Many Voices, Big Impact

Mental health lived experience submission on the Sustainable Health Review Interim Report

2018

Presented by:

HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

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Many Voices, Big Impact: Lived experience submission on the Sustainable Health Review Interim Report

BACKGROUND

In June 2017, the Western Australian government announced a Sustainable Health Review (SHR) to prioritise the delivery of patient-centered services of a high quality in the appropriate place at a sustainable financial level. A SHR Panel (the Panel) was convened to guide the review, chaired by Ms Robyn Kruk AM[1]. A Consumer and Carer Reference Group and a Clinical Reference Group also provide expertise to the review. Extensive consultation took place which included over 300 public submissions, 19 forums across Western Australia (WA) and additional sessions with stakeholders. In January 2018, an Interim Report was released which identified 12 Preliminary Directions including 9 Recommendations for Immediate Action and Areas for Further Work[2]. The final report and recommendations are due to the State Government in November 2018.

Following the release of the Interim Report, key stakeholders in the mental health area met to discuss the Interim Report findings. Stakeholders included:

- The Western Australian Association for Mental Health (WAAMH): the peak body for community managed organisations in the mental health sector.
- Carers WA: the peak body that represents the needs and interests of carers in Western Australia.
- Consumers of Mental Health WA (CoMHWA): the peak body by and for people with lived experience of mental health issues in WA.
- Health Consumers Council (WA): provides an independent voice advocating for patients in WA.
- Helping Minds: a community-managed organisation which provides support to children, young people, adults and families that are affected by mental illness across the whole of WA.
- Mental Health Matters 2: a volunteer systemic advocacy and action group specifically focussed on the needs and interests of individuals and families with experiences of mental distress, alcohol and other drug use and/or criminal justice involvement.

Stakeholder analysis of the Sustainable Health Review Interim Report

All the stakeholders had made individual submissions and/or had participated in the community consultations (a summary of common findings and recommendations

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[1] Further information can be obtained from https://ww2.health.wa.gov.au/Improving-WA-Health/Sustainable-health-review/About-the-Review

[2] *Sustainable Health Review Interim Report* (2018). State Government of Western Australia. https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Sustainable%20Health%20Review/sustainable-health-review-interim-report.pdf

from these submissions, and an analysis comparing the gaps between these recommendations and those of the SHR Interim report can be found in Appendix 1). Between the key stakeholders there was agreement that:

a. The focus on mental health in the Interim Report needed to be strengthened given the prevalence and impact of mental health issues.

"In terms of non-fatal burden only, mental and substance use disorders along with musculoskeletal conditions had the greatest impact, accounting for nearly one-half of the total non-fatal burden between them"[3]. (AIHW 2016).

b. There is insufficient connection in the SHR Interim Report to the work outlined in the WA Mental Health, Alcohol and Other Drug Service Plan 2015-2025 (the Plan) which sets out the state government's strategic direction for mental health including the service mix needed for a sustainable system, and for which extensive consultation had been conducted prior to its release in 2015.

c. There needs to be a rebalancing of investment into community-based services. While the mental health system in WA is under-resourced, it continues to be dominated by hospital-based services which are often accessed in crisis resulting in over-reliance on expensive acute services such as Emergency Departments. The Plan seeks to rebalance the mental health system towards prevention and early intervention by providing services and supports in the community where people live.

d. The perspective and expertise of lived experience of consumers and families/carers needed to be amplified to inform the Final Report as it was felt that this had not been done as well as hoped during the consultation period. There is sufficient evidence that co-designing with mental health consumers and their families and supporters leads to better outcomes for them which in turn means that resources are used more efficiently[4].

Based on these recommendations, it was decided that the key stakeholder organisations would partner to hold two forums focussed specifically to hear from people with lived experience[5] with respect to what is needed in the area of mental health to support Recovery. (Recovery in this context is defined as 'a personal process of attaining a life that is meaningful, empowered and fulfilling from the person's own perspective, irrespective of diagnosis and/or symptoms'.[6]), and to

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[3] Australian Institute of Health and Welfare. (2016). *Australian Burden of Disease Study: impact and causes of illness and death in Australia 2011.*

[4] Cheverton, J. & Janamian, T. (2016). *Value co-creation: a methodology to drive primary healthcare reform.* MJA(204) 7. Retrieved from: https://www.mja.com.au/system/files/issues/204_07/10.5694mja16.00124.pdf

[5] Where this term is used, it encompasses individuals with experiences of mental distress and families, carers and supporters.

[6] *Consumers of Mental Health WA*. (2018) *Definitions*. Retrieved from: http://www.comhwa.org.au/about-us/definitions/

share their views on the SHR and the Interim Report. Two conversation-based workshop events were held in June 2018, with the findings to be compiled in a report to be presented to the SHR Secretariat and panel for incorporation into the final SHR Report.

The following section of this report outlines the findings from these events, and the recommendations that emerged from these findings. Further detail about the event process and logistics can be found in Appendix 2.

LIVED EXPERIENCE VIEWS ON A SUSTAINABLE HEALTH SYSTEM

The two consultation events were titled, “Many Voices, Big Impact” and were based around small group discussions that captured themes relevant to sustainability in health, with a focus on mental health. The small group discussions focused on four vignettes (Appendix 3). The vignettes sought to reflect experiences of people shared at previous consultations and forums, including those for the development of Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015-2025 and the Mental Health Act 2014. They also sought to reflect the experiences of under-represented groups including ethnic minorities, LGBTIQ, young people, Aboriginal people and those who live in regional, rural or remote areas.

The vignettes deliberately spoke of the broader context of people’s lives where they intersect with other areas such as aged care, criminal justice, finance, accommodation and support and employment. Mental health does not operate in a vacuum and including context on people’s broader lives facilitated the inclusion of the social determinants of mental health which are largely overlooked in a medical model of treatment and care.

Three questions were asked in relation to the vignettes. These questions were:

1. What could have been done in terms of prevention for both the individual and family?
2. What needs to happen now to resolve the current situation for both the person and their family?
3. What would ‘best practice in working with consumers and families/carers’ look like in this situation to provide person-centred and family-inclusive service?

A fourth question was asked which was broader in nature:

4. If you were (or were advising) the Director General of the Health Department, with a limited budget, where would you direct the resources in order to create sustainability?

Themes

People with lived experience who attended the two events were active and engaged and gave extensive feedback to all the questions. This feedback was collated and several common themes were identified, as detailed below. The key themes speak to

concerns and issues of importance for a sustainable health and mental health system, and shaped the recommendations for the SHR Report which follow.

1. Stigma and discrimination awareness and prevention

- People with lived experience identify the need to develop or strengthen stigma-reduction programs across the community in areas such as sporting clubs, workplaces and schools, as important. This is recognized as being particularly important within under-represented communities such as ethnic minorities, LGBTIQ and Aboriginal communities where there may be heightened stigma around seeking mental health support despite there being a high need. By reducing stigma around mental health, it is hoped that more people would seek help earlier, thereby reducing crisis-driven help-seeking and suicide.

- People with lived experience, carers, family members and supporters also identify stigma reduction *within* health services as important, particularly for people with certain mental health diagnoses, for example, personality disorders[7].

- Individuals and carers with experiences of alcohol and other drug use[8] describe being discriminated against within general health and mental health settings where they were too often told to 'deal with' their addiction before treatment/support could be given for mental health issues, resulting in an ability to access services.

What people say is needed:

- *"Breaking down the stigma / normalization."*
- *"Education – reduce stigma – community based, community support"*
- *"Campaign to remove stigma."*
- *"ALL health staff and clinicians trained and held accountable to trauma informed, person centred, recovery focus, non-stigmatising, culturally appropriate care."*

2. Prevention, early intervention and community support

- This theme relates to the population-level prevention of mental health and AOD issues before they occur, through prevention and promotion initiatives that address the determinants and risk factors of mental health and AOD challenges. The importance of addressing the social determinants of mental health and the need to address these early to prevent the onset of mental health and AOD issues was consistently raised.

[7] Dominic Markham (2003) Attitudes towards patients with a diagnosis of 'borderline personality disorder': Social rejection and dangerousness, Journal of Mental Health, 12:6, 595-612, DOI: 10.1080/09638230310001627955

[8] Van Boekel, C., Evelien,P.M., Brouwers,J., Weeghel,H., Garretsen,F.L. (2011). *Stigma among Health Professionals towards Patients with Sustance Use disorders and its consequces for healthcare delivery: Systematic Review.*

- This theme also touches on the early identification of any mental health or alcohol and other drug issues in their initial presentations in a person's life and the need to provide timely, culturally appropriate and effective responses to minimize the impact on the person and their family/carer and community. This element of prevention and early intervention is also seen as important to ensure that engagement with inappropriate service responses does not in fact contribute to the worsening of the situation for the person and their family/carer or community and that staff are supported to deliver services in a trauma-informed way.

- This theme also relates to the early intervention at each experience (or 'episode') in order to get the help required as early as possible. People with lived experience who attended the forums identified that listening to and responding effectively to an individual or family member's request for help when they are flagging early signs of need are effective ways to avoid / minimise the need for more acute, hospital-based responses. Failing to respond early may result in transport by ambulance (and sometimes accompanied by police), hospitalization with perhaps involuntary detention and enforced medication and the subsequent significant impacts on the person's accommodation, employment, informal supports and recovery journey. This element of early intervention requires a service to be skilled in listening to and acknowledging individuals and families/carers as partners in care, and to be willing to do so. The need to listen to individuals and families/carers and the results of not doing so were extensively flagged in the 2012 Stokes Review[9]. Again, the need for trauma-informed practice and care is significant to ensure that the act of becoming involved in services does not result in further disconnection and disengagement[10].

- Being able to avoid stressful environments such as emergency departments is seen as important for many people, as high acuity settings such as this can be traumatising for people in distress, and are not seen as the right places for people experiencing a mental health crisis. Prevention, early intervention and community support can help to reduce the need for emergency department attendance and acute care episodes.

What people say:

- *"This is about social determinants – let's go upstream."*
- *"Address social factors in all health services as MH doesn't discriminate."*
- *"Addressing social factors can ease distress."*

[9] Stokes B. (2012). *Review of the admission or referral to and the discharge and transfer practices of public mental health facilities/services in Western Australian*.

[10] Mendes, A. p.23. (2014) *The Value of Peer Support: An Exploration of the Therapeutic benefit of Peer Support for Families and Supporters of Individuals with Co-occurring Mental Ill Health and Substance Use Issues.*

3. *Effective system-navigation tools, supports and resources*

- Lived experience participants, family members, carers and supporters indicated that trying to find the right service, at the right time and in the right place is stressful for many people experiencing mental distress and their families and carers. Resources to help easily find what is needed could be online, however not everyone is conversant with or has access to technology, particularly among under-represented groups in the mental health and AOD sectors. It is identified that having a services co-ordinator role or peer support worker with local skills and knowledge and relevant experience to work with the individual and/or family carer to navigate the system/s would be extremely beneficial. This would also help to reduce the distress which is commonly experienced by individuals and families in trying to navigate a complex system, if not a number of different systems, to find the right supports.

- People at the forums indicated that the need for this system navigation resource is heightened for people who have multiple-unmet needs across the health, mental health and alcohol and other drug areas and who are also likely to experience social disadvantage in areas such as income, housing and employment. Individuals with these experiences are likely to be frequent users of expensive, acute, crisis services such as Emergency Departments.

What people say is needed:

- *"Knowing what services are available."*
- *"Knowing you can access confidential support."*
- *"Having someone to help navigate the system (case management) / find services."*

4. *Greater and more effective service and system linkages, integration and co-ordination*

- Integration within the health system (between hospital and community) is identified by people with lived experience as a key area for improvement. Even where this is mandated by legislation within public mental health services, it is not happening. The Mental Health Advocacy Service, which is authorised under the Mental Health Act 2014 undertook an Inquiry in 2017 into Treatment, Support and Discharge planning. A Treatment, Support and Discharge Plan is mandated under Sections 185-188 of the Act. The 2018 report identified that "no mental health services were fully compliant with the Act, and many were not compliant at all"[11].

- While the issue of integration within health and mental health services is identified as important by people with lived experience, it is seen as critical that

[11] Mental Health Advocacy Service. (2018). *Treatment, Support and Discharge Plans Inquiry (March to September 2017).* Retrieved from: https://mhas.wa.gov.au/assets/documents/TSD-PLANS-final-report-19-March-2018.pdf

this integration also occur with allied systems, for example, housing. Discharging someone to homelessness is likely to result in that person re-engaging in an Emergency Department setting rather than in a lower-cost primary healthcare setting[12]. Similarly, services which address both mental health and AOD presentations, and which are skilled and competent in managing co-occuring presentations is a priority.

- Programs such as the 2017 Prison Transition Team (PTT) which operates as part of the Statewide Forensic Mental Health Service need to be evaluated and expanded if shown to be successful. The PTT seeks to address the gaps for people with serious mental health issues leaving prison and seeks to connect them with community mental health services before their release.

What people say is needed:

- *"Holistic approach."*
- *"He doesn't need to go to juvenile detention. He doesn't need hospital. He needs someone to support him with addressing trauma, linking with services and providing support and stability as directed and informed by him."*

5. Individuals and families/ carers to be genuinely involved as partners in treatment and care

- Despite a plethora of policies, frameworks, standards and principles which speak of the need for 'person-centred' and family-inclusive care, participants at the forums spoke of the reality of continuing to experience exclusion from decision-making and the overlooking of informal supports as critical partners in Recovery[13], which often resulted in people not receiving care as early as possible. This often leads to their accessing services at the acute, crisis stage and/or involvement with the criminal justice system.

- The requirement to deliver on 'person-centred care' cannot be met without equipping the workforce with specific knowledge and skills in deep listening and reflective practice, ensuring transparent and accountable decision-making and implementing a robust and effective complaints mechanism which informs a continuous quality improvement process.

[12] Gazey A, Vallesi S, Cumming C and Wood L. (2018) Royal Perth Hospital Homeless Team. A Report on the First 18 Months of Operation. School of Population and Global Health: University of Western Australia, Perth, Western Australia. DOI: 10.13140/RG.2.2.26289.68960.

[13] Martin, R., Ridley S. and Gilleatt, S. (p.8) (2015). *Multiple unmet needs, families and consumers. A Literature Review for the In Community Project.* Curtin University.

- The need for accessible, culturally appropriate and effective individual and systemic advocacy services were also highlighted by people with lived experience at the Many Voices, Big Impact events.

What people say is needed:

- *“GP needs to talk with the whole family.”*
- *“Support – more community support to mother and family.”*
- *“Respectful of the relationship and other support relationships (family and friends).”*
- *“Wherever he goes, that organisation should be ‘carer aware’.”*

6. The need for culturally appropriate services and supports across the spectrum of care

- People with lived experience, family members, carers and supporters consistently identified the requirement for culturally appropriate services across a spectrum of need. Services which are culturally competent and safe for people from Aboriginal, LGBTQI and culturally and linguistically diverse communities are identified as being vital for mental health prevention, in the initial management of mental health challenges, and in the ongoing management and coordination of care and support for people experiencing mental health challenges.

- Culturally appropriate and safe care and support options are considered vital components of best practice care for people experiencing mental health challenges. This includes the need for: services that are led by people in those communities; services that employ Aboriginal staff; the need for culturally competent LGBTQI services; the need for services which respect the relationships and connections of people from culturally diverse backgrounds accessing care and support; and the need for culturally appropriate language and communication to be used within these services to create a safe space for people accessing care and support.

- The need for culturally competent and safe services that are integrated and which link people to care within the community is also highlighted by people with lived experience. Services that are easily identified and that are trusted are also seen as being important to facilitate support for people experiencing mental health challenges and their families and carers.

What people say is needed:

- *“Culturally appropriate services and language access.”*
- *“Culturally competent services and supports (services that know how to access interpreters, if needed).”*
- *“Culturally secure and appropriate care and support options re Aboriginal/non-Aboriginal workers.”*

RECOMMENDATIONS

The key themes above shaped a number of recommendations for incorporation into the final SHR Report, which are outlined in the following section. This report does not detail the recommendations laid out in previous submissions by the key stakeholders. However, it is suggested that the recommendations contained in those submissions are considered alongside the following recommendations from the “Many Voices, Big Impact” SHR consultation events.

Recommendation 1: That the initiatives in the ‘Better Choices. Better Lives. The WA Mental Health, Alcohol and Other Drug Service Plan 2015-2025’ (the Plan) be funded and progressed with a focus on those that balance the system upstream, improve lived experience engagement, and address integration and coordination challenges.

- Extensive state-wide consultation was undertaken across the sectors to develop the Plan which has specific deliverables and a clear timeline. Priority needs to be given to funding and delivering on this Plan rather than duplicating work already done in and for the mental health and alcohol and other drug sectors in WA.

Recommendation 2: That the rebalancing of investment towards prevention and community supports is prioritized.

- The role of services is to provide resources to support a person and family/carer to live “a contributing life”, using the language of the National Mental Health Commission. This life is lived in a geographical setting and within a community of choice, kinship or acceptance. Therefore, supporting communities and ensuring that culturally appropriate services are located and readily accessible within the community is a critical aspect of supporting a person’s access to a contributing life.

- The monies raised from the divestment of the Graylands Hospital site should be used only to help balance the mental health system and to achieve sustainability.

Recommendation 3: That specific, culturally-appropriate services and resources are made available to prevent mental health challenges, and to enable better co-ordination and integration within and across service systems.

- If mental health is truly everyone’s business, then this needs to be actualised in very real ways for people from a range of culturally diverse backgrounds experiencing mental distress or alcohol and other drug use and their families and carers.

- This would include an investment in stigma prevention and processes to address discrimination as well as developing system navigation roles, including culturally appropriate peer support workers, to help individuals, families and carers traverse the differing layouts and cultures of physical health, mental health and allied systems, which include Housing, Criminal Justice and Child Protection.

- Services and support options that are culturally safe and competent for people from diverse backgrounds including Aboriginal, LGBTQI and culturally and linguistically diverse communities must be considered a vital component of best practice, and should be available across the spectrum of intervention, from primary and secondary prevention to tertiary care and ongoing community support.

- Culturally appropriate services should be designed to be integrated and to provide consistent and linked-up care across the spectrum of need, and active efforts should be made to ensure that these services are easy to identify and access.

- Initiatives already operating to divert people from acute services and to fill existing gaps in the system, such as the WA Police Co-response, the Start Court, Prison Transition Team need to be resourced and learned from to inform broader contexts.

Recommendation 4: That an independent Mental Health Commission continue its commissioning role as per its current model (at a minimum).

- Concerns were raised as to the likely consequences of any dilution of the Mental Health Commission's role in commissioning services and leading mental health and alcohol and other drug sector reform and the delivery of the Plan. These concerns include the loss of a ring-fenced budget for mental health or transparency as to its application; loss of gains made in listening to and partnering with people with lived experience with regard to the design, development and review of mental health and AOD services and much needed culture change within public mental health services. Co-design and co-production initiatives have not been prioritised or implemented across medically-focussed public mental health services to date.

- The Mental Health Commission was identified as a leader in encouraging and modelling co-design and co-production processes with people with lived experience in the mental health and alcohol and other drug areas. This shift in working with lived experience as partners is a critical element to achieve the cultural change and focus on person-centred services as per Directions 2 and 7 of the Interim Report.

Recommendation 5: Reform must not only happen, but how we 'do' reform must happen differently.

- Innovative models of co-design and co-production need to be implemented and evaluated to help transform culture and service responses and to progress reform in a way that is most likely to achieve a more sustainable health system. Initiatives such as Recovery Colleges; safe spaces and recovery houses led and staffed by peers; and Open Dialogue, Implementing Recovery through Organisation Change (ImROC) are all evidence-based initiatives that have been trialled and evaluated in other jurisdictions.

  Reform should also capture the need for a shift in the culture of the mental health system, which can be perceived as having a lack of understanding of and being remote

from truly trauma informed care and the social determinants of mental health. Strong central leadership is felt to be vital to this change and all staff must be involved in the reform.

- In conjunction with individuals, families, clinicians and communities working together more effectively in healthcare, more accessible and effective individual and systemic advocacy services need to be available so that when things go awry, these situations can be remedied, learned from and improved upon as part of a transparent and accountable continuous quality improvement process.

CONCLUSION

The findings and recommendations in this report are reflective of lived experience voices in relation to sustainability in WA's health system, with a focus on mental health. It is vital that the concerns, ideas and recommendations of people with lived experience are incorporated into the final SHR Report. Mental health is a key public health issue in WA and must be strongly represented in the final SHR Report to ensure a sustainable health system in the future. There is evidence that co-designing with mental health consumers and their families and supporters leads to better outcomes for them which in turn means that resources are used more efficiently, reinforcing the importance of this report and the findings and recommendations from the Many Voices, Big Impact consultation events.

FOR FURTHER INFORMATION

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Appendix 1. Themes and gaps from initial stakeholder submissions

All the stakeholder organisations made individual submissions and/or had participated in the community consultations for the SHR Interim Report. Below is a summary of common findings and recommendations from these submissions, and an analysis comparing the gaps between these recommendations and those of the SHR Interim Report.

Common themes

The common themes across the earlier submissions to the SHR from the key stakeholders were identified as:

1. Increasing attention to prevention required.
2. Making public mental health services safer for people.
3. A balanced approach: increased investment in community-based supports that are closer to home and facilitate recovery.
4. Holistic care: addressing the social determinants of poor mental health and responding to people's needs holistically.
5. Pathways and integration: addressing barriers that make it difficult for people to access the support they need and to transition through the health system.
6. Consumer and carer participation.
7. Sustainability of informal supports (carers).

Gaps

The gaps between the recommendations of key stakeholders' written submissions and the Interim Report were identified as:

Peaks	SHR Interim Report	Gaps
1. Increasing attention to prevention • Recommitment to the rebalancing targets of the plan. • Resource mental illness and suicide prevention with a focus on those most at risk including Aboriginal people – 4% target by 2020 and 5% by 2023.	Direction 1: Keep people healthy and get serious about prevention and health promotion	• Mental health not addressed. • The Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015-2025 is not mentioned.
2. Making public mental health services safer for people • Recovery. • Trauma informed care.	Direction 2: Focus on person-centred services	• Absence of mental health content. • Trauma informed care not addressed.

• Broader range of treatments (not just hospitalisation and medication). • Recognising carers. • Integrating physical care. • Reducing stigma.		• Recovery only addressed briefly. • Integrating physical and mental health care not addressed.
3. A balanced approach; increased investment in community-based supports that are closer to home and facilitate recovery • Peer based supports. • Contemporary recovery-oriented services. • Supports to prevent hospitalisation.	Direction 3: Better use of resources with more care in the community Direction 4: Facilitate effective interaction between acute and community-based mental health services to deliver mental health reforms across the WA health system	• Role of carers and family not covered. • Peer based supports not addressed. • The Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015-2025 is not mentioned.
4. Holistic care; addressing the social determinants of poor mental health and responding to people's needs holistically. • Integrating physical and mental health care. • Integration between mental health and AOD services. • A genuine recovery-oriented response in clinical health services.	Direction 1: Keep people healthy and get serious about prevention and health promotion	• Integrating physical and mental health care not addressed. • Integration between mental health and AOD services not covered. • Medical model prominent.
5. Pathways and integration; addressing barriers that make it difficult for people to access the support they need and to transition through the health system. • Develop a comprehensive health	Direction 2: Focus on person-centred services in WA Direction 4: Facilitate effective interaction between acute and community-based mental health services to deliver mental health reforms	• What would this look like? • Developing a peer consumer and family/carer workforce not identified.

system navigation and integration plan, including a specific mental health component. • Treatment and discharge planning. • Coordination in transition from acute to community. • The possibility of developing a peer consumer and family/carer workforce.	across the WA health system	
• **6. Consumer and carer participation.** • Develop co-commissioning and commissioning practices which foster genuine partnerships and integrated delivery. • The critical role of carers and the value of identifying them early. • Informed decision making regarding treatment, including the adverse impacts of medication. • Peer models of support in areas of prevention, community support and also navigation.	Direction 7: Create and support the right culture The SHR Report acknowledges: Consumers and carers are not central enough (p.64) Consumers and carers are frustrated that they are not given sufficient opportunity to contribute to the design of services that are meant to be serving their needs. (p.16)	• Absence of genuine co-design models. • Peer models not included.
7. Sustainability of informal supports (carers) • Sustainability of public health system is dependent on sustainability of informal (unfunded) care provided by family and friends.	Direction 7: Create and support the right culture The SHR Report acknowledges: Consumers and carers are not central enough. (p.64)	• Not included: physical and mental health of carers; young carers; additional pressures on Aboriginal carers; communication with carers. • Mental Health Act 2014 and carer involvement not addressed.

		• Training and resources for carers not identified.

Appendix 2. Many Voices, Big Impact events: Gathering lived experience input

An open invitation for people with lived experience to attend the two forums was distributed through key stakeholders' networks. The events were titled, "Many Voices Big Impact", and were designed to provide people with lived experience with an opportunity to share their views about, and have input into, the SHR Interim Report consultation process.

A $15 payment was made available to people with lived experience who were not attending in a paid employment capacity. Giving the information about this payment upfront helped to let people know that they would receive some offset to travel or parking expenses. This is important to engage people on limited incomes who are otherwise left disadvantaged by the very act of engagement.

A half-day forum was held on Tuesday 26th June 2018 at The Rise, Maylands and was attended by 62 people with lived experience with some regional attendance. Several SHR Panel members and SHR Secretariat attended as observers and listeners. Ms Robyn Kruk addressed attendees about the SHR Interim Report and ongoing developments with relation to the SHR.

An evening forum (5.30pm – 8pm) was held on Thursday 28th June 2018 at Citiplace Community Centre, Perth. This was attended by 30 people with lived experience. Mr Timothy Marney, Mental Health Commissioner, briefly addressed the group. A Panel member attended the forum for a short time.

Both forums were developed with and facilitated by a person with lived experience. Peer support was made available at both forums for any individuals who might need additional support in recognition that discussions of this kind can reactivate difficult and distressing experiences.

Lived experience speakers addressed both forums and were a powerful and effective way to ground the following small group discussions in what is needed to make a real and sustainable difference in people's lives. This is particularly important where individuals, families and supporters are traversing mental health and other health areas, including but not limited to, alcohol and other drug and physical health.

Appendix 3. Vignettes

MATT'S STORY
Matt is a 55 year old farmer who lives in the Wheatbelt area. He and his wife are active members of their local community.

Times have been tough in recent years because of poor weather conditions and Matt is hoping for a better season this year to balance the books. However, he is feeling increasingly hopeless that this is going to happen.

Recently, Matt has been finding it difficult to get a good night's sleep as he mulls over what changes the future might bring. As a result, he is tired during the day and finding it hard to get through his workload. His wife, Sue, is worried about him as he has taken to going into town to have a few drinks after sun-down.

Last week, he was stopped for a random breath test and is now facing a charge of drunk driving and driving while unlicensed as he had forgotten to renew his driver's licence. Matt finally agrees to talk to someone, but he is reluctant to see the town GP with whom he is on a number of committees.

SHANAYE'S STORY
Shanaye is a 28 year old Aboriginal woman who is studying Health Sciences at university. She lives in the south-east metro area of Perth close to her family. Shanaye has two young children aged 3 and 1 and her partner is a FIFO worker.

Shanaye was diagnosed with bi-polar disorder two years ago and is on medication which is prescribed by her GP. She also has diabetes of which there is a family history. Shanaye feels as though she is falling behind with her final-year uni workload.

Around the same time she runs out of medication and finds that she can get a lot of work done during her high-energy times but that she then crashes for a couple of days. Shanaye's mother, who is a member of the Stolen Generation, is increasingly concerned about her and insists on accompanying her to her next GP appointment. The GP recommends a short hospital stay in order to stabilise Shaneye's conditions.

ABDO'S STORY
Abdo, 16, has been couch-surfing mainly in the northern suburbs since becoming homeless last year when his mother died. He was born in the Sudan and migrated with his mother when he was 7.

Abdo was diagnosed with an Acquired Brain Injury after a skateboard fall at 10 years old. He has found it hard to sustain shared accommodation as he is prone to aggressive outbursts and finds living with other people difficult. He has an increasing juvenile criminal record for stealing, assault and disorderly conduct. Abdo has recently been charged with Common Assault and is appearing in Perth Children's Court tomorrow. He is likely to be remanded to Banksia Hill Detention Centre as he

does not have a stable address or an appropriate adult to provide surety.

Abdo has a number of diagnoses including Depression, Anxiety and Conduct Disorder. He finds it hard to keep his medication secure while couch-surfing and increasingly reverts to cannabis and alcohol to self-medicate.

He has been assaulted on a few occasions when sleeping on the streets and has gone to the Emergency Department from which he has been discharged with some medication and a referral to the Child and Adolescent Mental Health service. Although there are a number of services involved, they report that it is difficult to engage with him due to his lack of fixed address.

JULIE'S STORY

Julie (52) and her partner Michelle (63) have run their own successful catering business for 10 years. Julie has noticed that Michelle was becoming increasingly forgetful; found it difficult to recall how to do routine tasks and was becoming easily confused when travelling to venues. A specialist assessment confirmed that Michelle has developed Younger Onset Dementia.

Both Julie and Michelle are concerned about accessing culturally competent in-home support for now as Julie needs to continue to run the business. They also have concerns about how to access appropriate residential care when the need arises.