Comments on the draft state disability plan 2013-2016

Gill Pierce and Ben Ilsley

Carers Victoria’s
Submission July 2012
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.

© Carers Association Victoria 2012.

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, all other rights are reserved.

Requests and inquiries concerning reproduction and rights should be addressed to the Copyright Officer, Carers Victoria, PO Box 2204, Footscray, Victoria, 3011.
Introduction

Carers Victoria acknowledges and supports the thrust of the Draft Victorian State Disability Plan 2013-6 and in particular:

- The challenge of developing clear policy directions and plans within an environment of uncertainty about future system reforms including the proposed NDIS and NIIS and the uncertainty about their financing.
- The ‘whole of Government’ endorsement of the 4 key policy directions in the draft state plan. We wonder if this will this be accompanied by individual departmental implementation plans.
- The shorter time frame for the plan and the intention to support the state disability plan by two yearly implementation plans for 2013-14 and 2015-16. We are uncertain how the implementation plans will be developed and hope there will be an opportunity for further contribution. Many of our comments may relate more closely to implementation plans although high level policy intentions need to be included in the final state plan.

The draft plan has a limited approach to the needs of caring families and friends. This is one major area of dissatisfaction. Others are the poor inclusion of people with a psychiatric disability and the key issue of access to housing and support.

The demographic facts

Most people with a disability live with family or friends. In 2003, of all people with a severe or profound disability aged between 5 and 65:

- 2.5% lived in cared accommodation
- 84% lived with family
- 3.2% lived with unrelated people, probably friends, and
- 10% lived alone in the community.

The numbers of people with a disability who are living in cared accommodation has progressively decreased.¹

The sustainability of specialist and mainstream disability services and supports is reliant on the care provided by families and friends. This was estimated by PricewaterhouseCoopers to be 77% of all care for people with a disability.²

While section 4.4 of the plan lists better recognition and support for the role of families and carers, the state plan needs to recognise the fundamental nature of care and caring in relationships in families. It needs to establish a framework for a dual focus on people with a disability and their families, i.e. both person centred and family focused care and support. There is frequently an interconnectedness and interdependence of needs between families and the person with a disability, including during key lifecycle transitions and key life events. While this is acknowledged in the draft plan in relation to families of children (e.g. pages 10 and 25), for most adults with a disability family relationships are equally critical to their identity, ongoing support, community participation and well being. Most but not all adults with a disability have strong and mutually supportive relationships with their families; relationships that are frequently the most enduring in their lives, regardless of whether they continue to live together or not. The draft plan moves to a person
centred individualised approach for adults with a disability – rather than a person and family centred approach. What is needed is a policy framework which ensures that eligibility for care and support extends to both people with a disability and their caring families; that is policy which focuses holistically on the comprehensive needs of the person and their family, regardless of age (unless this is specifically excluded by the person with a disability).

Establishing a person centred and family focused approach to adults with decision making disabilities will assist to generate a significant body of research and practice knowledge concerning family roles, responsibilities and relationships and the development of partnership between families, people with a disability and services providers.

**An expressed key objective of the state plan – a fifth key policy direction – should state the principle that eligibility for disability care and support should extend to both people with a disability and caring families.**

In addition, it is desirable that the state plan sets a framework for system reform which integrates services for people with a disability with services that support their caring families.

A system that is easier to navigate and which reduces the number of transactions made by people with a disability and their families is desirable. It can make more efficient use of limited funds by reducing duplication and fragmentation of services and improving the continuity of care. The perspectives of people with a disability and the perspectives of their families can be combined and broadened to better recognise critical higher order policy, funding and practice questions.³

**Psychosocial facts about carers**
Most caring families recognise the interconnectedness of family needs with those of the person needing support and assistance. Many agree that adequate services and supports for the person with a disability can lead to a better life for all family members.

Caring family members have diverse needs and circumstances. Their need for support is not always directly related to the extent or nature of care they provide. There is an expanding evidence base about the poor health and well being of some carers,⁴ financial disadvantage; the proportion of primary carers with disabilities or illnesses themselves;⁵ higher rates of anxiety and depression then the general population;⁶ and social isolation.

While the draft report includes data concerning the education, income, employment and health care needs of people with a disability (e.g. page 23) and the low workforce participation rates of caring families, it does not address the increasing evidence of poor health and well being of caring families or their experiences of poverty and social isolation. Their needs must be addressed by the disability services system as well as mainstream services in an integrated and seamless services system. Caring families also need to be assured of a ‘good life’.

‘High needs’ families can include:

- families of people with significant decision making disabilities
- families with multiple care responsibilities
- sole caring parents
• ageing parents
• families who care for people with very challenging behaviours, and
• young people with significant caring responsibilities.

The Productivity Commission in its final report recommended a funding stream for support for some caring families (page 15). Carers Victoria believes that this intends to acknowledge the direct support needs of some high needs families (such as for in home assistance, behaviour management support, assistance with complex medical care). Some caring families need assistance in their own right to sustain family care. Recent Victorian reports (e.g. the Cummins report on Vulnerable Children and the Victorian HREOC report on Relinquishment) give evidence to this. Crisis driven systems in turn are far more costly. The state plan should set a framework to ensure high need and at risk families are eligible for specialist disability support and assistance such as in home or behavioural support and capacity building, as well as more traditional carer supports such as information, counselling, respite and mutual support.

**Current developments in the disability sector**

The state plan requires a policy framework that can acknowledge the different needs of individuals and families with different types of disability and that encourages ongoing improvements in sector practice. In particular it should acknowledge the lived experiences of caring families of adults with decision making disabilities.

Note that:

• While the Disability Services Act includes high level policy requiring services providers to develop ‘working with families’ policies, the Office of the Disability Services Commissioner (DSC) notes few providers have developed these and those which exist are not planned or consistent. The DSC recommends the development of mechanisms to strengthen, clarify or negotiate roles and relationships between adults with a disability, their families and services with a view to improving mutual understanding and collaboration. Many complaints about services stem from the lack of policy and practice guidelines in engaging with families. Other families may not complain but can feel disempowered, with poor recognition of their role and expertise.

• The Victorian Law Reform Commissions guardianship report recommends the introduction of supported and co decision making approaches to ensure improved human rights for people with decision making disabilities. Our broad brush estimate is that 60% of people with a disability are likely to have some level of decision making disability which will require family support.

• There is increasing recognition in the mental health sector of the importance of families in the lives of services users. This is demonstrated in practice principles (e.g. Bouverie and the Chief Psychiatrist).

• There is increasing acknowledgement that unpaid family care does not cease on the entry of a person with a disability to shared supported accommodation. Extended and multi generational care often continues in family roles as advocate, monitor, negotiator, monitor of service quality, complainant, repository of expertise about the person with a disability, interpreter, financial supporter, organiser of social events, encourager and emotional supporter. Family relationships are frequently the most enduring.
We recommend that all four policy directions are further redeveloped to enhance a framework for carer partnership and inclusion.

**Disability Data**
Carers Victoria wishes to emphasise that the ABS data used in the development of the report is inaccurate and confusing. Page 6 provides a visual summary of all people with a disability in Victoria – not those under 65. In addition it focuses on severe and profound disability. As such this omits the additional group who are regarded as potentially eligible for NDIS by the Productivity Commission. This group are those who require supports in self management and planning. It includes people with less severe intellectual disabilities and those with enduring psychiatric disabilities. Please refer to Carers Australia’s second submission to the Productivity Commission.

**People with a Psychiatric Disability**
The plan attempts to be consistent with a possible NDIS. This is a sensible approach, and is required if service system and policy fragmentation is to be avoided. This means the inclusion of people with a psychiatric disability; a new and significant development when it comes to Victorian State Disability Plans. However, this change cannot be taken lightly. There are legal, cultural and systemic/structural implications. Currently, the draft state disability plan really only includes this group in name. When equivalent similar plans and programs have done this at the Commonwealth level, for example the Disability Action Plan, people with a psychiatric disability have been included in theory, but not in practice. This can be a worse outcome that non inclusion because the resulting inactivity for this group can dilute and confuse other policy responses and advocacy efforts.

A more serious inclusion of people with a psychiatric disability would, in the first instance:

- Make very explicit mention in the document that this is a change. Strong emphasis is needed because the status quo (readership of the document, representatives, and structures) has momentum.
- Energetic efforts to engage with and include people with a psychiatric disability, their families and representative bodies in the development of the plan. Existing silos are likely to mean that these groups are unaware of the plan and its importance for them.
- Consideration of reviewing the Disability Act 2006 to include people with a psychiatric disability.
- Acknowledgement that formal transition planning may be needed to examine implications for the disability and psychiatric disability sectors and services.
- Be inclusive of the needs of people with a psych disability who may be eligible for disability services and interfaces with clinical and acute.

**Housing Access**
Access to affordable and suitable housing is fundamental for all. Without it, other important goals such as choice and control over support services, social participation, employment, health and wellbeing are not possible.

The majority of people with a disability live at home with family members (above). While this can be a positive choice, it can also be an economic necessity that undermines autonomy and choice- and the lives of all family members of a person
with a disability – see AHURI housing careers paper. Housing policy for people with a disability must be broader than a narrow focus on primary homelessness and the housing needs of those with profound physical and/or sensory disabilities.

Language here can be important. Here are some observations regarding the plan:

- The previous plan included access to housing. It referred to the need to support people with a disability to access housing. This is a much weaker aim than providing housing or achieving housing access. It largely reflects the limitations of a Victorian Disability Plan in achieving real outcomes in collaboration with the Office of Housing and the Commonwealth. Claims about the rights of people with a disability to choose where they live are empty without real measures to help them surmount the barriers to realizing their choices.

- Issues of access to housing for people with a disability are often reduced to those of physical access. Economic and social barriers to housing access are at least as significant and disabling.

- Housing is included in the plan alongside other participation needs. This does not give access to housing the emphasis it needs as a fundamental to citizenship, participation and human rights.

- It is noticeable that the document does not use the language of social exclusion/exclusion. This may be a significant loss. (On another topic, access to employment is largely described as important for social participation rather than a route out of poverty).

Access to housing is also of profound important to the success of an NDIS – refer to Carers Australia’s submission to PC. Firm accords between the Commonwealth and States are needed to address these issues. Lack of housing security and certainty is of equal importance and concern as the lack of certainty in access to needed supports.

In recent years, Carers Victoria has advocated for the following concrete tasks and steps (2011):

- Changes to and investment in longitudinal data collection about people with a disability and their families.

- Victorian based population based planning for accommodation and support for people with a disability, including people with a psychiatric disability.

- Provision of housing assistance for people with a disability through setting clear targets and long term funding allocations. The previous state disability and housing work was limited to debate about preferred models of housing and support, and so avoided the key issues of scarcity, access and choice.

- Changes to policy settings and pricing to encourage/allow housing associations to provide housing to people, particularly singles, on very low incomes. The Henry Taxation review recommended that people with a disability should be given a housing supplement for this purpose.

Growth strategy goals currently undermine any aims to assist people with a disability (VAGO report):

- Working with the Commonwealth to reform Commonwealth Rent Assistance. It is currently poorly targeted and inadequate for those who live in high rental cost areas, i.e. any of the capital cities.
Continuation and refinement of the National Rental Assistance Scheme (NRAS), in collaboration with the Commonwealth. Study of the scheme is required to ascertain its effectiveness and reach for people with a disability. More work on targeting and incentivisation (supply side) may be required if the scheme is to benefit those who need it most and so produce the market and housing system impacts required.

Policy and conceptual work to match eligibility settings between disability services and mainstream housing assistance. Currently, Disability Services Branch policy settings provide housing and support based on disability need, whereas the Office of Housing prioritises according to housing need. This issue, also of great importance to a future NDIS, creates inequities and system/market distortions.

**Individualised support and the market approach**

Carers Victoria gives qualified support to the intention of individualised, person centred care and the need to empower people with a disability and their families. This will allow people with a disability and their families greater freedom, choice and control with their services and supports. Within limits they can choose the services they receive, who will provide them and when. It is an empowerment model which shifts control away from providers and towards people with a disability and their families.

Our caution comes from the knowledge that international evidence about the long term cost effectiveness of self directed and self managed care is limited. For skilled individuals, there is considerable evidence that better value for money can be obtained through self management. The use of a financial intermediary can also minimise or reduce the costs of operational overheads.

However, the evidence of cost effectiveness at a systemic level may not be conclusive. The small numbers of evaluation studies are fraught with methodological problems, and have a short term focus. Most appear to focus on individualised funding for one disability services type rather than individualised funding for an entire market of services.

Important considerations are:

- **Assessing an individual or families capacity to self manage their care.** Stability in the care situation and ‘readiness’ must be precursors to self directed or self managed care. Feelings of loss, grief and confusion can be features of an initial disability diagnosis. They can be accompanied by the need for discussion, information provision, encouragement and emotional support to determine a course of action. For many people with a disability and their families, case managed early transition support together with care management by an intermediary will be essential until equilibrium is reached.

- **Budget transparency in care packages, regardless of their means of delivery.**

- **Clear boundaries around essential services (admissible and inadmissible).** There will be a need to control and regulate the boundaries of essential services and to manage risk.

Self managed care and consumer empowerment and choice are anticipated to stimulate competition and innovation in the market. However, there are market distortions in community care in the form of supply imbalances for some high needs groups such as adults with cognitive difficulties and very challenging behaviours; and people with profound and multiple impairments. ‘Cherry picking’ within the community
care market has been demonstrated in relation to provider reluctance or refusal to provide services to the most vulnerable.

Victoria’s transition to an NDIS must encourage:

- The initiation of new and responsive individual or group programs to fill gaps in the current services system through investment in infrastructure for community and program development.
- Capacity in the system for identifying, establishing, and supporting the development of new individual or group participation options.

While there are many benefits there are also risks in individualised community access and participation—particularly the risk of isolation. Many people with decision making disabilities may wish to participate in new small group programs such as recreation participation or small group holidays. These may require base funding or transition funding to seed their initial development, and essential outreach and ‘back of house’ work.

There may be a place for a continuation of block funding and highly specialised programs in certain circumstances. These include:

- Services where coordinated and multidisciplinary approaches are required. Examples may include early childhood intervention programs which combine early educational and developmental intervention, family capacity building, family counselling and mutual family support.
- Complex care situations such as those involving young people with care responsibilities for a parent with a psychiatric disability or acquired brain injury. The coordinated family interventions and family support services required are highly specialised and should be provided from block funded agencies. They may not be readily delivered through individual packages of support.
- Block funding may also be appropriate for some day programs, particularly for people with a significant intellectual disability or those with a psychiatric disability. While we support the thrust to increase community access and participation for people with a disability, the value of group programs in the provision of mutual support, non judgemental acceptance and the development of social relationships with peers needs to be acknowledged. Assumptions about choice, self determination, and community participation make little sense when they are applied to adults with significant decision making disabilities who have difficulty with communication and making major life decisions. Differentiation of the pathways of different disabilities into policy and practice is required.
References

11. Carers Australia (2011) op cit