GOVERNMENT OF
WESTERN AUSTRALIA

Sustainable
Health Review

Public Submission Cover Sheet

Please complete this sheet and submit with any attachments to the Sustainable Health Review Secretariat

Your Personal Details

This information will be used only for contacting you in relation to this submission

Title	Mr ☐ Miss ☐ Mrs ☐ Ms ☐ Dr ☐ Other ☐
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Publication of Submissions

Please note all Public Submissions will be published unless otherwise selected below

☐ I do not want my submission published

☐ I would like my submission to be published but remain anonymous

Submission Guidance

You are encouraged to address the following question:

In the context of the Sustainable Health Review Terms of Reference listed below, what is needed to develop a more sustainable, patient centred health system in WA?

- Leveraging existing investment in Primary, Secondary and Tertiary healthcare, as well as new initiatives to improve patient centred service delivery, pathways and transition;
- The mix of services provided across the system, including gaps in service provision, sub-acute, step-down, community and other out-of-hospital services across WA to deliver care in the most appropriate setting and to maximise health outcomes and value to the public;
- Ways to encourage and drive digital innovation, the use of new technology, research and data to support patient centred care and improved performance;
- Opportunities to drive partnerships across sectors and all levels of government to reduce duplication and to deliver integrated and coordinated care;
- Ways to drive improvements in safety and quality for patients, value and financial sustainability, including cost drivers, allocative and technical efficiencies;
- The key enablers of new efficiencies and change, including, research, productivity, teaching and training, culture, leadership development, procurement and improved performance monitoring;
- Any further opportunities concerning patient centred service delivery and the sustainability of the WA health system.

Submissions Response Field

Please type your response into the field below. Alternatively you may provide your submissions as a separate attachment (Suggested Maximum 5 pages).

Thank you for the opportunity to provide a submission. Ours is attached separately.

Please note that HelpingMinds also supports the recommendations in the submission by WAAMH.

GOVERNMENT OF
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Sustainable Health Review

Supporting families and friends of people with mental health issues

helpingminds
Mental Health Services & Carer Support

HelpingMinds provides a range of supports to families and individuals experiencing issues arising from mental distress. We work directly with family members and friends in an ongoing caring role and with individuals who require support as a result of a mental health issue.

The number of family members and friends in Western Australia providing care to a person with disability due to a psychological condition has been estimated at around 61,000[1]. However, academic researchers suggest that this figure is a considerable underestimate and that approximately 15 per cent of all Australian adults are providing ongoing care and support to a family member or friend with disability related to mental ill health[2]. Many young people, including children, are also in ongoing caring role for their parents and other family members living with psychosocial disability.

Over 72,000 people in Western Australia have identified as requiring assistance due to a psychological condition. The vast majority of people who need assistance receive it from their family and friends who provide support in cognitive and emotional tasks, personal and health care, mobility, household tasks, transport, and reading and writing tasks[3].

The lives of people with mental health issues and their family members and friends who support them can become closely entwined. HelpingMinds encourages a 'family centred' approach to service delivery. This places the individual at the centre but closely acknowledges the needs of the person's support network including their family members or friends who provide ongoing support and who may require support themselves to continue this role in a positive manner[4].

In WA, the Carers Recognition Act 2004[5] requires health and disability service providers to identify family members and friends who are in an ongoing, unpaid caring role.

Both people with mental health issues and their family members and friends in an ongoing caring role, experience lower levels of physical and mental wellbeing than the general population. There is evidence of the efficacy of psychoeducation and other supports to be provided to reduce the negative impacts of the caring role, and to address the health needs of people living with mental health issues[6].

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[1] Australian Bureau of Statistics. 2014. Caring in the Community, Australia, 2012. Table 14.

[2] Pirkis, J., Burgess, P., Hardy, J., Harris, M., Slade, T. and Johnston, A. 2010. 'Who cares? A profile of people who care for relatives with a mental disorder'. *Australian and New Zealand Journal of Psychiatry*, 44:929-937.

[3] Australian Bureau of Statistics. 2015. Survey of Disability, Ageing and Carers: Psychological Disability, 2012 – Australia. Tables 3 and 8.

[4] COPMI. 2014. Family Recovery.

[5] Carers Recognition Act 2004 https://www.slp.wa.gov.au/pco/prod/filestore.nsf/FileURL/mrdoc_28814.pdf/$FILE/Carers%20Recognition%20Act%202004%20-%20%5B01-e0-00%5D.pdf?OpenElement

[6] Wyder, M. and Bland. R. 2014. 'The recovery framework as a way of understanding families' responses to mental illness'. *Australian Social Work*.; US Department of Health and Human Services. 2009. Family Psychoeducation: The Evidence.; Price-Robertson et al. 2016. 'Supporting recovery in families affected by parental mental illness, CFCA Practice Resource.; Harvey, C. and O'Hanlon, B. 2013. 'Family psychoeducation for people with schizophrenia and other psychotic disorders and their families', Australian and NZ Journal of Psychiatry 47(6) 516-520.

Addressing the health and wellbeing of family members and friends in a caring role

Family members and friends provide the majority of support received by people who need support due to a mental health issue[7]. Family and friends carry out a wide range of roles including the provision of emotional, practical and personal care tasks. Family members and friends attempt to fill the gap when the person they care about is unable to engage with services, or is unable to access services that meet their needs. Across Australia, the value of this care, if it was to be replaced by paid staff, was recently estimated at $13.2 billion annually[8].

However, carers are more likely to experience disability, low income and unemployment than the general population[9], which puts their own physical and emotional wellbeing at risk. For this reason, in other jurisdictions, legislation has been enacted to allow carers an annual health check. In Australia, in the same way that a person turning 50 receives a letter encouraging them and entitling them to participate in certain health checks, a person who is identified as a carer could also be encouraged to visit their GP for a carer health check.

One of the reasons carers experience distress is due to inconsistencies in their treatment and recognition by staff across various government agencies. This creates barriers to them in their advocacy and support for the family member (or friend) they are supporting. Currently, the Carers Recognition Act 2004 applies only to the health and disability sectors. To achieve a more integrated and coordinated approach, this legislation should be applied to other state government sectors, particularly the mental health and AOD sectors, but additionally the education, child protection, justice and housing sectors.

Recommendations:

Implementation of training for staff in in communication with family members and friends in a caring role. Utilise the Practical Guide for Working with Carers of People with a Mental Illness[10]

Develop resources to clarify what information can be shared with carers under the Mental Health Act 2014 without breaching the individual's confidentiality.

When a person is identified in the health system as being in a caring role, this should trigger a referral to their GP for a health check. This could be adopted in a similar fashion to the UK model[11].

Review the Western Australian Carers Recognition Act 2004 to ensure its consistency with the Mental Health Act 2014 and the merger of the mental health and alcohol and other drug sectors under the Mental Health Commission.

Carer peer workers to be employed within hospital in the home initiatives to ensure that family members are supported to carry out their caring role for the person who is remaining at home.

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[7] Australian Bureau of Statistics. 2017. Disability, Ageing and Carers: Summary of Findings

[8] Diminic, S., et al. 2016. The Economic Value of Informal Mental Health Caring in Australia. Technical report. University of Queensland.

[9] Australian Bureau of Statistics. Disability, Ageing and Carers: Summary of Findings

[10] Mind Australia et al. 2016. A Practical Guide for Working with Carers of People with a Mental Illness. http://pmhccn.com.au/Portals/2/PublicDocuments/NetworkProjects/A%20Practical%20Guide%20for%20working%20with%20people%20with%20a%20mental%20illness.pdf

[11] National Health Service England. 2016. An integrated approach to identifying and assessing carer health and wellbeing. https://www.england.nhs.uk/wp-content/uploads/2016/05/identifying-assessing-carer-hlth-wellbeing.pdf

Treatment, Support and Discharge Plans to be available electronically through PSOLIS.

Each health service site to develop and make available a plain language glossary explaining the various roles of staff within the organisation.

Additional peer workers (carers and consumers) to be employed within health and mental health services.

Build support for consumers and carers to be involved in the co-design of services.

Ensure that adequately resourced independent advocacy is available for consumers and carers in the health and mental health sectors.

Aboriginal families in a caring role

'The Aboriginal kinship system can provide considerable support through the immediate and extended family network'[12]. However, this potential support may be excluded by health service providers, when family are prevented from being involved and as a result, lack the information they need to support the person who is distressed. Conversely, the family may be over relied upon, as they are forced to fill the gaps created by a lack of appropriate services.

Australia wide, the average age of Aboriginal carers is younger than in non-Aboriginal populations. A greater proportion of the Aboriginal population is in a caring role relative to non-Aboriginal people. Aboriginal carers are also more likely than other carers to be living with their own disability and health needs[13]. Being in a caring role, feeling a sense of responsibility for another person can generate conflict and anxiety[14], particularly when the carer is stretched across caring for generations of family members, as happens to grandparents.

Aboriginal people from country regions are frequently required to travel for health and mental health services. While evidence shows that having supportive people around is conducive to recovery, families report receiving little or no notice that a family member is being discharged from hospital, and that the person may be discharged with no secure accommodation organised nor any means of travelling home. Family members also experience difficulty in travelling to Perth to assist a hospitalised family member, and have difficulties accessing accommodation while they are required to be in the metro area.

In communities, challenges occur due a lack of culturally safe services in the local region, a lack of transport services, disengagement from services due to previous poor experiences, a lack of support to easily link between primary and acute services to community services, (including community services for carers/family members), and a lack of integration of mental health and AOD services. This increases the likelihood that a person experiencing mental health issues that may have been adequately supported with a range of community services instead ends up being hospitalised.

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[12] Wright, Michael. 2014. 'Reframing Aboriginal Family Caregiving', in Dudgeon, P., Milroy, H. and Walker, R. (eds) Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice, p. 246.

[13] Commonwealth of Australia. 2017. Aboriginal and Torres Strait Islander Health Performance Framework 2017 Report.

[14] Ward et. Al. 2011. 'With good intentions: complexity in unsolicited informal support for Aboriginal and Torres Strait Islander peoples. A qualitative study'. BMC Public Health, 11.686.

Recommendations:

The higher rates of caring and higher levels of disability amongst Aboriginal carers should be explicitly recognised and incorporated into demographic analysis of need.

Address shortcomings with the Patient Assisted Travel Scheme to ensure that individuals and relevant family members are able to travel and be available to the person receiving mental health or AOD services outside of their community.

Provide residential OAD services in country areas, for individuals, **and** for their family members and friends.

Provide more support for country patients being discharged from metropolitan psychiatric wards, and for their visiting family members.

Additional Aboriginal peer workers (carers and consumers) to be employed within health and mental health services.

Ensure that services are culturally safe which includes being able to involve the person’s family members and support them appropriately including through referrals to carer services.

Evaluate the impact of outreach and transport services in assisting people to engage with services. In our experience, these are essential to supporting engagement.

Silos between AOD and mental health services

People experiencing both mental health and AOD issues report barriers to accessing services in both the AOD or mental health sector. Families have told us this is a significant issue that adds distress to the individual and their family. Access to treatment and support is delayed, and people become less hopeful of finding the services they need. In many cases, families will separate due to ongoing distress, leading to the individual becoming isolated and at higher risk of homelessness. The lack of integration between agencies mean that people are more likely to fall through the cracks which exacerbates their own struggles and further impacts on the people around them.

Recommendations:

Review the Carers Recognition Act 2004 to ensure consistency in the recognition of family members and friends in a caring role at least across the health, mental health and AOD service sectors.

Invest in residential services that are able to support a person with mental health issues to participate in programs that support their withdrawal from substance use.

Develop programs to support the individual and their family during the period of waiting to enter residential AOD facilities.

Consistent with the ‘Guiding Principles of working with clients with comorbidity’, ensure that families and other supporters are involved in the treatment including addressing the recovery needs of the family.

Provide guidance and clear referral pathways to individuals with co-existing conditions and to family members and friends who provide ongoing support to the individual.

The Primary Health Sector, in their role as care coordinators for individuals with chronic conditions and mental health issues and problematic substance use, need to better utilise existing pathways to care and ensure that information is provided to the individual and their family members/friends who are in an ongoing caring role.

Young people in a caring role in WA

In WA, there are approximately 25,000 young people aged under 26 who are in a caring role for a family member or friend who needs support due to a chronic health condition or disability of some kind, including ongoing mental health issues or physical disability. Almost 7,000 of these young carers are aged under 15 years[15].

Many young carers will engage with WA Health services when the person they are supporting seeks medical treatment or is hospitalised. However, they are very unlikely to identify themselves as being in a caring role and so they may be overlooked which can place them at risk, both within health services, and when they return home.

There are many existing resources and strategies for ensuring the safety and wellbeing of young carers in health settings that could be introduced or expanded within the Western Australian health and mental health sectors.

Young people in a caring role may be playing a significant role in the wellbeing of the family and, in particular, the person they support. The person receiving support from a young carer is most likely to be a parent (58%), but could also be a sibling (31%). In the context of health services, young carers may:

- Prompt their parent to take medication
- Explain medical treatments to their parent
- Make phone calls on behalf of their parent, including seeking health services and making appointments
- Accompany their parent to appointments and to hospital
- Be requested by the parent, or sibling, to remain with them during their hospital stay
- Arrange the care of other dependents remaining at home so that they can accompany their parent to appointments or visit them in hospital
- Call emergency services, such as the ambulance, when their parent is unconscious or behaving in a manner that concerns the young person
- Act as an interpreter
- Provide physical care such as assisting with mobility restrictions
- Provide cognitive and emotional support which in turn assists the person to understand medication and treatment plans
- Care for younger siblings when their parent is absent or unable to do so
- Be responsible for shopping and food preparation
- Be responsible for purchasing medications for their parent

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[15] Carers WA. Caring in Focus – Young Carers. https://www.carerswa.asn.au/resources/carers-in-focus-factsheets/Caring-in-Focus_Young-Carers.pdf

It is vital that young carers are supported in carrying out these roles when engaging with health services, including mental health services.

While a young person whose parent has a mental health issue may be at higher risk of physical and mental health issues, there are effective strategies for reducing their risk that can be implemented within health and mental health services. ‘Quite small interventions have been shown to increase children’s resilience in ways that can provide them with a significant degree of protection[16].’ In summary, what mattered most to young people in a caring role who were dealing with health professionals, was being listened to, understood, and receiving information in response to their needs.

It can be difficult for health professionals to identify when a young person is in a caring role[17]. Often the young person will be experiencing shame and stigma, and their parent may be concerned about child protection issues. However, if young carers are not identified as being in a caring role, a number of negative outcomes can emerge that impact negatively on the safety and wellbeing of the young person.

- The young person does not receive the support they need and, as a result of being overlooked and ignored, experiences greater shame and stigma[18].
- The young person becomes anxious about the wellbeing of the person they support, and fearful for the future of their family.
- Decisions are made about the patient without input from the young person in a caring role which can negatively impact the care the person receives when they are discharged home to the care of the young person.
- The parent who is the patient can become anxious because they may usually rely on the young person for support but they can see that the young person does not know about the future treatment plans, will not be in a position to help when the person returns home, and may be carrying a heavy load during the time when the parent is unwell[19].

What do young carers want to know from health professionals?

In summary, young carers have stated that they want health staff to introduce themselves, to explain their job, and to give the young person the information they need to carry out their caring role. The following resources and suggestions can assist in meeting those needs.

It can be helpful to provide a plain English glossary of health care professionals as per the example below.

https://www.carergateway.gov.au/young-carers-and-healthcare-professionals

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[16] Cooklin, A. 2013. ‘Promoting children’s resilience to parental mental illness: Engaging the child’s thinking’. *Advances in psychiatric treatment*, vol. 19, 229-240.

[17] RANZCP. 2012. Supporting carers in the mental health system. Position Statement 76. https://www.ranzcp.org/Files/Resources/76-Support-for-carers-in-the-mental-health-sys.aspx

[18] Cooklin, A. 2013. ‘Promoting children’s resilience to parental mental illness: Engaging the child’s thinking’. *Advances in psychiatric treatment*, vol. 19, 229-240.

[19] Rampou, A., Havenga, Y. and Madumo, M. 2015. ‘Parenting experiences of mothers living with a chronic mental illness’. *Health SA Gesondheid 20*, 118-127.

When explaining information to the patient, it's important to make sure that the young person who will be providing support when the person is discharged also understands what's required of them. This will help the young person carry out their caring role when the family member is discharged and returns home, but it will also support the patient if they can see that the young person understands and feels confident.

When scheduling appointments, keep in mind that transport can be an issue for young people, and that they may be at school and need appointments outside of school hours.

It is important that children and young people are not used as interpreters when the patient needs medical information to be provided to them in another language. While in some cultures, children do participate in discussions about important issues with their adult family members, this does not mean that the child/young person has the necessary medical knowledge to accurately interpret and translate medical information, most particularly in the context of being asked to convey potentially distressing information.

Current carer strategies within health services – assess whether they are adequate to support young carers

While it is a requirement of the Carers Recognition Act 2004 that carers of all ages are identified in WA Health services, specific strategies may need to be adopted to ensure that young carers are identified and their caring role recorded in the patient's file. The following are useful resources to assist staff in identifying and engaging young carers, and in encouraging and supporting young carers to self-identify.

- Information to encourage young carers to self-identify and feel confident in speaking up. http://www.youngcarers.net.au/tips/talking-to-medical-professionals/
- Training for staff – provide copies of the Working with Young Carers: A Guide for Medical Professionals http://www.youngcarers.net.au/resources/for-medical-professionals/
- Encourage young carers to self-identify and self-advocate https://www.carersvictoria.org.au/Assets/Files/20170726-cvic-factsheets-young%20carer-tips%20for%20self%20advocacy.pdf

Recommendations.

Ensure systems are in place during admission or preadmission so that young people in a caring role for the patient are identified and offered information and or referral to appropriate services and supports.

Ensure resources are available within mental health services to facilitate engagement with clients who are parents and to discuss their needs as a parent.

Develop location specific resources for staff to increase their awareness of and confidence in working with young carers. Identify which existing staff roles are best placed to assist young carers, for example, Carer Champions, Carer Peer Workers or Carer Consultants.

Assess information currently provided to carers meets the needs of young people.

Ensure that information about the rights of carers is available in a format that younger carers can understand.