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Productivity Commission inquiry into the economic impacts of mental ill-health

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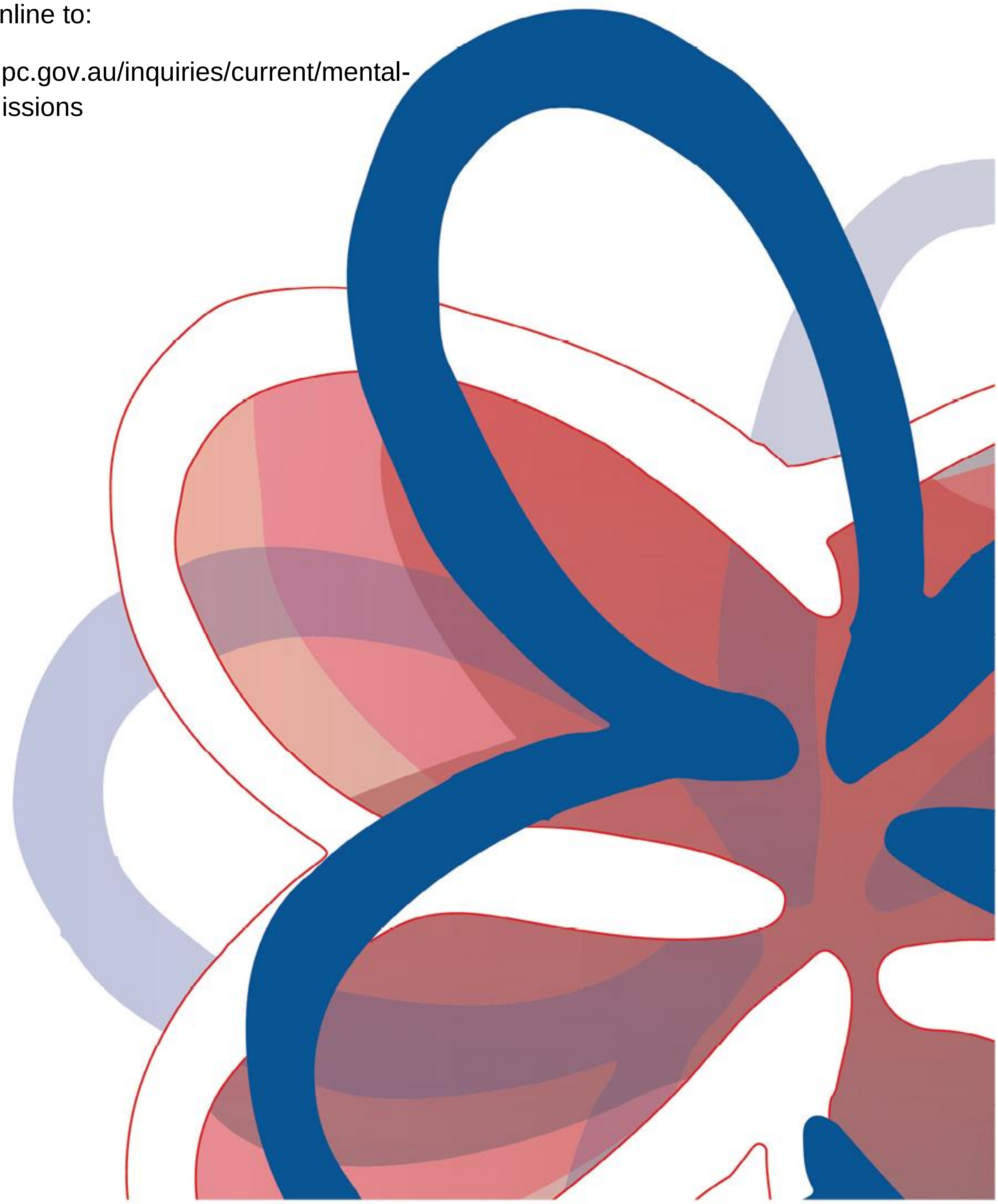

SUBMISSION: INQUIRY INTO THE ECONOMIC IMPACTS OF MENTAL ILL-HEALTH

This submission has been prepared by the ACT Mental Health Consumer Network in response to the Productivity Commission.

About the ACT Mental Health Consumer Network

The ACT Mental Health Consumer Network is a consumer-led peak organisation representing the interests of mental health consumers in the ACT in policy and decision-making forums. The Network is a member based organisation committed to social justice and the inclusion of people with lived experience of mental illness. Run by consumers for consumers, our aim is to advocate for services and supports for mental health consumers which better enable them to live fuller, healthier and more valued lives in the community.

The Network sought input from our members who reviewed the Issues Paper released by the Productivity Commission, with particular focus on the questions that explicitly sought the consumer perspective, or to which consumers felt the consumer perspective should be brought.

Overall comments

While mental health is a key driver of economic participation, and improved population mental health could reduce costs to the economy over the long term, the contributions that can be made by people with a lived experience of mental ill health as a result of their lived experience and the perspective that it brings should not be devalued. Prevention and early intervention programs may not be universally effective, so consideration should always be given to how people who experience long term, persistent mental ill health can be supported to participate socially and economically, and it is people with that lived experience who are best positioned to inform policy development and program design. Lived experience is necessary expertise for designing services and programs that are safe, effective and of good quality, and for ensuring the successful implementation of policy initiatives.

That we have chosen to focus our submission on questions directly related to consumers should not be taken as an indication that the consumer perspective is not relevant or necessary to address the other questions raised in the issues paper. It instead reflects that the issues paper covers a wide-ranging and comprehensive set of questions that other organisations may be better prepared to address within the timeframe allowed for submissions.

What does improved participation, productivity and economic growth mean for consumers? What outcomes should be measured and reported on?

Consumers can, and want to make meaningful contributions to their communities through social and economic participation. Being able to return to a ‘contributing life’ is a recovery goal for many people who experience mental ill health. However, the lack of flexibility regarding the definition of what constitutes participation can be a barrier for many people. Focusing on gaining and keeping paid employment as the sole means of making a valuable contribution is problematic when many workplaces lack the understanding of mental ill health to support people who experience it and when services that appropriately support people in employment are rationed due to funding constraints. For consumers who want to build their skills or further their education, barriers to entry are imposed by not only the lack of adequate and appropriate services and supports within educational settings, but also by the limitations on who can access social welfare payments, and the capacity trade-off when a low income needs to be supplemented by paid work, leaving some consumers with no option but to choose between gaining new qualifications or working in jobs that are deleterious to their mental health and wellbeing.

For these and other reasons, improved participation for consumers means that the systemic and structural barriers that prevent them from participating are removed. This includes barriers created by negative perceptions of the capacity of people with severe and persistent mental illness to hold positions of responsibility, to undertake complex and intellectually demanding jobs, and to think strategically, communicate with influence and to take on leadership roles both within the mental health sector and externally. Improved productivity means that workplaces are flexible, mentally healthy and supportive, and that volunteer work and paid employment are equally valued. It means that people are given the time and support to do quality work that reinforces, rather than detracts from, their mental health and wellbeing. Economic growth means that everyone can lead a contributing life and benefit from their own and others’ contributions.

What workplace characteristics increase the risk of mental ill-health among employees, and how should these be addressed by regulators and/or employers?

Consumers generally agree that a lack of flexibility in working conditions, negative perceptions regarding mental ill health and workplace cultures that are at best unsupportive and at worst hostile all negatively impact mental health and wellbeing. Employers and regulators should put measures in place to promote not only employee wellbeing and supportive workplace cultures, but also understanding and acceptance of the impact of work on mental health, and vice versa. Even people who work in flexible, supportive and inclusive workplaces experience mental health issues as a result of other social and biological factors, so employers and regulators need to consider how these factors impact a person’s ability to work and to implement measures that support a person to continue to work to their capacity regardless of whether the workplace is the source of their mental ill health.

What are some practical ways that workplaces could be more flexible and supportive for people who experience mental ill health?

Giving people access to the supports that work for them is crucial to mental health recovery and to enabling sustainable working arrangements for people who experience mental ill health. This means allowing time off for appointments with health professionals, including psychosocial and sensory needs in workplace health and safety assessments, and making reasonable adjustments that will support the person to work effectively and efficiently. Some consumers may find that the presence of a support worker assists them; others may find that open plan offices have a deleterious effect on their productivity due to sensory processing issues or aspects of the environment that exacerbate symptoms. They may benefit from flexible start and finish times if there is a seasonal component to their condition. Opportunities to debrief and access peer support are also beneficial.

It is particularly important to note that the restricted availability of health professionals in some areas means that people do not have the option of choosing when or how often their appointments are, so flexible hours would also mean that a person could access treatment and support without having to use personal leave. This in turn would mean that productivity would be conserved by enabling attendance at these appointments, rather than lost.

In addition to flexible hours, workplaces need to develop a whole of person approach to reasonable adjustment for people who experience mental ill health. Physical, psychosocial and sensory adjustments may all be reasonable and necessary for the person to function optimally in the work environment. Co-workers and managers need to be assisted to understand and respond appropriately to triggers, warning signs and increased support needs in order to ensure that the person maintains their capacity to work even if their mental health deteriorates.

Supportive workplaces are those that understand and accept diversity. A practical step towards correcting negative perceptions of people who experience mental health conditions would be to improve collective understanding through undertaking non-clinical mental health and disability awareness training that has been co-designed by people with lived experience.

What would support people with a mental health condition (whether episodic or not) to find and keep a job?

In addition to the previous, there are two important points that need to be made to answer this question.

Having a permanent safety net would give people with a mental health condition security. Loss of income due to periods of acute illness can lead to circumstances that ultimately exacerbate the person’s condition, meaning their return to work is further delayed. There are significant barriers to accessing income support payments which mean that if returning to work means potentially losing that payment, and a person is not confident that they can keep a job (either because their illness is episodic or because it has a permanent functional impact), trying to take on paid work poses a significant risk to their wellbeing. If a person’s eligibility for a payment was not compromised by periods of paid employment, then finding and keeping a job would provide further security rather than threatening what little they already have. For the sake of clarity, it is not necessarily the amount of the payment that should be preserved when a person is undertaking paid work, but their eligibility for that payment, which could stay at $1 while the person is working unless their person’s income or hours reduce, or employment ceases.

Considerable work needs to be done to improve community understanding and acceptance of mental ill health for people who experience it to find and keep jobs. Negative perceptions mean that disclosing a mental health condition can in and of itself affect a person’s employability. Many of the consumers who contributed to this submission have experienced covert discrimination, and some have experienced outright bullying and victimization as a result of their mental health status being known to an employer, manager or co-workers.

For a person with a mental health condition, paid work can mean a loss of security, and places of employment can be a threat to their safety. These issues need to be addressed concurrently with the provision of flexible and supportive adjustments to working conditions in order for people with mental health issues to find and keep jobs, regardless of whether their condition is episodic.

People who experience mental ill health during their working lives often find that, as a consequence, they cannot return to working in the field or at the level of their previous employment. However, retraining in a new area can be cost prohibitive. Supported, financed retraining and assistance with finding and maintaining new employment would reduce a person’s period of unemployment resulting from their mental ill health, and improve the sustainability of their employment in the new field.

Do students in all levels of education and training have access to adequate mental health related support and education? What are the gaps?

Education providers, particularly in the tertiary and vocational education and training sectors, tend to rely heavily on the availability of external secondary health providers to meet students’ mental health needs. This is because education providers’ resources are limited, and the services they provide are not necessarily equipped to support students who have pre-existing mental ill-health, low-prevalence disorders or complex needs. Services provided by educational institutions tend to be free to all students, which means they are in high demand. So, even if the service can provide the type of support a student needs, they may not be able to provide it as frequently or responsively as is required.

Returning to study, whether to complete a deferred qualification or to retrain, is a daunting prospect for anyone. It can be especially so for a person who had to withdraw from study or change profession as a result of a mental health condition. Perceived stigma, and self-stigma can be barriers to accessing the available support services. Reasonable adjustment plans are not optimised for mental health conditions, and access and inclusion services can make assumptions about what a person with a mental health condition ‘should’ be able to do, which can mean they do not receive all of the supports that would be appropriate for them. Outside of these services, education providers do not consistently use approaches to teaching that support people who learn in different ways. Access to support is based on proving a deficit or impairment, which is not a constructive or recovery-oriented approach.

How effective are the supports and programs available to students?

The supports and programs available to students are often targeted to address the needs of students generally rather than the needs of students who experience mental ill health that is not directly related or attributable to the stresses and pressures of study. This means that, while they can support students to manage their wellbeing in an educational context, their capacity to support students outside of this context is limited. As with employees and volunteers, students’ mental health is influenced by biological and social factors outside of the learning environment, but the supports and programs available have a limited capacity to address those factors, and are not well equipped to support people who experience severe or persistent mental ill health. This means that those people are often unfairly excluded from these environments which could be enablers for further participation and increased productivity if they were made more inclusive and accessible.

Many education providers also now offer online learning, from single courses through to full qualifications. Off-campus and online students do not have access to the same supports available on campus, such as face-to-face counselling, support groups and academic skills and learning assistance. Education providers should look at ways to provide timely and appropriate support to these students, because online studies remove some of the most challenging barriers to entry for people whose mental ill-health impacts their ability to attend classes and engage in social interactions with other students.

What role do non-government organisations play in supporting mental health through social inclusion and participation, and what more should they do?

Non-government organisations provide a wide range of services that support people who are socially isolated as a result of mental ill health to access the community.

They provide recovery oriented psychosocial supports, assist with goal setting, decision making and advocacy, and often have higher frequency contact with people than mainstream clinical services do. One of the most important roles that these organisations play is in providing peer support, which people have limited, if any, access to in clinical settings. In the absence of peer workers, social inclusion programs can be infantilising, and consumers can feel like the barriers they face are not well enough understood for the program or service to support them.

Mentoring and system navigation are other services that consumers want and non-government organisations can provide. Being able to talk through the challenges in a way that is validating and supportive is of more use to consumers than being told how to do something they already know how to do. Conversely, services that do not assume a consumer must know how to, or be able to do something (such as accessing the NDIS, applying for housing, enrolling in a course) without support because they ‘only’ have a mental health condition, and that provide tailored and appropriate support in these areas are incredibly valuable.

What indicators are most useful to monitor progress in improving mental health outcomes through improved social participation and inclusion?

The key to improving social participation and inclusion lies in removing the barriers that currently exist. While those barriers are in place, it is difficult to attribute changes in mental health outcomes to increased participation. In the first instance, therefore, an important indicator is accessibility. This includes the built, sensory and socio-emotional environments in which people participate. Another important indicator is changes in negative perceptions about mental ill health in the form of reductions in stigmatizing attitudes and discriminatory behavior, as these negative perceptions contribute to exclusion and non-participation. In our 2018 survey of mental health consumers in the ACT, respondents indicated that their interpersonal relationships and feelings of social isolation were major concerns that negatively impacted their mental health.

With respect to measuring outcomes, aggregate data is often provided to government through service providers and agencies that are reporting against their own outcome measures. This has the potential to skew the data because it is collected in the context of a consumer’s experience of service, rather than their experience of social participation and inclusion more broadly. That is, there is a difference between ‘I feel less isolated because I attend a group run by this service’, and ‘I am able to participate socially in ways that have meaning and value to me’. For this reason, outcome measures should be consumer-rated, and they should be qualitative as well as quantitative to ensure that information about what works is adequately captured. Better mental health outcomes through improving social participation and inclusion are contingent upon people feeling integrated and connected with society as a whole, so outcomes should be measured at that level as well as at the level of effectiveness of funded programs and services.

How could non-clinical mental health support services be better coordinated with clinical mental health services?

Currently, services that are not co-located are poorly integrated. A multidisciplinary treatment team within a public community mental health service may coordinate care within that service, but they do so with limited input from community managed mental health services, NDIS providers, primary and allied health professionals and in some cases also from the consumer whose care they are coordinating. For services to ‘wrap around’ a person, they must talk to each other and be guided not only by a person-centred approach, but by meaningful engagement with the person.

While there is an argument to be made for a single comprehensive clinical record as a means of centralising health information, the usefulness of such an instrument relies heavily on the quality of the information provided by services and programs. Since qualitative health data can be subjective and lack detail, and there can be administrative delays in finalising and uploading key resources such as discharge summaries, it is not so much the concept as the implementation of this measure that will determine its success in coordinating care.

Communication is also hampered by the culture within mental health services that privileges clinical notes over observations made by trained support workers whose interactions with consumers tend to be more frequent and detailed. This can mean that the people best positioned to identify when a consumer requires extra support or clinical intervention are not able to provide it, or even advocate for it. Clinical services need to recognise the validity of support workers as members of the treatment team and ensure that there are mechanisms for support workers to initiate increased support from both clinical and non-clinical services when the need is identified.

Are there significant service gaps for people with psychosocial disability who do not qualify for the NDIS? What are they?

People with psychosocial disability who do not qualify for the NDIS have limited access to non-mainstream services. The services that are available tend to provide diagnosis-driven therapies and supports rather than supports that address functional impact. There is very little opportunity to coordinate supports provided by different services beyond referral and initial contact.

People who are not eligible for the NDIS contend with the same eligibility constraints that existed pre-NDIS. Access to services can be restricted by diagnosis, by geography, or simply by demand exceeding supply. Appropriate supports can be cost prohibitive for many people with psychosocial disability, and they can be inflexible with respect to availability, meaning that opportunities for social and economic participation are constrained by the requirements of the service, rather than by the person’s capacity.

Further, the NDIS provides a universal eligibility qualifier in the form of an individual’s package. Eligibility cannot be contested by an individual service. For people with psychosocial disability who are not eligible for the NDIS, services can make subjective judgements about functional capacity, which means that their support needs are not fully met by the services available.

People with psychosocial disability are by definition functionally impacted by mental illness. To maximise their opportunities for social and economic participation, they should be provided with reasonable and necessary supports determined through a single eligibility process, administered by staff who are trained to use appropriate assessment tools to determine the level and type of support required. Even for people who are eligible for the NDIS, it is debatable as to whether this has been provided. For people who are not eligible, no mechanisms exist that consistently or appropriately make the attempt.

Is the DSP providing income support to those people with a mental health condition who most need support? What changes are needed?

While the DSP provides a basic income for people who are not able to work for an extended period as a result of disability, it is in many cases insufficient to cover the costs of living in addition to the cost of treatment, care and support that is required to support a person to return to work. It should also be noted that Sickness Benefit and Newstart without job seeking requirements are also provided to people who cannot work as a result of mental illness, however the payment rate is much lower than the DSP and the duration much shorter. For these reasons, DSP recipients and people who are eligible for income support on the basis of illness or disability should be bulk billed for all specialist appointments, tests and assessments directly related to treatment or management of their condition.

Assessors who make decisions about eligibility for these payments should be trained to apply the impairment tables fairly and appropriately for mental health. Consumers often feel that negative perceptions towards people who experience mental illness are a factor in decision making regarding their eligibility, or that they are being assessed by a person who does not have a complete understanding of the functional impact of mental illness, or that the medical reports they provide are second-guessed. Assessors need to recognise the expertise of the treating clinicians who provide supporting documentation, and use the information provided to assist their decision making.

For people who are eligible for the DSP, returning to work can be better facilitated by providing ongoing income support. That is, for people whose conditions are permanent, eligibility should not be impacted by paid employment. The amount of the payment should vary depending on income, but in cases where a condition is demonstrated to be permanent, eligibility should also be.

How could income support payments better meet the needs of people whose capacity to work fluctuates over time?

In addition to the above, people whose capacity to work fluctuates over time already have the option to turn income reporting on and off, but must attend a Centrelink office in order to do so. While it is possible to do this over the phone, callers are often kept on hold for unreasonably long periods if they get through at all. For this reason, people should have the ability to notify Centrelink that they have started or stopped work through the online portal, and this should be tied to the ability to report employment income online.

Income reporting is also unnecessarily complex, with offset reporting dates resulting in people having to report earnings they haven’t been paid. This can create financial pressure. This pressure could be relieved somewhat if reporting and payment dates aligned with the person’s pay cycle.

What can governments and NGOs do to improve:

- **supports to prevent and respond to homelessness and accommodation instability**
- **integration between housing, homelessness and mental health services**
- **housing support for people to transition from hospital, residential care or correctional facilities**
- **flexibility of social housing to respond to the needs of people experiencing mental health conditions**
- **other areas of the housing system to improve mental health outcomes?**

People experiencing mental health conditions need secure, affordable housing that meets their support needs. They need options such as short- and long term supported accommodation; support to live independently; and support to maintain not only tenancies but also mortgages. Periods of mental ill-health can lead to changes in circumstances that threaten housing stability.

Housing and homelessness services need to be administratively co-located and coordinated with both clinical and non-mainstream mental health services, to ensure that wrap around supports can be put in place. Poverty and housing instability must be addressed before we can expect to see improvements in mental health outcomes for individuals. Housing services need to adopt the principles of trauma-informed care to ensure that accommodation is safe, accessible and appropriate. Support to transition from hospitals and other facilities must also take into account the possibility of transitioning back into those facilities, to ensure that people continue to be supported through recurring episodes of acute illness.

What changes need to be made to improve the mental health workforce?

The mental health workforce is heavily weighted in its composition towards people with professional backgrounds in mental health who do not have direct lived experience. Consumers find that they experience better outcomes when they are supported by people who also have lived experience – that is, peer workers, peer educators and people in other peer-identified roles. Simply employing more peer workers is not a sufficient response, however. People working in peer-identified roles find themselves marginalised, discredited and sometimes bullied in their workplaces because the people they work for, and with, have negative attitudes towards people who experience mental illness. This includes assumptions about their intelligence and capacity, as well as about their professionalism and the validity of their qualifications. There needs to be a shift in the culture of mental health services to ensure that people in peer-identified roles are valued in their positions and have opportunities for career development and advancement both within and outside of the mental health sector.

What can be done to reduce stress and turnover among mental health workers?

The causes of stress and turnover among mental health workers are multifactorial. Staff who are not adequately trained and supported to work with vulnerable people are more likely to feel stressed. Working in an environment that does not recognize the incompatibility of efficiency and person-centredness adds additional stress, as does under-resourcing and the tendency to see services as duplicative, rather than complementary.

As an example, consumers have found that they temporarily lose access to their ongoing community supports when they are admitted to an acute mental health facility, because some services are seen as duplicating the supports available in the facility. However, supporting a person who is distressed requires a relationship based on trust and an understanding of the person’s history, which is often beyond the capacity of inpatient services to develop. When community supports have in-reach capacity when consumers transition to an inpatient setting, consumers feel less isolated and better supported, and this has a flow-on effect for staff in the inpatient setting. Appropriately responding to consumers’ distress leads to fewer instances of restrictive practice and a reduction in occupational violence, which reduces stress and improves retention of staff.

A better understanding nationally of the prevalence of mental ill health among mental health workers is needed to ensure that appropriate supports are funded and implemented. This applies equally to the peer, clinical and community based workforces. While debriefing, mentoring and wellbeing programs will provide some support at the individual level, changes need to be made to minimum staff ratios to reflect the fact that the type and level of support required by people who access mental health services is different to those that may be required by other health services. Expanding and supporting the peer workforce will also have a positive effect on turnover through improving care coordination and communication between consumers and their treating teams.

People who choose to work in mental health sometimes do so without fully understanding the potential impact of vicarious trauma or their own traumatic experiences, or their internalised stigma. They can find themselves comfortably equipped to work with people with mild to moderate mental illness, but then find working with people with severe and complex mental illness to be challenging and distressing. This has a negative impact on the person they are working with, who can often perceive the person’s distress which leads to the erosion of the trust and safety that is necessary for them to work together. Mental health workers need to be supported to understand their own motivations and limitations to ensure that they and the people they work with are able to achieve positive outcomes.

How could training and professional development be improved for people working in mental health (including peer workers)?

While people working in mental health often have extensive clinical knowledge that is enhanced and updated through professional development opportunities, the training that is provided can lack context. That is, it does not always improve their understanding of the lived experience of mental illness and its social, economic and cultural consequences. The only way to authentically and meaningfully do this is to provide training opportunities that are co-designed and co-delivered by people with lived experience. Understanding the lived experience perspective is the key to providing appropriate treatment, care and support. This is also true for peer workers, who use their lived experience purposefully to provide support to people who are working towards their own recovery. While they have lived experience, it is also contextual, and it is important to distinguish between shared experiences and what is unique to the individual.

Training for people who work in mental health must also include information and strategies for managing the workers’ own mental health. Operating under the flawed assumption that working in mental health is in any way protective of an individual’s mental health is problematic, and leads to poor outcomes for consumers and workers. Insisting that consumers try strategies and approaches that the worker themselves does not use negatively impacts the workers’ credibility and reinforces power differentials that block genuine and productive therapeutic relationships from developing between consumers and mental health workers.

While some training that is offered to mental health workers includes a lived experience story or interacting with ‘simulated patients’, this content is often included to provide a context, or a practical example for the learning content, without recognising that context works both ways. It is important for mental health workers to not only understand how their work relates to the lived experience, but also to understand how the lived experience relates to their work. Flexibly applying clinical knowledge in a way that centres the person is an important skill for mental health workers, but one that is underdeveloped. Lived experience content could be used to assist mental health workers to understand the needs of the individual, rather than just to provide an example of how the needs of the diagnosis can be met.

Training outcomes could be further enhanced by seeking consumer endorsement of the trainers and their content. There are increasing numbers of trainers with both lived experience and content expertise who are known and trusted by consumers, and who can provide a complete understanding of the learning content and its application from a lived experience perspective as well as from professional knowledge and expertise. While not all training can be co-designed, there is scope for co-validation, which would further ensure that consumers know the people who work in mental health are being trained using methods and approaches that are safe, effective and will improve the quality of care.