Psychiatric Disability Rehabilitation and Support Services Reform Framework

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 that 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 Ben Ilsley, Policy Adviser, Carers Victoria

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1. About this submission

Carers Victoria welcomes the opportunity to respond to this Consultation Paper. Victoria’s Psychiatric Disability Rehabilitation and Support Services (PDRSSs) can have significant positive impacts on the lives of people with a psychiatric disability and, in turn, their carers and families. PDRSSs are designed to assist people in their community of choice and are oriented to supporting recovery. There are obvious synergies between PDRSSs and the roles, needs and concerns of those family members and carers who provide day to day assistance to people with a long term disability resulting from a mental illness.

When people with a psychiatric disability and their families receive support from a PDRSS, reports and satisfaction ratings are for the most part positive. At the same time, there are service gaps and missed opportunities apparent in the sector that, if addressed, could dramatically improve the lives and outcomes of people with a psychiatric disability and their families.

This submission will not respond to all the questions and concerns raised in the consultation paper. Rather, it will comment on those issues of most importance to caring families. Carers Victoria will also use this opportunity to share some relevant work that it has done in relation to other sectors and jurisdictions, particularly the disability sector and the development of a National Disability Insurance Scheme (NDIS).

2. Main areas for comment

2.1 The need for reform

Carers Victoria supports the process of PDRSS reform in principle. Family members and carers will be seeking the following improvements from any future reforms:

- geographical equity of access to the full range of available services
- consistent and transparent service eligibility processes
- increased choice of service responses and providers
- reduced fragmentation and system complexity
- improved continuity of care
- a consistently high level of family/carer involvement in the care of their family member
- access to high quality and flexible family and carer support
- access to PDRSS services earlier in an individual’s illness.
As documented in the consultation paper, the systemic measures are required to meet these ends. Here are some of the more important ones:

- population based planning and resourcing, consistent with recommendations previously made by the Victorian Mental Health Reform Strategy
- a focus on client and, where applicable, family outcomes, in terms of practice, service design and continuous quality improvement
- reforms and agreements to reduce the complexity generated by state and commonwealth government funding of community based mental health services
- alignment of and improved collaboration between PDRSS services and alcohol and drug services, housing, child protection via ‘One DHS’ reforms, and with area mental health services and Medicare Locals
- workforce reforms, including improved pay and conditions to encourage attraction and retention of staff
- a significant shift to not just services that are person centred, but also to whole of family focused.

2.2 The reform process: limitations and challenges

The Consultation paper proposes reforms that certainly aim to address many of the systemic issues listed above. However, this is occurring in an environment of dynamic change and reform. Some changes can be largely predicted, for example, legislated funding by the Commonwealth Government over the next few years for Personal Helpers and Mentors (PHaM), Day to Day Living and Mental Health Respite programs. Other reforms are less predictable. The long term sustainability and role of Medicare Locals is politically dependent. The course of the roll out of a National Disability Insurance Scheme (currently proposed to include individual support to 57,000 people with a 'significant and enduring' psychiatric disability) remains uncertain, as are the resulting impacts on existing service systems.

Significant fragmentation of mental health services arises not just between sectors and services, but also from the complexity of having both Victorian and Commonwealth funding in this space. This problem could be exacerbated by the continued increase in Commonwealth funding that will soon result in a 50-50 percent State-Commonwealth split of community mental health services. While the Consultation Paper refers to these problems, addressing this fundamental structural problem appears to be largely out of scope of the paper. This could result in a future
PDRSS system that is well organised according to its own internal logic but is limited by its inhabiting a relatively very small proportion of the overall mental health sector.

This submission recognises the political difficulties here in that the Victorian Government is limited in its leverage over the design of Commonwealth funded services. The Consultation Paper might be seen as adopting an approach that seeks to minimise the contribution played by the PDRSS sector in producing systemic fragmentation, while also hoping to facilitate or influence other changes beyond its boundaries.

The introduction of an NDIS could present opportunities to reduce rather than increase service system fragmentation. Pooling of Victorian and Commonwealth funds (i.e. PDRSS, PHaMs, D2D Living, Mental Health Respite and Community Mental health funding streams) could result in a streamlined, simplified system for service users. There are key questions here about the extent to which an NDIS eligible population of people with a significant and enduring psychiatric disability will coincide with the current PDRSS population. If as expected, the overlap is not complete, then further questions arise as to whether the Victorian government would continue to fund services for non-NDIS eligible clients using dollars that have not been pooled into an NDIS. If it does so, great efforts would then need to be made to ensure that such service system design does not add further complexity and inequities through production of a two tier system.

The Consultation Paper’s proposed reforms present other apparent tensions and unknowns that are worth highlighting:

- If larger scale services are at an advantage in delivering quality and efficiencies, how will local responses and innovations be promoted?
- The Productivity Commission’s proposed NDIS uses the market to promote competition between organisations and services, increasing value and quality for consumers of service. Although it will take several years before an NDIS is rolled out fully, this possibility poses questions as to how this might impact on the current sector’s culture. What sorts of collaboration will be needed and when? For research purposes? For sharing evidence or practice expertise?
- As an NDIS develops, further challenges are likely to emerge regarding the optimum role of State and commonwealth governments in relation to a market
based system. For example, will the Victorian government see itself as having a role in supplementing a tightly bounded system or intervening on behalf of population groups who experience sustained market failure?

2.3 Comments about consumer directed care

Carers Victoria has produced a draft paper on Consumer Directed Care (attached to this submission).\textsuperscript{4} It reviews some of the Australian and international literature about existing models and programs and their outcomes. The field of literature is broad and includes services available for people with a disability, those who are aged and people with mental health programs. Many of the issues raised in the paper are relevant to the discussion about a PDRSS shift towards individualised funding. Here are some key points:

- There is a spectrum of different levels of individualisation and consumer control that have been trialled, with a corresponding set of terminologies.
- Uptake of consumer directed care, when offered, has generally been slow. Some groups of consumers, for example those with a physical disability, have been more enthusiastic than others.
- Many consumers who have taken up consumer directed care have reported significant benefits.
- Some family members who have managed care packages on behalf of a person with a disability, who is aged, have reported that the role can be time consuming and onerous.
- Some consumers and their families maintain a preference for their care/support packages to be case managed by a third party.
- There have been no jurisdictions in which the entire service system is market driven and configured around consumer directed funding. This is an important finding for the development of an NDIS in that macro market effects are yet to be tested. It is possible that Consumer Directed Care approaches provide most choice and benefit, while there are also alternative services that are block funded. It may not be valid to infer that because consumer choice is increased by having the option of consumer directed care, that universal roll out of consumer directed care also increases choice in a straightforward way. This refers to the likelihood that a wholly market driven system would reduce choice because of some degree of market failure for some consumers and service options.
In relation to people with a psychiatric disability, the following points are likely to be relevant:

- Consumers will need to be presented with options that provide different levels of control. This should include opt out provisions in which consumers choose to use a third party to organise their package.
- Pricing of packages through an NDIS should not disadvantage those with limited capacity to manage or control their support package.
- Families should not be automatically expected to manage care packages on behalf of their family member, nor should any family member be disadvantaged by not taking on such a role.
- Some people with a psychiatric disability will need specialist support to facilitate meaningful decision making. Likewise, families may need support and skills training if they are to identify and support the decisions of their family member. That is, resources will be needed to build the capacity of consumers and their families, not just the capacity of services. Issues pertaining to supported decision making of people with decision making difficulties are discussed at length in the Victoria Law Reform Commission’s report on Guardianship Laws. There may be some alignment here with future resourcing for capacity building to accompany a reviewed Victorian Mental Health Act.

Fiona Williams, a prominent UK social policy academic, has highlighted useful distinctions between ‘choice’, which can lead to empowerment as a consumer, and ‘voice’, which requires a collective approach leading to citizenship. This distinction is valuable in regard to the emergence and evolution of Consumer Directed Care. Empowerment as a consumer of services can be seen as a necessary step for people with a disability and their families but nonetheless has limitations and hazards. Strong and effective systemic advocacy and representation will be as important as ever in complimenting and monitoring any market driven system.

### 2.4 Assessment processes

The Productivity Commission’s final report on Disability Care and Support refers to the inclusion of people with a ‘significant and enduring psychiatric disability’ within Tier 3 (individualised supports) of the scheme. The report also explains that eligibility should be based upon an individual’s functioning according to the World Health
Organisation’s International Classification of Functioning (ICF). Importantly, this acknowledges that disability has a social context. Carers Victoria also welcomed the report’s reference to nine life domains rather than the previous reliance on three core activity restrictions as used by the Australian Bureau of Statistics (ABS)’s Survey of Disability, Ageing and Carers.8 Using the ICF as a guide is much more inclusive of people with intellectual, cognitive or psychiatric disabilities. Carers Victoria recommends that a reformed PDRSS system is informed by the process of NDIS design and, where appropriate, begins a process of alignment.

Carers Victoria has had some opportunity, via the Network of Carers Associations, to have input to a national process to develop NDIS’s assessment processes and tools. Dyson Consulting has been commissioned by the Commonwealth Government to do this work. The Productivity Commission’s report recommended that assessment of support packages should take into account the needs, wants and aspirations of people with a disability accessing the scheme.9 The Network of Carers Associations have advocated that a similar approach should be used to assess not only the capacity and willingness of family members to provide care, but also to determine their own needs for support.

2.5 Planned Respite funding

It has been noted that the PDRSS reform process will defer inclusion of Planned Respite Services until a later date. This submission will take this early opportunity to provide additional information and comment. Carers Victoria has had a long term interest in respite for carers, as both a representative body for carers of a person with a disability, a mental health problem or is aged, and as a funded service provider delivering respite services funded by Victorian and Commonwealth governments.

The Victorian State government currently spends approximately $3M per year on its Respite for Carers program, divided between 12 organisations. In 2006, the Commonwealth Government also began to deliver mental health respite services as part of the 2006-11 COAG National Action Plan for Mental Health. This Mental Health Respite for carers program has continued with Victoria’s share of the funding surpassing the level of funding provided directly by the state. In 2008-09, the Commonwealth spent $58.4M nationally on the respite program, delivered through the Department of Families, Community, Housing and Indigenous Affairs (FaHCSIA)10.
Given that the Commonwealth provides the lion’s share of mental health respite funding in Victoria, there may be a case for the state to reassess its spending in this area. The PDRSS reform process is an opportunity to rigorously review the objectives and effectiveness of respite services.

Carers routinely express satisfaction with respite services when consulted by government or service providers. However, there are reasons for applying more scrutiny to this finding. As a group, carers of people with a mental illness also report that they have many unmet needs. Respite services have become part of an orthodox and very limited service offering to carers. Respite is rarely offered in the context of offering a meaningful alternative.

At the same time, evidence also suggests that uptake of respite services for carers of a person with a mental illness can be lower than expected or is patchy. It is not known whether this applies also to state funded services.

It is possible to present a critique of respite services for carers of a person with a mental illness on conceptual and effectiveness grounds. Here are some salient points:

- The term ‘respite’ can be used in different ways and contexts, causing confusion for service users, service providers and policy makers. ‘Respite’ can be a service type, an activity or a carer outcome. The latter use can have value in measuring service effectiveness, and, as a subjective outcome, can be self assessed. Akin to respite as a carer outcome is the concept of ‘respite effect’. This may have broader utility in assessing the comparative benefits of different service interventions. For example, day programs can have a respite effect for family members, as can employment support services, or acute inpatient services, or PaRCs. However, ‘respite effect’ should still be seen as just one of many possible positive and meaningful outcomes for carers.

- The language of ‘respite’ is the flip side of the ‘carer burden’ coin, and as such is problematic. It can be seen to imply that a carer is not coping, but should. Feelings of shame and guilt may prevent help seeking. Consumers and carers may also infer that the term implies that caring (and the person with a mental illness themselves) is burdensome.
• Respite service guidelines and funding structures emphasise short term interventions to provide ‘relief’ for the carer so they can continue to provide care in the same way as before the respite.
• The evidence base for the effectiveness of respite services is underdeveloped and/or inconclusive.\textsuperscript{12}
• Access to respite services often requires or assumes that the client identifies themselves as a carer. Many family members providing care do not naturally self identify as a carer, seeing themselves instead as a partner, a mother, brother, etc. For many people providing care, these are more natural and normalised social roles, and roles they do not wish to relinquish in favour of the ‘carer’ label. In addition, many individuals are sensitive to the fact that their family or friend with a mental illness rejects the term ‘carer’, finding it demeaning.
• Respite services are often rationed to one identified carer per family. This approach can neglect other members of the family who need support, including young people with caring responsibilities, and potentially be confining for the person who does identify as a carer.

2.5.1 Good Practice
Early guidelines provided by FaHCSIA for mental health respite services were perceived to be derived from respite models for people with a disability or an elderly person needing care.

Over recent years, service providers and advocates have provided FaHCSIA with the following feedback:
• Residential models of respite are not always seen as appropriate or desirable by carers/family members and/or the person with a mental illness. FaHCSIA’s guidelines initially used a distinction between ‘direct’ and ‘indirect’ respite. Direct respite referred to substitute or residential care provision, or supporting the person with a mental illness to go away on a camp without their family. Indirect respite might refer to a carer being funded to use activities that provide a respite effect, such as attending psycho-education sessions. During the first few years, service providers were encouraged to provide indirect respite only if direct respite was not appropriate or acceptable. This was later de-emphasised, with neither category having more precedence over the other. Many experienced
mental health professionals found the distinction artificial and bureaucratic rather than having any great meaning for families. There is now widespread acceptance that good practice is that which is flexible enough to meet the family’s needs.

- Successful respite requires that the person with a mental illness not only consents to any intervention, but is engaged in it. To achieve this, respite needs to be meaningful for all parties involved, recognising that the needs of carers are often interdependent with those of the person they care for. This point was made clearly as early as 1998 in SANE’s Blueprint for Planned Respite Care. Insuring that respite is meaningful for the person with a mental illness is also strongly consistent with adopting a recovery oriented approach. Some state funded mental health respite programs that have provided one-to-one approaches for the person with a mental illness have achieved this.

- Good respite practice (involving and working with consumers) begins to look very similar to other PDRSS service type practice (such as Home Based Outreach programs, Day Programs) that is genuinely family focused. This is an example where current PDRSS service categories are artificial rather than aligned with the lived experiences of the people involved.

- Meaningful respite for both those with a psychiatric disability and those caring is often best achieved within the context of an ongoing relationship with a trusted worker. Such a relationship, if resourced, can be part of providing long term support to a family rather than short term, more rationed service responses.

### 2.5.2 Current systemic issues

Providing the bulk of mental health respite funding through the Commonwealth creates additional problems that are difficult to address. Practice guidelines and policy formation tends to promote consistency and collaboration between FaHCSIA programs but these programs are not positioned well to integrate with broader state funded programs. In effect, this reinforces the artificial divide that can exist between ‘carer services’ and those for the person with a mental illness. The interdependence of people with a mental illness and their family members is made to be peripheral and any aspirations to using a whole of family approach become unrealistic.
2.5.3 Opportunities

A future NDIS could avoid the reproduction of similar Commonwealth-State silos affecting families by pooling government funds. Although there is much more work to be done, the Productivity Commission’s final report does refer to the needs of carers and families and how they might be met through a new scheme. Of particular note, the Commission has accepted that families will have a broad range of needs determined by many factors and not necessarily neatly predictable by condition or level of disability. Family make-up, access to informal and formal supports and current family circumstances and transitions all need to be taken into account. A tiered approach with flexible responses is needed.

Families need:

- Whole of family assessment: Needs, wants and aspirations of all parties are considered. Intentions to continue caring, how often, in what way and for how long are highly relevant.
- Service system identifies family members and their caring roles – negating the need to identify as a carer.
- Adult specialist services to identify children with a parent with a mental illness, as per Cummins Report. There are useful lessons from the Families with a Parent with a Mental Illness (FaPMI) program that could apply to, or include, PDRSS services.
- Tiered, flexible responses based on family need and circumstances. Many families will need ongoing support, not just ‘respite’. Family members’ aspirations should be taken into account. For example, many current respite service offerings do not support the training or workforce participation of people with caring responsibilities, either because of a deliberate policy or because services are too rigid. Counselling (individual and/or family) and psycho-education should also be part of a range of possible supports, according to assessed need.
- Integrated responses that respond to the interdependence of need between people with disabilities and their families. Interventions must be meaningful for all parties to be effective.
- Ongoing support and flexible responses to crises and transitions.
2.5.4 Planned respite funding recommendations

Carers Victoria recommends:
That current state funding for Planned Respite services be retained but reoriented to pilot integrated programs that wrap around the family, including the person with a mental illness. Respite terminology should be avoided, referring to family support instead. This should not be designed or initiated as a specialist service; rather, it should lead the way towards a universal approach. The following will be needed:

- whole of family assessments (including children)
- support for people with a mental illness and their family members, where applicable
- an approach that is individualised/Consumer Directed and family focused
- brokerage dollars to purchase a range of supports. This could be from the state or levered from the FaHCSIA MHR program. The latter may create equity issues if this is perceived as some families ‘double dipping’
- a comprehensive evaluation.

Commonwealth funded services (PHAMs, Mental Health Respite Program, Young Carer Respite funding) in isolation are not positioned to achieve the level of integration of support required by families.

A pilot of the type suggested above would also build:

- development and documentation of practice wisdom
- expertise in logistical and bureaucratic problem solving.

These innovations would position Victorian services very favourably if and when an NDIS is rolled out. Many families would choose service offerings of this type if the market made them available.

There would also be opportunities for this work to influence service design and practice at the national level.

2.6 Further comments about the need for family focused services

PDRSS services are not consistently family focused in their practice. This is a source of some frustration and bewilderment for families. Some possible barriers to progress in this area include:

- funding formulae and structures that emphasise individual needs. These can be interpreted to exclude carers/family members
- rehabilitation principles e.g. Boston’s Principles of Psychosocial Rehabilitation that emphasise intrapersonal issues but not interpersonal ones (except in relation to workers)
- unacknowledged influence of dominant medical models that can result in an anti-psychiatry stance but that has not always resulted in more holistic approaches including families.

There are some current opportunities to drive an agenda here:
- Vulnerable Children Report: this recommends legislative change to require identification of vulnerable children by adult specialist services, and additional resources to assist services to become family focused
- learning from existing and previous initiatives such as FaPMI, Building family Skills Together, FaST
- development and review of recovery principles and guidelines to reinforce the importance of interdependence for personal recovery
- reconfiguration of PDRSS funding models to support and facilitate family work.

2.7 Mutual Support and Self Help Services

It is noted that reform of this funding type has been deferred. One of the great strengths of the work done by these services is that it exists at the interface between the broader community and the specialist mental health service system. Many people find these services easier to access, less stigmatising and more reflective of their lived experience than other services.

In some ways, MSSH services have also been disadvantaged by their positioning. They are not always perceived as being an integral part of the state funded mental health service response that focuses on those who are most unwell and/or disabled. In some ways, MSSH activities could be seen to overlap with the primary health part of the system, which tends to be Commonwealth funded. Medicare Locals may have the potential to take a similar role to MSSH services at the local level.

There are a couple of flaws and shortcomings with this conceptualisation. One is that some state funded MSSH services do provide services for people with significant psychiatric disability, including those with low prevalence mental health disorders. The other is that state specialist MSSH organisations provide a whole of state co-
ordination of resources, information and advocacy that is currently not provided within the primary health system. Neither can it be assumed that the current evolution of Medicare Locals will be positioned to provide continuity of expertise that currently exists within the MSSH funded system.

2.8 Adult Residential Rehabilitation Services
Carers Victoria supports a shift away from transitional approaches to providing accommodation and support. As the Nous Group discovered in their evaluation, research literature and consumer preferences support approaches that offer greater security of tenure. Although reforms to ARRS have been postponed, Carers Victoria would like to take this opportunity to make the following comments:

- Any reform processes that result in displacement of people with a psychiatric disability must of course be done sensitively, ensuring that no individuals are disadvantaged and respecting the wishes of consumers and their carers.
- Criticisms made about ARRs based upon consumer preferences for living alone or with other individuals of their choice may also apply to other models of congregate supported accommodation.
- Any net loss of accommodation earmarked for people with a psychiatric disability must be avoided. Deinstitutionalisation policies in Victoria, although well intended, combined with housing market failure and government social housing policy to consistently fail many people with a mental illness and their families. Current problems are in part to do with the machinery and structures of government that have distinct psychiatric support and housing silos operating in parallel. While there is strong evidence that support and housing provision should be kept separate, this refers to the domain of practice and individual organisational domains. Separation of psychiatric support and housing at the policy level has no such evidence base. Carers Victoria continues to call upon the Victorian government for population based planning and investment in housing for people with a mental illness, with clear targeting – as is the case in Western Australia.\textsuperscript{14,15} Debate around the role of ARRs is in some ways symptomatic of, or even a proxy for, more fundamental discussions about systemic scarcity of housing and support.
There are parallels here with current discussions about the role an NDIS might take in relation to supported accommodation. Carers Victoria has argued that a continued shortage of affordable appropriate housing has the potential to reduce the effectiveness of an NDIS in assisting people with a disability to achieve intended outcomes. In addition, providing a small proportion of supported accommodation places without housing alternatives may create perverse incentives for individuals to choose or qualify for a service type that they would otherwise not choose. Economies of scale and operating pressures may also result in congregate care settings with a mix of people with different disability types.

The Productivity Commission’s approach to supported accommodation conflates support or disability need with housing need. That is, if a person has disabilities of a profound and complex nature, they are more likely to qualify for funded accommodation in a congregate setting. This approach meets service or logistical needs or conveniences rather than individual client choice or, indeed, service effectiveness. It may also be inequitable if the individual has other housing options or financial resources. The Productivity Commission estimates that 6000 people with a psychiatric disability would be eligible for supported accommodation nationally. This figure is based upon existing National Disability Agreement figures that do not adequately capture the needs of this population. On the other hand, government social housing policies prioritise housing largely based on housing need, not disability. This mismatch, which also applies here to state funded supported accommodation, needs urgent attention.

2.9 Further comments about Day Programs

Many of the shortcomings of current Day Programs discussed in the Consultation Paper are valid. However, Day Programs, if delivered effectively, can provide not only meaningful social engagement and activity, but also an important respite effect for family members and carers, allowing improved health and wellbeing and workforce participation for many. A focus on only individual outcomes renders this reality invisible to not only many service providers, but also policy makers.

It remains to be seen whether moves towards consumer directed care approaches within an NDIS will create increased demand for Day Programs in the future. Group
activities, including Day Programs, are likely to be vulnerable to economies of scale within a competitive marketplace, particularly those in regional or rural areas. Given that recovery necessarily exists within a social context, this may be a significant loss to the service system and to the lives of people with a psychiatric disability and their families.
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