

A large crowd of people is shown from behind, looking towards the left. The crowd is dense, and many people are wearing blue caps. The background is bright and slightly out of focus. A solid teal bar runs horizontally across the bottom of the image.

Being submission to the Mental Health Productivity Commission

2020

Acknowledgements

Being would like to thank the many people living with mental health issues who have contributed to the work of Being and have assisted this submission to come to fruition. We acknowledge all people who live with mental health issues for their strength and courage to challenge and face each day. You are the driving force of the work we do at **Being**. Your voice matters and is greatly valued.

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Being | Mental Health & Wellbeing Consumer Advisory Group

Being | Mental Health & Wellbeing Consumer Advisory Group (Being) is the independent, state-wide peak body representing people with lived/living experience of mental health issues. We are a consumer-run organisation working with this core population of people to achieve and support systemic change, as well as provide programs and services to support individuals recovery and healing.

Being's vision is for all people with lived/living experience of mental health issues to participate as valued citizens in the communities they choose. Participation is a fundamental human right as enshrined in Article 25 of the *International Covenant on Civil and Political Rights* (ICCPR). We work from the premise that the participation of consumers results in more effective public policy and facilitates individual recovery.

Six principles guide our work:

- Creating space for people with lived/living experience of mental health issues to have their voices heard;
- Ensuring that recovery-oriented and trauma-informed practice underpins all aspects of Being's operations;
- The belief that services and a life free of stigma and discrimination are the human rights of every person;
- Providing capacity-building opportunities for all people with lived / living experience to grow;
- Ensuring that persons with lived/living experience of mental health issues lead everything that Being does.

Being is an independent non-government organisation that receives core funding from the Mental Health Commission of NSW.

Contents

Trigger warning 5

Recommendations 7

Rights - Some lived experiences: 8

1. Mental Health Rights 9

2. A National Consumer Peak Body 11

3. Mental Health Complaints Commissioner 15

Peer run services – Some lived experiences 18

4. Fully Peer Run Services 19

5. A safe and stigma-free community 22

Trigger warning

The following document contains information that may be distressing. Mental health, suicide and self-harm are topics that are discussed in the paper.

If you are feeling distressed by the content of this material, support is available through the following channels:

Support is available from 24-hour crisis support lines:

- Lifeline: 13 11 14
- Suicide Call Back Service: 1300 659 467
- Mental Health Line: 1800 011 511
- Kids Help Line: 1800 55 1800
- Mensline Australia: 1300 789 978
- Domestic Violence Line: 1800 656 463
- NSW Rape Crisis Centre: 1800 424 017



Recommendations

1.	Mental Health Rights	That all mental health and social support systems in Australia make accountability to the human rights of people with lived experience of mental health issues core business.
2.	A National Consumer Peak Body	A commitment to fund a national peak mental health body that builds on and collaborates with the national consumer peak alliance through Being, COMHWA and VMIAC.
3.	Mental Health Complaints Commissioner	A commitment to establishing a Mental Health Complaints Commissioner in all states to ensure that the rights of mental health consumers are protected and that complaints processes are as streamlined as possible.
4.	Fully peer run services	<p>A commitment to establish the development of more fully peer run services across Australia.</p> <p>A commitment to funding more research into the effectiveness of fully peer run services.</p>
5.	A safe and stigma free community	<p>Mental health training and education in schools</p> <p>Implementation of mentally healthy workplace initiatives</p>

Recommendations at a glance

Rights - Some lived experiences:

“If respect is a basic human right, why don’t services work with me in a respectful way”

“I have been mistreated by the very system that is there to care for me. They tell me that I have rights, where?”

“My case manager told me to go into hospital just for two days so my medication could be increased. I did what she wanted, I followed her orders, I went to hospital, and I ended up locked in there for nearly 8 months. During that time, they tortured me, they drugged me until I couldn’t talk, they injected me when I got scared and angry cause I wanted out, they sent me into a little room by myself and locked the door. I felt like someone locked the door and threw away the key forever. That’s what it felt like. What hurts most is that my case manager lied to me. Now I have to go to weekly counselling to get the images out of my head from being in that joint, all the pain and hurt they caused me”.

1. Mental Health Rights

That all mental health and social support systems in Australia make accountability to the human rights of people with lived experience of mental health issues core business.

As well as the legal framework provided by the state mental health acts, the regulatory foundation for protecting the rights of people with lived experience of mental health issues derives from the relevant international human rights treaties which Australia is signatory to, as well as cross jurisdictional statements of rights and responsibilities such as the Mental Health Statement of Rights and Responsibilities.¹

We strongly believe that these statements of rights should be integrated more effectively into legislative frameworks so that they would be enforceable within law. The question of lived experience rights should be at the foundation of thinking about how any future mental health system in Australia should look. Rights should be the foundation for processes that allow for concrete accountability and not simply well meaning but empty words.

United Nations Convention on the Rights of Persons with Disabilities (CRPD)

The key international rights document relevant to the rights of people living with psychosocial disabilities in Australia is the Convention on the Rights of People with Disabilities,² which Australia ratified in 2008.³

¹

[https://www1.health.gov.au/internet/main/publishing.nsf/Content/E39137B3C170F93ECA257CBC007CFC8C/\\$File/rights2.pdf](https://www1.health.gov.au/internet/main/publishing.nsf/Content/E39137B3C170F93ECA257CBC007CFC8C/$File/rights2.pdf)

² <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

³ <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-ip-44/equality-capacity-and-disability-in-commonwealth-laws/legislative-and-regulatory-framework/>

There are eight guiding principles to the CRPD:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women and
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Currently Australia is not living up to these core principles in a number of ways. As regards non-discrimination and full and effective participation in society, Australia still struggles to reduce the stigma associated with mental health issues and particularly the stigma associated with the most debilitating and enduring mental health issues.⁴ As regards respect for individual dignity and autonomy Being has been advised by consumers that some people with mental health issues still struggle to have their advance care directives recognised when they are being treated involuntarily. Finally, as regards full and effective participation in society employers are still struggling to understand how best to support employees with mental health issues to achieve the best outcomes for businesses and employees.

⁴ <https://nswmentalhealthcommission.com.au/sites/default/files/Report%20-%20National%20Surveys%20of%20Mental%20Health%20Literacy%2C%20Stigma%20and%20Discrimination%20-%20NSW%20findings.pdf>

As a signatory Australia continues to have UN reporting obligations under the plan, with our most recent update submitted in September 2018.

Mental Health Statement of Rights and Responsibilities

In 2012 the Australian Health Ministers Advisory Council (AHMAC), Mental Health Drug and Alcohol Principle Committee, agreed to a cross jurisdictional Mental Statement of Rights and Responsibilities. This set of principles was developed to align with the CRPD.

NDIS

With the ongoing implementation of the National Disability insurance Scheme across Australia, it is becoming more and more important to see consumer rights as also being a core area for mental health advocacy. This has already been recognised by some states. For example, Being collaborated with NSW Fair trading and a number of other NSW NGOs and government agencies in 2019, to develop resources to support people with psychosocial disabilities to avoid scammers when purchasing NDIS services.⁵ Consumer rights are mental health rights when it comes to the NDIS.

2. A National Consumer Peak Body

A commitment to fund a national peak mental health body that builds on and collaborates with the national consumer peak alliance through Being, COMHWA and VMIAC.

For some years now, people living with mental health issues have strongly advocated for a national mental health consumer peak body to be established to represent the

⁵ <https://www.fairtrading.nsw.gov.au/resource-library/publications/talkin-together-toolkit/about-talkin-together2>

views of mental health consumers at a federal level and to tackle issues specific to this core population which are outside the realms of state jurisdiction.

At the same time there are pressing federal policy issues which regularly impact people with lived experience of mental health issues. These include (National Disability Insurance Scheme) NDIS transition issues, privacy issues related to My Health Record and issues related to accessing and maintaining access to the Disability Support Pension (DSP) for people with psychosocial disabilities.

Mental health consumer and survivor communities have established groups to uptake this gap and to look at potential funding opportunities that will contribute the establishment and operational running costs for a national consumer peak body. Some have adopted an approach of advocating directly and meeting with state and federal health and mental health Ministers, to no avail. Many have attempted to shine a light on the collective voices through such conferences as The Mental Health Services conference (TheMHS), where symposiums, presentations and meetings have been held highlighting the need to ensure our voices have been heard.

Specific reference can be made to the 2018 and 2019 TheMHS Conferences, where several presentations, symposiums, and meet ups took place to advocate the importance of the collective consumer voice being heard through a mental health consumer peak body.

Off the back of a consumer meeting held at the TheMHS conference on 29th August 2019, and on behalf of the large number of consumers attending this meeting, a statement was delivered to the three state based mental health consumer peak bodies,

to include Being ⁶, CoMHWA ⁷, VMIAC ⁸, with a request for the three organisations to collaborate in the establishment of a national consumer peak body.

The three peaks continued discussions on how best to establish a national peak, and through the inclusion of a number of other state-based consumer organisations (both existing and newly established) the National Mental Health Consumer Peak alliance was formed.

Currently there exists a bureaucratic opinion that consumer and carers groups belong together. This can be seen through federally funded investment into bodies and organisations such as the Consumer and Carer Forum, Lived Experience Australia (formerly The National Consumer and Carer Private Network, and the scoping activity to establish a peer (consumer and carer) worker association. Whilst we acknowledge the tremendous work undertaken through these bodies, organisations and processes, we cannot, we cannot argue that the broader consumer population feel unheard at a national level.

Whilst Being, the New National Mental Health Consumer Peak Alliance, and consumers generally acknowledge the intersection between consumer and carers views, we must not detract from the fact that there are matters of differentiation that can be divisive and psychologically triggering between consumer and carers.

One such area is in power imbalances existent between consumers and carers. Well intentioned carers, who love and carer for the person living with mental health issues can be a tremendous support, however, there also exists power imbalances when we have carers speaking on our behalf. Further areas which can negate the consumer

⁶ <http://being.org.au/>

⁷ <http://www.comhwa.org.au/>

⁸ <https://www.vmiac.org.au/>

experiences and perspectives include stigma, discrimination, medication compliance, the right to privacy, self-harm and suicidality.

The concern for many consumers is that in reality, they want their voices heard independently of others. Inadequate representation can occur when we have differing lenses to an individual's experiences. Such is the case for many consumers who have shared with Being, through our member survey process and via conferences and forums. One consumer stated in a recent survey "No one knows what I have been through, not even my family. How can they advocate for me when they didn't receive the drugs, the ECT, or get locked in seclusion. They can't, they saw it from a different perspective. They saw it from I needed treatment, I needed to be locked up. They didn't see it from the harm that was caused, from the trauma I have to live with for the rest of my life. Yeah I'm angry, wouldn't you be if you had someone else advocating for you based on their needs?'. Another consumer mentioned "I don't have family, I live in isolation, why are carers representing me through advocacy. We need our own voice, our own advocates, our own national peak body. Then I will feel represented with my NDIS issues. Thankfully we have organisations like being to represent us". And finally "I love my carers, I need them and I want them in my life particularly when I am unwell. But should they be representing me at a state and national level, absolutely not!".

Article 21 of the United Nations Convention On The Rights Of People With Disability states "Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice..."⁹. One could question if we do have equal and equitable opportunities when we see National Carers organisations in existence and not consumer organisations.

⁹ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-21-freedom-of-expression-and-opinion-and-access-to-information.html>

It is vital to build a national mental health peak consumer body from the ground up, rather than from the top down, because each state in Australia has its own mental health act, with its own challenges for consumers. In addition to this, each of the organisations which are included in the current national peak alliance already have a constituency of consumers who they represent and engage with. Collectively they speak up for a significant number of people living with mental health issues.

Centralising mental health governance at a federal level without ensuring the active participation and representation of the current state peak bodies risks building a system that does not take advantage of the insights of organisations that have long histories of on the ground engagement and grass root representation.

Whilst our recommendation denotes the establishment of a national mental health consumer peak, it is integral that the current three consumer peak bodies are funded for establishment costs. Through such a model, the three state-based peaks can not only bring together their history and expertise in establishing consumer run organisations but also assist those states and territories who do not have such representational bodies. This method would also bring together a strong 15,000 collective membership base from the three organisations, many of whom have been driving forces in the communications and discussions for a national mental health consumer peak body for some time now.

3. Mental Health Complaints Commissioner

A commitment to establishing a Mental Health Complaints Commissioner in all states to ensure that the rights of mental health consumers are protected and that complaints processes are as streamlined as possible.

Accountability to basic human rights commitments is only possible if there are bodies made available that allow people with lived experience to make services accountable for their actions. We are strongly supportive of bodies such as the Victorian Mental Complaints Commissioner for this reason.

Under the *Mental Health Act 2014*¹⁰ Victoria established a Mental Health Complaints Commissioner to ensure that the rights of mental health consumers in the Victorian public mental health system were protected. The Complaints Commissioner supplements the role of the Mental Health Tribunal in Victoria.

Like the Mental Health Review Tribunal in NSW,¹¹ the Mental Health Tribunal in Victoria has the role of reviewing decisions made to involuntarily treat mental health consumers. They ensure that the consumer rights articulated under part three of the Mental Health Act 2014 are given due weight in decision making processes when a consumer is subject to involuntary treatment in the government mental health system.

However, the Victorian mental health act unlike the NSW Mental Health Act legislates in addition to this a Mental Health Complaints Commissioner. The Complaints Commissioner functions as a centralised mental health complaints body with scope to investigate, mediate and resolve complaints relating to government mental health services in Victoria. This provides mental health consumers in Victoria with an appeal body that goes beyond the specific and somewhat limited role of the Mental Health tribunal and the Mental Health Review Tribunal in NSW but still possesses a solid understanding of mental health.

¹⁰

[http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/0001F48EE2422A10CA257CB4001D32FB/\\$FILE/14-026abookmarked.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/0001F48EE2422A10CA257CB4001D32FB/$FILE/14-026abookmarked.pdf)

¹¹ <https://www.mhrt.nsw.gov.au/the-tribunal/>

Although it might be argued that in NSW we now have the Ageing and Disability Commission to function as a complaints body for mental health consumers, their current stated goal is to protect adults with a disability from abuse neglect and exploitation by someone they know, rather than oversight with regard to problems with the government funded mental health system. In effect in NSW we do not yet have a mechanism of complaint in relation to the mental health system that is equivalent to the Mental Health Commissioner in Victoria.

Complaints not relating to involuntary treatment can be taken to the Minister for Mental Health, the NSW Ministry of Health, or to relevant LHD bodies. None of these channels have complaint resolution as their primary goal and we have frequently been told by consumers, that lodging a complaint about the government mental health system through these channels can be a frustrating and often fruitless task.

Peer run services – Some lived experiences

“it’s a real shame that funding for CAN (Consumer Advisory Network) finished. If only the government knew that that organisation saved my life through their helpline and services. I wish they were here today, there’s times when I feel like its not worth it that I wish I had them to ring. Instead I ring the mental health line or lifeline. All they want to do is call the police rather than just someone to talk with”.

“sometimes you just want to talk to somebody who understands, you want to hear from a peer”

“People need to see others with mental illness who are living happily and healthily with the illness, to elicit hope in the person, who is recently diagnosed.”

“Services should be “facilitators of wellness, not prescribers. You just want somebody to stand by you. That’s what peer run services are”.

“ the living standards of where you live can help your recovery too...I notice since I’ve been in that flat I’ve got a lot better, I feel like going out now, socialising, not locking myself away from society so much”.

“if you can speak with someone who may still be going through issues, and if you share some of the issues that you are going through as well, it may just give them something to relate to, a bit of hope that we can all move past this.”

4. Fully Peer Run Services

A commitment to establish the development of more fully peer run services across Australia.

A commitment to funding more research into the effectiveness of fully peer run services.

Recent research into the experience which people with lived experience have of emergency departments ¹² and emergency services ¹³ suggest that emergency departments are often ill equipped to provide the best possible supports to mental health consumers experiencing difficult and overwhelming emotions. While we welcome the 25 million dollars which the NSW Ministry of Health have recently committed to developing a semi-clinical Safe Haven café model in NSW ¹⁴ we feel that the next step would be to pilot fully peer run services in NSW and Australia wide as well.

Strong examples of fully peer run models of service provision are already available in Australia. We see these as examples of the kinds of services which have the potential to supplement current clinical, or partially clinical services. In Australia the governments of Queensland and South Australia have already funded a number of peer run services.

Brook red in South Brisbane is a fully lived experience governed, managed and operated organisation. ¹⁵ They currently operate four peer run services which provide one on one

¹² https://acem.org.au/getmedia/60763b10-1bf5-4fbc-a7e2-9fd58620d2cf/ACEM_report_41018

¹³ <https://www.beyondblue.org.au/docs/default-source/default-document-library/beyond-the-emergency-report.pdf>

¹⁴ <https://www.health.nsw.gov.au/mentalhealth/resources/Pages/towards-zero.aspx>

¹⁵ <https://www.brookred.org.au/about-us>

support, resource linking, workshops, activities and groups.¹⁶ They also run a non-crisis warm line from 5.00 pm to 9.00 pm, Monday to Friday.

Flourish Australia has a fully peer run services in Hervey Bay and Warana.¹⁷ The Hervey Bay service¹⁸ provides a resource centre located in a house in Hervey Bay which is accessible from 9 to 5 daily and provides

- One to one support and group activities,
- A warmline open during office hours, after hours and on weekends for non-crisis support and
- A rest and recovery house located in a three-bedroom house, where people can take time out and develop new self-care strategies.

In South Australia the Lived Experience Telephone Support Service¹⁹ provides a peer run telephone helpline and online chat service that can provide advice about other services and arrange follow up well-being calls.

These successful services demonstrate that fully peer run services are a feasible alternative to current clinical, or semi-clinical models of care.

Why are fully peer run services a preferred option?

Studies of consumer run services in the US have demonstrated improved outcomes relative to traditional clinical services in a range of different areas. These include improved levels of:

¹⁶ <https://www.brookred.org.au/our-programs>

¹⁷ <https://panoramaonlinemagazine.com/2019/08/27/the-gardening-gang-gets-going-with-help-from-bunnings-and-taubmans/>

¹⁸ <https://www.socialventures.com.au/sva-quarterly/the-value-of-a-peer-operated-service/>

¹⁹ <https://www.linkstowellbeing.org.au/service-listing/lived-experience-telephone-support-service>

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- Empowerment
 - Social Inclusion
 - Wellbeing
 - Housing and
 - Employment

In a literature review of research into the effectiveness of peer run services released in 2015, the SAX Institute²⁰ recommended the replication in Australia of the large-scale studies of the effectiveness of consumer run services which have already been carried out in the United States.

In 2017 Social Ventures Australia (SVA)²¹ carried out an evaluation of Flourish Australia's Hervey Bay peer run service, which found that for every \$1 invested in the service \$3.27 worth of social and economic value was generated for the stakeholders. It was found that significant value has accrued to the local mental health service. There have been lower rates of hospital admissions, re-admissions and shorter admission times. This was found to be the case even for those people who are long time users of the local in-patient service.

People with lived and living experience accessing the service also experienced a range of positive outcomes including developing larger social networks, building hope, self-determination and developing a stronger sense of identity.

SVA found that within a fully peer run service it was easier to break down the barriers between the service and its users and that the greater engagement led to improved

²⁰ <https://nswmentalhealthcommission.com.au/sites/default/files/publication-documents/The%20Effectiveness%20of%20Services%20Led%20or%20Run%20by%20Consumers%20in%20Mental%20Health%20-%20Sax%20Institute%20-%20August%202016.PDF> , Pg 5.

²¹ <https://www.socialventures.com.au/sva-quarterly/the-value-of-a-peer-operated-service/>

outcomes for people with lived experience. A fully peer run service was also found to be a great source of inspiration and hope for those using the service.

5. A safe and stigma-free community

Given the ongoing impact of stigma on people with lived experience of mental health issues and the ways in which it limits the basic human rights of people with lived experience it is vital that stigma reduction be a core feature of any future mental health funding commitments.

Mental health training and education in schools

The Productivity Commission should investigate opportunities for mental health training to be provided to all educators to identify signs of emotional distress in young people. This mental health training should be a professional requirement for all educators, including primary, high school and tertiary education providers. Through a program implemented in all schools, staff would be better equipped to identify signs of emotional distress within their cohorts and present options such as school-based counselling or welfare support. Such a program, implemented across all schools, can reduce mental health trauma and stigmatisation. A consistent mental health training module for students should also be included within this. Following a similar structure to the Universities Australia *Respect. Now. Always.*²² program students should be required to complete age-appropriate training and then complete a quiz or agreement at the end of each required module. Such modules could include communication techniques, language, mindfulness, stress management, anti-bullying, and seeking help.

Through having programs that are consistently provided to all schools and educate both staff and students, there will be an increase in social and economic productivity. For

²² <https://www.universitiesaustralia.edu.au/project/respect-now-always/>

staff, having required mental health training will also give rise to a mentally healthy workplace. Such a workplace will be more flexible, and staff centred and will lessen the rates of absenteeism. For students, such a program may bridge the gaps between people who are experiencing emotional distress but unable for any reason to access support. This early prevention method could help with reducing the need for future hospitalisations or emergency crisis care as young people would be aware and more likely to receive community-based assistance prior.

School-aged emotional distress and mental health concerns affect many people, and there can be significant barriers to accessing support. The Productivity Commission must investigate the potential for a national mental health training curriculum for students and teaching staff. Such a program should have regard to.

- The ability of all schools across Australia to implement such a program and training modules for staff and students, and
- The use of E-mental health and face-to-face mental health training and supports.
- The need for such a program to be accessible for people living in regional, rural, or remote areas of Australia, and
- The requirement for education to be evidence-based and quality controlled.
- Education and supports to be culturally available to all people, including an emphasis on the Aboriginal and Torres Strait Islander lens of mental health, and
- Accessibility for people experiencing physical or intellectual disability.

Implementation of mentally healthy workplace initiatives

Following on from the application of a school-based mental health education and training program, the members of Being have stated that many workplaces are not conducive to wellbeing and often exacerbate mental health issues. Having a mentally healthy workplace should be of great concern to all business and service operators and managers. Employees experiencing higher levels of adverse mental health will often be absent from work for extended periods, and or exhibit lower quality and production of

work (also known as presenteeism). Both absenteeism and presenteeism limit the ability of employees to add to the businesses production, and without managers being able to implement steps to assist the individual, these employees often find themselves at risk of losing their employment. This places stress on the social and economic productivity of individuals who, as a result of unrecognised mental health issues, do not meet deadlines or risk burnout from being overwhelmed in their workplaces.

The benefits of various workplace mental health systems have been explored by a recent KPMG study into the economic costs of mental health.²³ Businesses need to consider where and in what ways employee job control may be available. Job control can take shape through the offering and implementing reasonable adjustments to fit employee needs, and for the requirements to be regularly reviewed, such as flexible working hours or locations, workload management, and regular communication with staff.

Other initiatives which would move towards mentally healthy and safe workplaces would include mental health training for managers and business owners/operators. This training should consider language and communication styles, staff and people management, trauma and general mental health screening and assistance. In focusing on employee centred modules, managers will be able to identify signs of emotional distress within their staff and provide opportunities for support before potential decreased productivity.

The Productivity Commission should consider the implementation of standardised mental health training for business owners and managers. This training must have regard to:

²³ https://mhaustralia.org/sites/default/files/docs/investing_to_save_may_2018_-_kpmg_mental_health_australia.pdf

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- The accessibility of education and training standards to small, mid and large businesses,
 - the ability for training and programs to be implemented in regional, rural, or remote locations,
 - the enforceability of having a nationwide required standard practice and professional development,
 - training and education programs to be evidence-based and quality controlled,
 - the ability for training and education programs to be linguistically available to all managers and business operators within Australia, and
 - the requirement for a diverse cultural understanding of mental health and wellbeing to be communicated effectively and comprehended.