (The Better Start and Helping Children with Autism programs), and through the Victorian Department of Education and Early Childhood Development have greatly assisted children with a disability and their families. In addition, multidisciplinary group programs which encourage the child’s development, as well as build the capacity of parents and provide them with emotional and practical support, information and advice need strengthening and further development.

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42 Carers Victoria (2010) Response to Mental health Bill Exposure Draft
Waiting lists for early childhood intervention services remain; adequate support for inclusive kindergarten and child care is difficult for families to access. Mainstream settings are requesting additional help from early childhood intervention professionals.

Carers Victoria recommends that over the next 4 years the Victorian Government invests in:

- 1000 Early Childhood Intervention Services at $7 million and
- 500 Kindergarten Inclusion Support packages at $5 Million

7. Pay equity for the disability and welfare sectors

Carers Victoria strongly supports the social welfare sector’s campaign to improve the currently inequitably low wages of care and support workers. Carers Victoria holds with the view that there is a sex discrimination element to the sector’s historically low wages. In brief terms, the Victorian Government should commit to fully funding the findings of Fair Work Australia based on the following:

- Incomes for Australian women are lower than those for men because of the lower wages of female dominated sectors
- Increased wages will improve the recruitment, retention and continuity of the workforce, and improve the quality of care provided to people with a disability, mental illness or who are frail and aging and their families.
- Paying care workers adequately elevates the value of care in general. This is much needed in society, increasingly so as the population ages.

Carers Victoria recommends that the Victorian Government commit to fully funding pay increases to ensure pay equity for those working in the disability and welfare sectors.