



**Carers Victoria submission  
Victoria's next 10-year mental health strategy  
Discussion Paper released August 2015**

**Carers Victoria  
September 2015**

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### **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 a person with a disability, mental illness, chronic health issue or someone with an age-related condition. The people being cared for could be a parent, child, spouse, grandparent or a friend.

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

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

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## 1. Carers Victoria summary of recommendations

Carers Victoria makes the following recommendations for the Department of Health and Human Services (DHHS) to consider in developing the new 10-year mental health strategy:

**Recommendation 1:** That the 10-year mental health strategy implementation process recognises and supports care relationships and proposes detailed plans to support the mental health of carers, families and the people they care for.

**Recommendation 2:** That the Victorian Government develops an overarching whole-of-government Victorian Carer Strategy to assist and support carers to fully participate in all areas of their lives.

**Recommendation 3:** That the new vision is implemented in a way that recognises the importance of community and connection for carers, and ensures that all people (including carers) are able to access mental health services when and where they need them.

**Recommendation 4:** That the new 10-year mental health strategy specifically addresses the health and wellbeing needs of carers with adequate carer-specific supports and services.

**Recommendation 5:** That the principle of family and carer inclusion includes greater community recognition of and engagement with carer contributions to Victoria's social life and the economy.

**Recommendation 6:** That the principle of co-production involves a wide range of carers and carer groups and be supported by government investment which promotes genuine carer involvement.

**Recommendation 7:** That the DHHS supports Carers Victoria to expand the Carers ID program that enables early identification and referral of carers to appropriate support services.

**Recommendation 8:** That the DHHS promotes adequate information resources for carers, through supporting the online Victorian Carer Portal as 'the place to go' for all Victorian carers.

**Recommendation 9:** That the DHHS encourages providers to actively involve carers in decisions that affect them and ensures appropriate accountability processes for the quality of service provided.

**Recommendation 10:** That the DHHS addresses gaps in supported decision-making mechanisms through improved awareness and better promotion of carers' rights in mental health organisations.

**Recommendation 11:** That the DHHS supports a comprehensive and independent individual advocacy service for all carers of people with mental health conditions in Victoria.

**Recommendation 12:** That the 10-year strategy recognises the challenges to access identified in the MHCSS review and addresses inadequacies in essential carer support services.

**Recommendation 13:** That the 10-year strategy ensures the Commonwealth and the Victorian Governments work together to maintain and improve appropriate services within and outside the NDIS for carers and the people they care for.

## **2. Introduction**

Carers Victoria welcomes the opportunity to provide input to the Victorian Government in response to the discussion paper 'Victoria's next 10-year mental health strategy' (the discussion paper) released in August 2015.

The paper outlines a vision to guide mental health policy and strategic investment, proposes key outcomes and strategies and invites submissions in response to how a new strategy can provide a long-term vision for mental health in Victoria.

Carers Victoria supports the Victorian Government's commitment to develop a clear 10-year Mental Health Plan for Victoria 'that places the wellbeing of individuals and communities at the heart of an integrated system'.

In its Victorian Election Platform 2014, Labor promoted the 'development of carer-friendly practices system and programs in the mental health system'. It similarly committed itself to 'advocate to the Commonwealth Government for effective funding and support for carers'.

These commitments, together with the announcement to 'develop a clear plan to support carers appropriately' as part of this process, are encouraging and positive steps, but action beyond commitments is necessary. Investing now in the development and support of family and friend carers will improve their capacity for mental health care and strengthen the sustainability of the mental health system in the future.

## **3. Background – carers and the role of Carers Victoria**

Carers<sup>1</sup> provide unpaid care and support to a family member or friend needing assistance with a disability, mental illness, chronic health condition or age-related needs. Carers come from all walks of life, across all age groups and all cultures. Not all people with a caring role identify themselves as carers, and may instead identify themselves in terms of their family and friend relationships.

There are an estimated 773,400 family and friend carers in Victoria, which is 13.6 per cent of the Victorian population. Of these, 217,800 (3.8 per cent of the Victorian population) are primary carers, defined as providing the majority of ongoing care to the person requiring assistance.<sup>2</sup> Women are more likely to be carers than men, with 70 per cent of primary carers being women.

Carers Victoria supports caring families through information, online and face to face training and education programs, respite support, counselling and systemic advocacy. Carers Victoria had 28,545 interactions with carers through our carer advisory line, counselling and other support services during 2013-14.

## **4. The cost of providing care**

In a report prepared for Carers Australia by Deloitte Access Economics, it was estimated that in 2015 families and friends will provide around 1.9 billion hours of care in Australia. This is equivalent to each carer providing 673 hours per year or 13 hours

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<sup>1</sup> The terms 'carers', 'family carers' and 'caring family/ies' used in this submission includes the diverse range of people in care relationships, including carers and people receiving care in same-sex families, 'families of choice', friends and others who provide unpaid care.

<sup>2</sup> Australian Bureau of Statistics (2013) *2012 Survey of Disability, Ageing and Carers*, Cat. No. 4430.0.

per week. Deloitte Access Economics estimates it would cost \$60.3 billion per year if all informal community care was replaced and delivered through formal care systems.<sup>3</sup>

Caring can have negative effects on the carers' own financial situation, retirement security, physical and emotional health, housing arrangements, social networks and career. The impact is particularly severe for carers of people who have complex chronic health conditions and both functional and cognitive impairments.

## **5. Response to discussion paper**

Response to specific discussion paper questions:

### **a. Why would a new strategy for mental health be important to you?**

Carers Victoria's vision is to create an Australia that values and supports carers. Our purpose is to ensure that caring is a shared responsibility of family, community and government. We want to support carers better; we want to make carers' lives better.

However, as identified in the discussion paper<sup>4</sup> and accompanying technical papers, consumers and their families experience difficulties accessing services, including people in rural and regional areas; people from culturally and linguistically diverse backgrounds (CALD); Aboriginal and Torres Strait Islander people; lesbian, gay, bisexual, trans/transgender, and intersex (LGBTI) people; people with disability; older people, people in the justice system; young people; and, people with alcohol and other drug (AOD) issues.

In spite of the documented impacts of caring on carers' own mental health, they remain a vulnerable, often overlooked and neglected group that requires a specific strategy to provide better access to targeted support services to help them in their caring role and, equally, to maintain their own health and wellbeing. For example, Carers Victoria notes there is no technical issues paper accompanying this discussion paper to discuss carer and family supports, particularly how the new strategy could assist carers in the caring role and to maintain their own mental health.

This is despite major challenges for carers being recently identified by a number of recent reports. Concerns raised include a lack of flexible and accessible respite options for carers<sup>5</sup>, unaddressed physical and mental health needs of carers<sup>6</sup>, and stigma and discrimination.<sup>7</sup>

Confirming these reports, carers have reported to Carers Victoria that they experienced mental health issues as a direct result of the magnitude of their caring responsibilities. The reaction of clinical care teams or the wider community can be a barrier for carers who are experiencing mental health issues: carers have stated that they can be hesitant in seeking assistance for themselves; often because of fear of stigma or past negative experiences with health professionals. Many carers who are also consumers told of their frustrations at the lack of service or service provider continuity which means they have to retell their stories and be subject to different care and treatment regimes.

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<sup>3</sup> Deloitte Access Economics (2015) *The Economic Value of Informal Care in 2015*, Carers Australia, p. 15.

<sup>4</sup> For example, see: Discussion paper - Victoria's mental health strategy, p. 21.

<sup>5</sup> E.g. MHCA, 2012, *Recognition and Respect Mental Health Carers Report*, p. X.

<sup>6</sup> Over two-thirds (71%) of respondents reported a deterioration of their health in the previous 12 months as being a direct result of caring for someone with a mental illness. Ibid, p. 18.

<sup>7</sup> MHCA, 2010, *Mental Health Carers Report*, p. 31.

These can be factors that impact on the severity of mental health problems experienced by carers.

Carers Victoria's new Strategic Plan lays out our plan and priorities to develop more and improved information platforms, training and education programs, and innovative new services and support packages to build carers' capacity for a successful transition to the reformed services systems.<sup>8</sup>

This response to the new mental health strategy discussion paper provides an important opportunity for Carers Victoria, the DHHS and the wider community to work in partnership to deliver better mental health services and supports for both consumers and carers.

## **b. What will work to deliver better outcomes for individuals, families and the Victorian community?**

### *Recognising and supporting the care relationship*

The discussion paper rightly promotes a social model of health that recognises social, psychosocial, biological and medical factors all play a role to maintain and improve mental health and wellbeing. Importantly, this model takes a holistic view of mental health, rather than focussing on models of 'illness' or 'disease'. Targeted interventions, rather than a 'one size fits all' service, will be as important as universal whole-of-population responses.

Carers Victoria supports the strategy's focus beyond the mental health treatment system to include prevention, early intervention, social support and primary care. However, the discussion paper fails to properly recognise the important contribution that carers and families can make to achieve all of these aspects, especially prevention and early intervention.

Any proposed mental health strategy should therefore place support for care relationships at the centre of mental health planning, policy and implementation. The strategy also needs to explicitly consider the mental health of *both* carers and the people they care for in order to enhance the sustainability of families and care relationships.

**Recommendation 1:** That the 10-year mental health strategy implementation process recognises and supports care relationships and proposes detailed plans to support the mental health of carers, families and the people they care for.

### *Whole-of-government Carers Strategy*

Carers Victoria believes that the new mental health strategy needs to be linked to an overarching whole-of-government Victorian Carers Strategy.

While the Victorian *Carers Recognition Act 2012* recognises the role of carers and the Carer Action Agenda supports the government to meet its obligations under the Act, there is no detailed strategy to improve the position of Victorian carers.

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<sup>8</sup> Carers Victoria, 2015, *Carers Victoria Strategic Plan (2015 – 2018)*.

Similar to the NSW Carers Strategy<sup>9</sup>, this framework could outline what the focus of reform will be for the next five years across government, for example:

- to improve the ways carers are involved and included as partners in decision-making and service delivery;
- to improve the design and delivery of services and programs that facilitate carers' health and wellbeing;
- to advance educational, training and employment opportunities for carers; and
- to improve the use of the available data/ research to facilitate evidence-based policy and program development.

A coherent future strategy for carers would complement the new mental health plan and minimise the risk of a siloed approach to addressing carer needs and priorities. The development of the strategy should occur through a co-design approach inclusive of carers, the private sector, non-government organisations, government departments and carer associations.

Without an overarching Victorian Carer Strategy, the development and implementation of policy addressing the mental health of consumers and carers runs the risk of taking a fragmented and siloed approach to the issue. This will make it difficult for carers to access the full range of supports they need when they need them.

**Recommendation 2:** That the Victorian Government develops an overarching whole-of-government Victorian Carer Strategy to assist and support carers to fully participate in all areas of their lives.

**c. All Victorians have the opportunity and right to experience their best mental health. Is this the right vision for the next 10-year mental health strategy?**

Carers Victoria supports the ambitious outcomes and actions set by the discussion paper to achieve comprehensive access to the support Victorians need to experience their best mental health throughout all life stages. We agree with the discussion paper's broad vision and goal 'to support carers and families in their caring role, because recovery is not a journey that one walks alone'.<sup>10</sup>

Carers Victoria considers that any effort to maximise the opportunity for the best mental health for carers requires a recognition of the importance of building community connections for carers and a mental health support system that helps to ease the caring load on carers.

Indeed, at recent consultations for the Mental Health Community Support Services (MHCSS) reform and the 10-year mental health strategy, the issues most often raised by consumer and carer participants were concepts of 'connection' and having a sense of 'community'. As a key part of building this connection, the participants also spoke of the need to be able to access appropriate mental health services when and where they need them, including under the reformed MHCSS system and the National Disability Insurance Scheme (NDIS).<sup>11</sup> As in other care areas, there is growing recognition in the mental health sector that the social, emotional and financial load on carers often increases substantially when access to services for the person with mental health

<sup>9</sup> NSW Department of Family and Community Services, 2014, *NSW Carers Strategy 2014-2019*.

<sup>10</sup> DHHS, August 2015, *Victoria's next 10-year mental health strategy – Discussion paper*, p. 3.

<sup>11</sup> These points will be discussed in more detail later in the submission.

conditions is limited. The 10-year strategy should therefore consider the particular challenges for carers in accessing support services, including a lack of or gaps in services and a lack of awareness and understanding of those services.

**Recommendation 3:** That the new vision is implemented in a way that recognises the importance of community and connection for carers, and ensures that all people (including carers) are able to access mental health services when and where they need them.

#### **d. This mental health strategy is for all Victorians. Is this the right scope?**

Carers Victoria supports the discussion paper's broad scope which encompasses the 'specialist mental health treatment system *and* prevention, early intervention, social support and primary care'. This broad scope gives an opportunity to take into account all people in carer relationships and their needs. However, we believe that the discussion paper and issues papers missed the opportunity to consider carers and family health and wellbeing in more detail in terms of specific support needs.

As briefly discussed above, family members and friends who support people with mental health conditions are one of the population groups at higher risk of poor mental health with greater vulnerability to adverse social and economic circumstances. For example, the Australian Unity Wellbeing Index Survey identified that carers have the lowest collective wellbeing of any examined group.<sup>12</sup>

Key issues related to carer health and wellbeing include:

- *Physical and mental health needs:* Carers supporting their family member or friend with mental illness often face their own challenges with deteriorating health (often as a direct result of the caring role). Carers repeatedly reported they do not feel their wellbeing needs are addressed and they are left without adequate supports.<sup>13</sup>
- *Stigma, discrimination and isolation:* People with mental health conditions and their families and carers experience discrimination and stigma on a daily basis. This occurs in areas such as employment, housing, health services, schools and other life domains.<sup>14</sup> In many cases, this increased isolation and loneliness negatively impacts on carers' health and wellbeing.
- *Exclusion and lack of respect:* Carers often feel that they are not listened to or respected by health professionals, including GPs and psychiatrists. In many cases, this leaves them feeling excluded and with insufficient information to provide adequate care.<sup>15</sup> This compounds difficulties finding the services needed for the person they are caring for which causes considerable stress and anxiety.

Given the poor mental health and the unique challenges they experience, carers need to be positioned at the centre of public mental health planning and service delivery. The strategy should therefore address the health and wellbeing issues of carers as a distinct 'consumer group' in its own right.

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<sup>12</sup> Australian Unity Wellbeing Index, Survey 17.1, Report 17.1, October 2007

<sup>13</sup> MHA, Mental Health Carers Report, p. 10.

<sup>14</sup> MHA, Adversity to Advocacy: The Lives of Mental Health Carers, October 2009, p. 9.

<sup>15</sup> MHA, Mental Health Carers Report, p. 8.

**Recommendation 4:** That the new 10-year mental health strategy specifically addresses the health and wellbeing needs of carers with adequate carer-specific supports and services.

## e. Response to Principles

### Principle of family and carer inclusion

The discussion paper states DHHS's commitment to involve 'carers and family members in service development and delivery'. It states that they are an essential stakeholder in a reformed mental health system.

However, many current services (including mental health services) still lack the capacity to work in a family and carer inclusive way. For example, we have heard repeatedly from carers that services staff and many other professionals continue to ignore carers as an important partner in service planning and delivery, that their individual needs are not being addressed and no practical support is offered with the caring role.

Principles of family and carer inclusion also need to include wider public recognition and respect for the vital work carers undertake, including the social and economic consequences of their caring role. Indeed, informal caring means significant savings for government<sup>16</sup> while the carer's own financial security is compromised because they may have trouble finding suitable employment or working sufficient hours due to their caring role. This also results in an adverse impact on their retirement income.

The current lack of community and government understanding of the extent and impact of the caring role has negative consequences for carers; they can be left socially isolated. However, carers have reported to us that community understanding about caring is important and community groups (e.g. church, school, hobby and sporting groups) can contribute enormously to their wellbeing.

**Recommendation 5:** That the principle of family and carer inclusion includes greater community recognition of and engagement with carer contributions to Victoria's social life and the economy.

### Principle of co-production

The recent MHCSS and AOD services review and the ongoing 10-year strategy consultations, including DHHS's regular consumer and carer forums, provide a valued platform to listen to carers and to consult on what they believe needs to happen to achieve good mental health in the Victorian community.

Carers Victoria believes that such platforms need to be expanded in order to truly involve a wider range of the diverse carer community (including people from culturally and linguistically diverse backgrounds (CALD); Aboriginal and Torres Strait Islander people; lesbian, gay, bisexual, trans/transgender, and intersex (LGBTI) people and young carers under 25) in the 'co-planning, co-designing, co-delivery and co-reviewing of policies, service design and delivery'. It is critical that the Department invests in how to most effectively include the voices of consumers, carers and their representatives and other relevant bodies in any future service planning, implementation and

<sup>16</sup> Deloitte Access Economics (2015) The Economic Value of Informal Care in 2015, Carers Australia.

evaluation. This could, for example, include funding self-advocacy training, educational and systemic advocacy opportunities.

Failing to acknowledge care relationships and not including carers in the design and delivery of service reforms would result in carers remaining unappreciated, undervalued and unsupported. This would make caring unsustainable into the future.<sup>17</sup>

**Recommendation 6:** That the principle of co-production involves a wide range of carers and carer groups and be supported by government investment which promotes genuine carer involvement.

#### **f. Outcome: Enabling genuine choice**

##### **Response to Outcome 1: People with mental illness, families and carers are involved in and have genuine choices about decisions that affect them.**

Carers Victoria agrees it is vital that both carers and consumers are free to decide their preferred options to provide or to be provided with care, as well as accessing appropriate formal services.

##### *Carer identification and the Carers ID program*

For this to happen, support services need to better identify carers, with more investment committed to early carer identification. Carer consultations have shown that many service providers and professionals don't give enough consideration to identify, support and involve carers and family members as part of the care team and in decision-making processes. Carers emphasised, for example, the importance of early identification and referral for specific populations, such as young carers.<sup>18</sup> At the recent MHCSS consultations, a number of carers also stated that more professional skills development needs to be conducted for staff, including how to identify and work with carers and families.

Carers Victoria has successfully launched an innovative Carers ID initiative to partner with service providers to improve carer awareness and support the early referral of carers to specialist services. It has been particularly successful during the pilot phase with Mental Health Intake organisations. Carers ID supports professionals in both public and private hospitals, health networks and other organisations to identify carers and easily refer them to Carers Victoria for support. Current components of the program include an e-referral process, information resources and staff carer information workshops. By reducing the barriers to referral, we will increase the number of carers identified and supported.

**Recommendation 7:** That the DHHS supports Carers Victoria to expand the Carers ID program that enables early identification and referral of carers to appropriate support services.

##### *Information and carer advocacy/ carer online portal*

Another key enabler for genuine choice is adequate information and advocacy. Carers want to have current information on the health conditions and associated medical

<sup>17</sup> Percival, R., & Kelly, S. (2004). *Who's Going to Care?: Informal Care and an Ageing Population*. Report prepared for Carers Australia by the National Centre for Social and Economic Modelling.

<sup>18</sup> MHCA, 2009, *Adversity to Advocacy – The Lives and Hopes of Mental Health Carers*, p. 42.

management<sup>19</sup> for the people they care for. They also seek information about their rights and responsibilities, where to go for help, the legalities involved, as well as treatment options and support services for consumers.

Moving into a caring role can happen quickly and at a crisis point, with little support and assistance to help carers navigate complex service systems. Independent research undertaken by Carers Victoria has shown that 60 per cent of carers find it initially difficult to locate the information and supports they need.<sup>20</sup>

With DHHS funding, Carers Victoria is developing an online Victorian Carer Portal to assist caring families find the much needed information, tools and support when they need it, personalised to their caring situation and role. The Carer Portal is designed to provide links to specific services for carers, including carers for people with mental health conditions.

**Recommendation 8:** That the DHHS promotes adequate information resources for carers, through supporting the online Victorian Carer Portal as ‘the place to go’ for all Victorian carers.

#### *Active engagement with carers enables genuine choice*

In addition, genuine choice is most effective when families and carers are actively engaged in decision-making. In many cases mental health treatments can be unsustainable without carers. Yet, carers have reported that clinical staff can be dismissive or even antagonistic of their role and their insight into the consumer’s health and behaviour and avoid consulting with carers about changes in treatment. Carers and consumers can also be confronted with service providers who do not appreciate how every aspect of a person’s everyday life is affected. For example, a young carer whose mother lives with depression reported that she was instrumental in getting her to appointments by assisting her with dressing and meals but the doctor didn’t appreciate that without this assistance her mother would not be able to attend appointments.

Carers have reported that in order for them to have opportunities to become involved in decision-making, there firstly needs to be improved recognition of carer rights to be involved in decisions about care for the consumer at the individual level. Secondly, at the service provider level, there is a need for improved accountability and complaints processes for the quality of services provided. While carers hold an important role in safeguarding the people they care for, barriers may be practical, for example complaints processes can be daunting if they require specific forms of evidence or paperwork. Other barriers are that carers do not always have the right, or may believe that they do not have the right, to complain about poor services being delivered for the person they are caring for.<sup>21</sup>

Carers Victoria therefore supports the discussion paper’s objective to ‘maintain, monitor and act on information about consumers’ and carers’ experiences of accessing and receiving services, with an ‘initial focus on the extent to which consumers, their families and carers are actively engaged in decisions that affect them’.

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<sup>19</sup> Carers Victoria research found a positive correlation between carer’s age or length of time caring and their confidence in managing medication (older carers and long-term carers were more confident).

<sup>20</sup> Quantum Market Research for Carers Victoria (2012) Caring Families Research Report, p. 13, see: <http://www.carersvictoria.org.au/file-assets/publication/e-learning-project> (accessed 14.09. 2015).

<sup>21</sup> The Victorian Disability Services Commissioner and the Victorian Mental Health Complaints Commissioner, for example, provide good practice examples of complaints services that allow carers (among others) to make complaints on behalf of the person they are caring for.

**Recommendation 9:** That the DHHS encourages providers to actively involve carers in decisions that affect them and ensures appropriate accountability processes for the quality of service provided.

#### Supported decision-making under the Mental Health Act 2014

The Mental Health Act 2014 sets out specific obligations on providers to consult with and inform carers. For example, mental health professionals are required to give regard to carers' views and have to keep them informed during compulsory assessment and treatment of the consumer.

While this legislation is a positive step to supporting the outcome of genuine choice, recent consultations have identified that there is low awareness among carers of their rights<sup>22</sup> to:

- be notified and consulted about key decisions;
- have patient information shared with them;
- be nominated to receive information and provide support;
- the right to seek a second psychiatric opinion; and
- the right make complaints on behalf of a patient.

In order to fully implement the intent of the legislation, there is a need for improved awareness and better promotion of carers' rights in mental health provider organisations.

**Recommendation 10:** That the DHHS addresses gaps in supported decision-making mechanisms through improved awareness and better promotion of carers' rights in mental health organisations.

#### Independent advocacy

To further support decision-making, Carers Victoria recommends a comprehensive and independent family advocacy service for carers of people with mental health conditions.

Representing yourself and your family members or friend as an advocate can be a very challenging and upsetting experience. It is therefore vital for carers to understand what their rights are, to be enabled to navigate complex systems and to negotiate legal and financial issues.<sup>23</sup> Previous research confirmed that there is a strong desire and need for 'independent, individualised support and casework advocacy' to provide help to carers of people with mental health conditions with complex issues.<sup>24</sup>

For caring families that require additional support, individual family advocacy should be made available to address issues relating to their caring role across service systems. In many circumstances, families need to advocate for their family members regarding care and support needs or complaints and therefore need access to individual advocacy.

Carers Victoria supports the newly established advocacy service which is provided to mental health consumers in Victoria. Independent Mental Health Advocacy (IMHA)

<sup>22</sup> DHHS (Department of Health), *Quick Guide: How does the Mental Health Act benefit carers?*

<sup>23</sup> Carers Victoria, 2011, *Discussion paper on Individual Advocacy and Caring Families*, p. 9.

<sup>24</sup> ARAFEMI, Victorian Carer Advocate Program Research Report, 2011, Executive Summary, p. 2.

supports people 'who are receiving compulsory psychiatric treatment to have a say about their assessment, treatment and recovery'.<sup>25</sup> However a model for independent community advocacy needs to be broader in scope, such as demonstrated by the successful pilot of the ARAFEMI Victorian Carer Advocate Program. Since that pilot in 2011, the substantial reforms in the mental health and disability support systems mean that the need for independent advocacy is even greater than before.

Establishing an individual advocacy service for carers would give them more genuine choices about decisions that affect their families. This service would also contribute towards building the confidence and capacity of family carers to be effective in their caring role.

**Recommendation 11:** That the DHHS supports a comprehensive and independent individual advocacy service for all carers of people with mental health conditions in Victoria.

#### **g. Outcome: Effective, coordinated treatment and support**

**Response to Outcome 6: People with mental illness and their families and carers can easily access effective, coordinated treatment and support when and where needed.**

##### MHCSS review and current reforms

The current MHCSS review has identified a number of challenges to ensuring effective coordinated treatment and support. These include restrictive eligibility requirements, the closure of niche services (e.g. group activity programs, like art therapy), inappropriate centralised intake and screening procedures<sup>26</sup>, long waiting lists and a lack of education and information for consumers/carers and mental health professionals.<sup>27</sup> Further, many people are 'still outside the system' and don't know about supports and services and how to access them. Recent consultations have also found that while the mandatory carer assessments are a positive step, they are often not followed up in practice by appropriate referrals to services. Needs assessment must not be seen as an end in itself, but a means of access to improved outcomes for carers.

Further, many carers feel that there is still inequitable access to community mental health services across Victoria. For example, consumers and their families repeatedly reported that they find the community mental health system is difficult to access if an illness is considered as being not 'severe' and 'high priority'.<sup>28</sup> This is compounded by issues with access to other public mental health services, like hospitals. For example, families reported that they are being turned away from these services due to a lack of acute mental health beds.<sup>29</sup>

Carers also stated that community agencies and government departments are disconnected from each other, further impeding on easy access to effective,

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<sup>25</sup> For more information about the IMHA service, see: <http://www.imha.vic.gov.au/> (accessed 14.09. 2015)

<sup>26</sup> A number of consultation participants found the phone based intake too impersonal and inappropriate to their needs and considered a lack of access to face to face assessments to limit alternative options. Feedback given at VICSERV consultation on recent MHCSS reforms, 27 July 2015.

<sup>27</sup> These issues were raised at recent MHCSS consultations with consumers, carers and service providers, conducted by Aspex Consulting on 14 August 2014.

<sup>28</sup> Carer feedback at a VICSERV consultation on the 10-year strategy and MHCSS reforms, 27 July 2015.

<sup>29</sup> The introduction of dedicated triage nurses to assess patients with mental illness symptoms in emergency departments can be a positive step.

coordinated treatment and supports under the MHCSS system. Such silos exacerbate difficulties experienced while caring as they often deal with a myriad of different organisations. Carers felt like they are 'going around in circles' to find the right solution to their particular problem.

As discussed above, carers also need access to their own services to adequately support them in their caring role. For this to occur, carers need to be identified and included (see recommendation 7). For example, respite might be especially necessary after an episode of acute symptoms to enable the carer to recharge and renew themselves. Other services valued by carers include information and training, counselling, peer support, mutual support and self-help (MSSH) programs.

**Recommendation 12:** That the 10-year strategy recognises the challenges to access identified in the MHCSS review and addresses inadequacies in essential carer support services.

### *Mental health carer supports and the impact of the NDIS*

Finally, another major impediment to effective, coordinated treatment and support is the uncertainty over the impact of the NDIS on carer support services. One of the main mental health carer support programs Mental Health Respite: Carer Support (MHR:CS) has been identified as a service which will transition into the NDIS.<sup>30</sup> Further, it is unclear whether previous MHCSS funds, which in Victoria will move into the NDIS, will still be available to NDIS participants to provide support to their carers.

It is crucial that support is maintained for those carers of people with mental illness who will be part of the service reform. Early feedback from carers and participants in the NDIS trial in Barwon has been that NDIS supports need to be better directed at supporting participants throughout their life course and especially during key transition periods.

There is particular concern that consumers who do not fit the requirement of having a 'permanent disability' and their carers may miss out on services which they have received to date. For example, people experiencing 'bad days' or periods of acute symptoms/requiring care but who can otherwise live independently may not fit the criteria of psychosocial disability. These people may still require 'check-in' services in addition to their family carers.

A further issue is that consumers can only commence receiving services from the NDIS if they are under the age of 65 years and that non-participants aged over 65 will need to access the aged care system. Carers and consumers raised concerns that they do not wish to be left without adequate support and transition planning on how to move from one service system to another.

Maintaining support for carers of people with mental illness will also be vital for cases where the consumer does not meet the eligibility requirements for the NDIS. Carers of people who are ineligible for the NDIS, or can't access it for other reasons, fear they are likely to lose the supports these programs currently offer. Concerns have also been raised about recent changes to the implementation of the MHCSS priority rating system which are perceived as having reduced access for consumers considered 'lower

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<sup>30</sup> Department of Social Services, Mental Health Respite: Carer Support, see: <https://www.dss.gov.au/our-responsibilities/mental-health/programs-services/mental-health-respite-carer-support> (accessed 14.09.2015).

priority'. Feedback also indicated that in anticipation of the NDIS, service providers have prematurely scaled back or completely withdrawn services and programs.

Easy access to effective, coordinated treatment will not be possible if the people who fall outside the NDIS and their carers are left without access to vital services. Carers Victoria welcomes the announcement of a 'clear plan to support carers appropriately during the transition' and considers that addressing any potential gaps in the future mental health system is a matter of urgency.

**Recommendation 13:** That the 10-year strategy ensures the Commonwealth and the Victorian Governments work together to maintain and improve appropriate services within and outside the NDIS for carers and the people they care for.

## 6. Conclusion

Carers Victoria would welcome any opportunity to give further feedback during the current consultation process and the mental health strategy implementation phase.

We particularly welcome feedback from the DHHS on which recommendations will be included in the 10-year mental health plan and are happy to discuss the proposed recommendations in more detail.