Peer Support

In Mental Health

An evaluation of service workers' perceptions of the effectiveness
of Peer Support in South Australia

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DON DUNSTAN FOUNDATION
INSPIRING ACTION FOR A FAIRER WORLD
Flinders University
The University of Adelaide

DIAMOND HOUSE

LIFE WITHOUT BARRIERS

Mental Health Coalition
OF SOUTH AUSTRALIA

neami national

mifSA
MENTAL ILLNESS FELLOWSHIP SOUTH AUSTRALIA

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List of Acronyms and Abbreviations

AIHW	Australian Institute of Health and Welfare
BB	Beyond Blue
DDF	Don Dunstan Foundation
DHC	Diamond House Clubhouse
LWB	Life without Barriers
MHCSA	Mental Health Coalition of South Australia
MIFSA	Mental Illness Fellowship South Australia
NDIS	National Disability Insurance Scheme
NN	Neami National
PS	Peer Support
SA	South Australia
WHO	World Health Organisation

Executive Summary

The Don Dunstan Foundation (DDF) is a registered charity and one of the leading think-tanks in South Australia (SA). The Foundation focuses on human rights issues and social justice, enacted through progressive research, public events and collaborative projects. Amongst these social issues, the Foundation is a key advocate for support in mental health, and in addressing mental illness through a variety of services within SA by creating awareness events such as AdMental.

This research report explores the current climate of Peer Support (PS) in mental health services in the state of SA. The report ultimately seeks to conclude with reasoning for its further use and expansion. This report provides an analysis and evaluation of current PS services as well as evaluations of their benefits and barriers. The method of analysis used in this report is thematic analyses and was conducted on qualitative data collected through a number of interviews with key representatives from five organisations: Diamond House Clubhouse (DHC), Life without Barriers (LWB), Neami National (NN), the Mental Health Coalition of SA (MHCSA) and the Mental Illness Fellowship of SA (MIFSA).

This report finds that PS in mental health services in SA, although effective, is not utilised to the capacity which it could be in order to ensure successful mental health models.

Findings

The findings in this report provide an evidence-base for the following statements:

- PS is about social engagement; building rapport and strong relationships are the first crucial steps towards recovery which are best developed through support founded on a mutual understanding of the illness.
- PS is an effective and valuable add-on to traditional methods of addressing mental health issues such as medication and therapy, rather than a stand-alone service.
- Stigma is one of the largest barriers faced in the field of mental health, experienced by both those who suffer from mental health issues and their supporters.
- Although a number of positive results and meaningful outcomes have been identified and reproduced using PS models, funding remains a common barrier that serves to hinder the expansion of such models to other areas of mental health support delivery.
- Discussions surrounding the value of PS are imperative, now more than ever, as the roll-out of the National Disability Insurance Scheme (NDIS) approaches.

Focus also needs to be put on the negative impact that this can potentially have on current mental health services and the people who engage with PS.

Recommendations

- **Normalisation**: Increased discussion of mental illness in the community;
- **Education**: Increased awareness and support at school level, both primary and secondary;
- **Collaboration**: More co-design programs, policies and procedures;
- **Evidence-based implementation**: Reintroduce proven programs such as Crisis Respite to extend support outreach;
- **Support**: Increased and continuous Australian Government support.

Introduction

According to a major report issued by the Australian Government Department of Health, an estimated one in five Australians will experience a mental illness in their lifetime (Department of Health, 2007). A more recent update in this field, provided by the Australian Institute of Health and Welfare (AIHW) in 2015, maintained these findings, explaining that approximately 20% of the population had experienced a common mental health disorder within the last 12 months (AIHW, 2017). This figure referred to by both the AIHW and the Department of Health is significant as it represents a cohort of 4 million Australians, comprised of both children and adults, which signifies the complex nature and extent of mental health issues in Australia. Furthermore, many organisations including Beyond Blue (BB) and the World Health Organisation (WHO) prefer to emphasise the positive dimension of mental health, highlighting the importance of mental health to every individual. Beyond Blue (BB) states that mental health is about wellness, rather than illness (BB 2016) and WHO defines mental health as a state of well-being in which every individual can realise their own potential, cope with normal stresses, work productively and contribute to their community (WHO, 2014). The underlying meaning and scope of these statements are supported in the many narratives featured in this report, thus confirming the need for the current project, and further research and work in this area.

Mental health of Australians has become a contentious topic with political, media and social disclosures evident in a number of recent incidents. For example, the announcement of Travis Cloke's indefinite break from the Australian Football League due to mental health concerns (ABC, 2017), as well as statements made by Senator Pauline Hanson regarding Autistic children in schooling and their impact on the learning of other students (ABC, 2017). Such comments place the issue of mental health at the forefront of contemporary debate. Notably, traditional methods of treating mental health issues, including psychological and pharmacological therapies (Drake, Mueser and Brunette, 2007), feature more prominently in comparison with PS models in discussions around mental health. However, what is of concern is that due to the variety in experiences of mental illness, and the varied impacts that some traditional methods are said to have – such as fatigue, loss of appetite and uncontrollable tremors (National Institute of Mental Health, 2016) – the concept of PS work has grown in popularity as a holistic alternative of support for others, from someone with knowledge and experience of the same illness (Consumer Activity Network, 2016). Although the National Disability Insurance Scheme (NDIS) is set to include support for adults in SA who suffer from a range of mental disabilities, there is still much uncertainty as to how this will affect current mental health services and those to whom it is provided. These reasons have sparked the need for further investigation into PS as an alternative method to stand-alone traditional methods.

A number of key studies (see Aschbrenner et al., 2016; O'Connell et al., 2017) have found that implementing a PS model – in which people who have a history of mental illness and who have experienced significant improvements themselves, offer services and/or substantial, innovative support to other people with serious mental illness (see also Davidson, Chinman, Sells & Rowe, 2006). As such, the aim for this project is to approach established mental health and social support organisations in Adelaide to collect information that evaluates the increased utilisation of PS work and explain the rationale for its use in this context. Showcasing the data will help to demonstrate how and why PS work is vital to the success of mental health support models in SA as well as elsewhere, and also highlight practical issues to be addressed that will reduce limitations and/or further support the delivery of such models. To focus the approach and better understand the current climate of PS work, a wide range of literature from the Australian and global context was reviewed and identified themes discussing the benefits of PS work, the use of technology, reducing risk and stigma, and field infancy and inconclusive findings, all of which address the utilisation of PS. These themes are explored herein to demonstrate how an established network of support might be useful in the treatment of mental health issues.

Discussions surrounding the benefits of PS were frequent throughout the literature – identifying key topics of recovery, social engagement and self-care. Each will be discussed separately due to their specific and individual nature. Davidson et al., (2006) and Lawn et al., (2008) discussed the recovery process and described the positive impacts that PS had, suggesting improvement of symptoms, an increased quality of life and positive attitudes, as well as a decrease in hospitalisation. Lawn et al., (2008) also argued that the focus of PS placed a greater emphasis on the path to recovery, rather than conceptualising mental health as being in a constant state of illness. The findings of Aschbrenner et al., (2016) were significant in that participants noted that shared learning and group problem-solving fostered friendships and provided essential support for behavioural changes, and was viewed as a pro-social and positive step toward improved mental health through a recovery narrative. Indeed, understanding the recovery process was suggested by Lawn et al., (2008) to be the most important aspect of addressing mental illness, as this step is what allows sufferers to make improvements and better themselves through increased agency, rather than through reliance on others or medication.

From a psychiatric perspective, social engagement as a benefit of PS is argued by Campos et al., (2016) to significantly improve quality of life for peers and members as it strongly encourages and increases levels of social inclusion and togetherness. The structure and monitoring styles of PS are what encourages social engagement of peers and members (O'Connell, Flanagan, Delpin-Rittmon and Davidson, 2017). Foster, McPhee, and McCloughen (2016) credit social engagement and its considerable benefits to the nature and delivery of the ON FIRE program. This allows children and adolescents to branch out from constricting monotony and engage in social activities such as camps and social outings and in turn, make friends. As such, it seems that PS has considerable potential to make positive change to not only the mental health sector but also to influence social change (Mead, Hilton and Curtis, 2001) which aids the recovery process and enables agency within mental illness sufferers.

Self-care and reflection for both peer workers and group members were also considered important benefits of the PS model. Specifically, these elements were viewed positively as they were seen to help people better understand themselves and what they were going through. Such a process is important as it enables both peer workers and group members to build a positive identity separate from 'the patient' and improve self-perception (Vandewalle, et al., 2017), in order to move forward. Boevink et al., (2016) and Davidson, et al., (1999) discuss self-care and reflect on identifying improvements in self-confidence and reduced social isolation amongst peers, leading to a lower need for institutionalisation. These findings were considered a result of the model structure itself, as members spoke with peers who understood similar experiences as their own (Davidson, et al., 1999). Self-care and reflection play an integral part in the recovery process for both peer and mental illness sufferers, and how a person views themself can make the difference between seeking help and taking the next step to improvement.

Another key theme to emerge from the literature was that of technology and its impact on fostering online forms of support. The material discusses concepts such as the use of online avenues as a method for delivering PS, its increase in accessibility and use, as well as its benefits for users. O'Leary, Bhattacharya, Muson, Wobbrock and Pratt (2017) discuss the benefit of access and convenience of online support as it is understood to reach a wider audience. Suggesting that the use of technology-based support is on the increase, Brunette et al., (2017) continue the topic of increased technology-based support within established support centres to aid accessibility to online PS groups. In doing so this enables PS groups to provide assistance to many people who may otherwise miss out due to lack of access to the internet, or funds to pay for services (Harding and Chung, 2016). In a study conducted by Nalsund, Aschbrenner, Marsch and Bartels (2016), they noted an increase in self-driven access to support online as members could do this in any place they considered safe and without face-to-face contact being necessary. The literature shows that technology, particularly online-based, has an important role to play in the implementation of PS, and in facilitating change and support, which is similarly evaluated in this current project.

The topic of stigma and its reduction was another theme to come to light throughout the literature. Vandewalle et al., (2017) and Davidson et al., (2006) discussed this in their studies, concluding that stigma and its related impacts impede the recovery process. By identifying associations between experiences of stigma and an assumed devalued self-identity in participants, Vandewalle et al., (2016) introduced a PS program where participants showed improvements in self-perception and worth. By doing so these participants were able to normalise their thoughts, actions and behaviour with life in the 'real world'; feeling accepted and as though they were now making valuable contributions to society. Talking about stigma is highly relevant, as tackling this issue is a key avenue for positively addressing mental illness as a whole. By addressing stigma-related issues and making changes those suffering from a mental illness are able to develop agency and live with a level of normality.

Risk was another important theme identified in the literature, which manifested in the recognition that not only are there risks to the health and wellbeing of mental illness sufferers, but there are risks posed for their safety when seeking help. Naslund et al., (2016) discussed extensively the risks involved in experiences of mental illness, particularly when engaging online. When seeking assistance, members may find themselves in a hostile environment or come across misleading information. These are the particular reasons why PS is so valuable in addressing mental illness (Naslund et al., (2016). PS programs educate sufferers with legitimate information and teach them how to navigate hostility online, should they encounter it.

The final theme identified within the literature was that of 'field infancy' (i.e. the limited knowledge in the field) and the need for more research-based evidence. At the conclusion of an early study, Coates and Winston (1983) argued for more comparative group studies to show further support for the concept of PS. Thirty years later, more studies have been conducted with suggestion that the field of PS, as an alternative method of treatment, is still in its infancy and that further research will continue to add legitimacy to the field (Mead, Hilton and Curtis, 2001) as well as showing the true effects of PS, adding valuable information to the ever-growing research base (Davidson et al., 1999). Continued growth and research is invaluable in the field of mental health as a whole, but specifically to the concept of PS, as it has the potential to build practice and culture.

The literature was insightful and identified a number of key themes, all of which showcased how and why PS is important to the future of mental health support models in Australia. The themes that are discussed above could be used to support arguments that advocate for continued and increased use of PS models when addressing mental illness. Although some of the literature produced mixed results and inconclusive findings, there was far more literature available that supported PS and its benefits, than not. The general conclusion drawn from the literature was that PS encourages a far more organic and innovative approach to mental illness in contrast to traditional methods. Consequently, these aspects have been integrated into this current study which explores why PS is vital to the success of mental health support models in SA, with conclusions and recommendations that will be relevant to this context, as well as other national and international mental health support settings.

Methodology

This research report investigates the importance of PS work in mental health services and its crucial role in the success of mental health models in SA. The research project was conducted for the Don Dunstan Foundation (DDF) and received ethics approval as part of the part of the collaborative agreement, as set out with the Arts Internship Program of the University of Adelaide. The timeframe in which the research project took place was from 10 March 2017 – 25 June 2017.

Aims

- Understand the current climate of mental health in SA through the perceptions of key members in the industry;
- Identify and explore past and current mental health models and programs in SA;
- Understand the effectiveness of PS work;
- Gain an in-depth understanding of stigma as a barrier;
- Explore impacts on clients who have sought a PS service; and
- Identify the potential role of the NDIS.

Recruitment

Members who participated in the study were selected through a purposive sampling method (Walter, 2013). This systematic sampling method was used, based on the purpose of the study, i.e. knowing that the study required the participation of key members of the mental health sector. Potential respondents were selected with input from the DDF Executive Director, David Pearson, who then made contact via email, on behalf of the researcher to request an opportunity for an interview (Campos et al., 2016). Six key mental health and social support representatives were provided with an information sheet giving an overview of the study (see Appendix 1) and requesting their participation in an interview to answer questions regarding the current status of mental health in SA and the need for PS work in mental health support in the future. Consent was obtained in writing through the use of a consent form (see Appendix 2) presented to representatives prior to commencement of the interview.

Qualitative Data Collection

Information presented in this report was collected through semi-structured interviews. These interviews were conducted with key members representing their organisation between 29 May 2017 and 6 June 2017. Interviews were structured around themes recognised in the literature review, and aimed to identify members' perceptions of PS in mental health in SA. Interviews ranged from 35 minutes to 90 minutes and were all audio-recorded. The interview schedule (see Appendix 3) was structured, based on the following key themes:

- Benefits of PS; recovery, social engagement and self-care;
- Technology; the ways in which it is incorporated into delivering PS;
- Stigma; as a barrier, and its effects;
- Risk – related to those who suffer a mental illness and those who offer support; and

Infancy – the need for more evidence to add to the research-base and for PS to be recognised as a legitimate form of support.

Interviews were held at the offices of each of the six participants, who were members/employees of key support organisations within the mental health sector. This resulted in five separate interviews. Each of the representatives currently hold varied support or mental healthcare positions within their respective organisations; have had a number of positions throughout their career; and many have 'lived experience' themselves. The following list describes the participant sample, their respective organisations, roles and the date when interviewed:

- Kylie Harrison – Community Peer Worker, LWB (29 May 2017)
- Belinda Brown – Senior Project Officer, MHCSA (1 June 2017)
- Shandy Alridge – Project Manager, MHCSA (1 June 2017)
- Kim Smith – Director, Diamond House Clubhouse (2 June 2017)
- Karen McCulloch – PS Worker, NN (5 June 2017)
- Robyn Miller – Training Coordinator, MIFSA (6 June 2017)

Analysis

Audio versions of interviews were transcribed manually by the researcher. An inductive content analysis approach (Walter, 2013) was then applied to the transcripts. Such an approach was necessary considering the extended exploratory nature of the study and the limited literature in this area. This process was also done manually by the researcher, in the form of thematic analysis. Coding was completed by the researcher (see Appendix 4), identifying key words, themes and phrases in relation to the broader themes identified in the literature review. Content that was identified as relevant and useful was organised into themed categories, structured to reflect the themes first identified in literature review and marked by colour coding; a number to signify which theme it fitted with, line number and a brief description or summary stating its relevance. Any other interesting and/or relevant elements of the interviews, not captured by the thematic framework were also highlighted in the process of data analysis, in order to add context and background to the information collected.

Limitations

The study encountered a small number of limitations during its course, which should be taken into account when considering the overall research process and the depth of conclusions that can be drawn from the findings. The timeframe of one semester (27 February 2017 to 26 June 2017) in which the project was to be completed did not allow for a comprehensive exploration and analysis to be conducted. The mental health sector in SA is diverse and multi-disciplinary, highlighting the need for interaction with a larger cohort of stakeholders (i.e. GPs, clients, psychologists, and so on) across a longer period of time, to provide a more comprehensive picture of mental health and the role of PS. Time constraints were also an issue in terms of the process of contacting and communicating with industry members. This proved to be a considerable challenge despite initial assistance from the DDF, as those who were approached by the researcher had full meeting schedules, client care responsibilities and other organisational priorities, and so initial contact took some time. A final and significant limitation was the sample size. Although the findings are valuable to the evidence base, and understanding of mental health in SA, they should be considered in the light of these limitations and the context of the study. As such, the conclusions and recommendations, while thought provoking, should not be generalised to apply to the current climate of the mental health sector, nationally or internationally, without further study.

Results

The interviews produced wide-ranging responses identifying key points and opinions, some of which were shared by a number of representatives, and others which offered a variety of different contexts to the one concept. The responses complemented the framework of exploration in the importance of PS work to successful mental health programs in SA and are reported in the following sections.

How mental illness is understood within the mental health sector is an important element of PS. All responses given reflected the definition provided in the introduction, in that ‘it is an illness which is either genetic or triggered by trauma and impacts on a person’s capacity to function “normally”’. It is usually diagnosed by a medical professional and can happen to anyone. Representatives also stated that the mental health sector prefers to associate mental illness with positivity which makes PS an even more effective and valuable tool.

> *We do like to think of it in terms of that recovery focus and around mental health rather than mental illness – we don’t want to think about things in a medical model which is about symptoms and symptom management, it’s actually about the whole person and a whole life.*
>
> Shandy Alridge (MHCSA)

> *It’s about wellness and it’s looking at their mental health needs or psychological needs.*
>
> Kim Smith (DHC)

Representatives unanimously described PS as an interactive and positive recovery-based approach that breaks away from the medical model. Adding a different element, PS achieves many things that traditional methods are not able to, such as a deep understanding and reciprocated rapport. People with ‘lived experience’ of mental illness aid recovery as a close mentor in whatever way is required by the client, based on their strengths, values, wants and needs. PS gives ownership of self to the client in their recovery journey, validates the illness, and supports the illness in a safe environment without prejudice.

> *It’s nothing about me, without me.*
>
> Belinda Brown (MHCSA)

> *It’s all about working alongside people with a mental illness and living a life well and helping the people live with their strengths and their values and having recovery-based ideas in mind.*
>
> Karen McCulloch (NN)

Contrary to literature that prescribes PS or traditional methods as stand-alone approaches, PS is described in the interviews as holding a significant position alongside traditional methods in the process of mental health support. This is due to its alternative and holistic nature and respect for the value of other professions as part of the recovery process. PS is a crucial element to the recovery process for many people and enhances the work achieved by all areas of support.

> *It is part of working as a team and I find that a multi-disciplinary approach works best.*
>
> Robyn Miller (MIFSA)
>
> *Traditional methods have their place, its only part of the picture, we live in a world that's full of the medical model and people gravitate towards it because we think doctors are Gods and we're actually talking about people.*
>
> Shandy Alridge (MHCSA)
>
> *PS is an add-on to everything else.* Kylie Harrison (LWB)

Responses show that PS is utilised in mental health support for many different reasons, but all with the over-arching goal of helping people manage and overcome their illness. The responses offered below highlight the necessity of PS to the mental health sector in SA. It puts into context why PS workers are an incredibly important element in aiding people who live with a mental illness.

> *It allows for co-design – we have about 70% of people involved have lived experience and what you get is a completely different product to what you get if you went off to some leadership company and so it opens minds and brings in that lived experience voice.*
>
> Shandy Alridge (MHCSA)
>
> *We're very strong on PS and lived experience – some people have made good decisions because of it and some not so good but it's all the experience so why not use it in a positive way.*
>
> Karen McCulloch (NN)
>
> *They do have a better understanding because they have lived experience.*
>
> Kim Smith (DHC)

Representatives offered many examples of the benefits of PS to mental health support and recovery in terms of social engagement, self-care and perceptions. Responses were given from the perspectives of representatives who have 'lived experience' as well as support providers. Responses addressed common themes of isolation, motivation, role-modelling, stigma, shame, and decreasing the need for medical services; and confirm why PS is vital to mental health support. These benefits and many more show that PS is a highly effective tool in aiding mental health in SA, and PS workers have an important role to play in the recovery process of many people.

> *So much of our mental health issues for aboriginal people is around loss and grief and once we started talking loss and grief, shame went out of it and we could take shame out of the picture.*
>
> Shandy Alridge (MHCSA)

> *Crisis respite diminished the need for hospitalisation long-term and thus waiting lines.*
>
> Karen McCulloch (NN)

> *Here they're treated as a person and not a mental illness or a symptom and they are able to have discussions – if they're at home and isolated they don't have that and then they become even more isolated.*
>
> Kim Smith (DHC)

> *It validates the experience, it makes it more real because people understand what these people have been through or are going through and to be able to see a PS worker who has come out the other side, who is functioning really well, that might be working; that can be really helpful to see.*
>
> Robyn Miller (MIFSA)

Discussions of technology-based PS were mixed, but predominantly positive and many representatives agreed that technology-based approaches are an effective tool for PS. While it allows for learning, it does require close monitoring and should play a supporting role in PS; however in some cases it is not implemented due to a lack of funding.

> *It has its place in the recovery process as a step to face-to-face interaction, but it's been a lifeline for a lot of people.*
>
> Belinda Brown (MHCSA)

> *Yes we incorporate technology a lot more than we used to because Centrelink is now going to MyGov, which requires people to go online or use mobile phones to access MyGov so we have a big priority at the moment.*
>
> Kim Smith (DHC)

> *That would be fantastic if I could just be there and say hey how are you doing? Instead of being on the phone you could actually see the person, but it's just funding, there's no funding for it.*
>
> Kylie Harrison (LWB)

Stigma is the largest barrier experienced by people with a mental illness. Similar views were presented of the Australian media with the poor representations and misinformation they presented. Stigma in the workplace and internal stigma are also significant barriers. These responses show the challenges PS faces in aiding the recovery process and the level of complexity involved in achieving recovery.

> *And the media, they don't do us any favours; every story they report on, someone got stabbed and it's because the person has a mental illness. They may not be having an episode but someone's gotten wind of the fact they've got it so that must have been the cause for that and so they promote this big scary picture of anybody with a mental illness.*
>
> Karen McCulloch (NN)

> *That [internal stigma] can be very difficult and challenging for people particularly in the early stages of their diagnosis.*
>
> Robyn Miller (MIFSA)

> *It's a battle of do I disclose that I have an illness or do I not? – If I do then it will be known and I will be treated differently.*
>
> Shandy Alridge (MHCSA)

Risk was another common theme of discussion amongst representatives, offering mixed responses; some organisations prefer to use risk assessments for the safety of the client so as not to trigger and re-traumatise, while others choose not to, stating that it reinforces stigma. Findings also show that, in comparison this is not an area for concern regarding risk in PS, but rather relapse and how it is received internally and by the community is what needs to be given attention.

> *This is not about 'I don't trust you'; I want to make you safe.*
>
> Belinda Brown (MHCSA)

> *Personally I don't like reading risk assessments because I feel that that's not what the person is and they're not defined by that.*
>
> Kylie Harrison (LWB)

> *There are always risks because the nature of mental illness is episodic on most occasions and people are vulnerable.*
>
> Robyn Miller (MIFSA)

There is great uncertainty within the mental health sector in relation to the upcoming installation of the NDIS within SA. For representatives who were able to offer a response the answer was unanimous. While the sector agrees that the NDIS is a program that will address the gap in disability support, its funding has been taken from original mental health funds, thus closing some successful programs that have been vital to the recovery for many people. Because of this, mental health support has been included as an afterthought, but to a minimal capacity and will be hard to qualify for as most mental illnesses are episodic.

> *We have to get the funding in order to provide that service.*
> Kylie Harrison (LWB)

> *We're all in the same boat; we don't know how it's going to play out. All we know is how the NDIS has played out in other states in Australia. The NDIS was not originally developed for people with a mental illness. It has been an afterthought because for them to be able to fund the NDIS they've taken the funding from mental health. So only 12% of current participants will qualify for the NDIS and it's only available to people who have a significant mental illness that impacts significantly on their day-to-day activities and their capacity to do those things.*
> Robyn Miller (MIFSA)

> *The mental health sector agrees that the NDIS is an amazing program that fills a much needed gap for disability supports for people at the highest end of need but, it's quite complex for a number of reasons. The NDIS was originally designed for disability only and mental health was bolted on later. The Productivity Commission expected that there would be about 64,000 people eligible for NDIS individual packages due to psychosocial disability, however there are about 230,000 people in Australia currently in receipt of psychosocial rehabilitation support through funded programs. About $350 million in funding for Commonwealth funded mental health programs (majority through DSS) has been deemed to be 'in scope' for NDS – i.e. at full roll-out these programs will cease to exist because their funding has been transferred to NDIS.*
> Shandy Alridge (MHCSA)

Many representatives agree that while PS has been in action for many years, it is not recognised as an effective method of support and does not receive adequate respect, structure, or funding compared to the medical model. Many believe that there is a need for more local research to be done that will bring respect and legitimacy to the role.

> *The evidence is there, there may not be tons of evidence in Australia, but lots of evidence all over the world about the value of peer work in*

the recovery process. The more local work we do the better, local evidence is really useful; the more we can get from our own country the better.

Shandy Alridge (MHCSA)

Research is really important and research has shown that all community mental health programs do help reduce people being hospitalised which reduces the amount of money that is spent by the community on those things and they're far more effective models.

Kim Smith (DHC)

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Discussion

This exploratory research project has investigated the current status as explained by key representatives of the mental health sector in SA, with the view to identifying the value and necessity of PS in the success of mental health models and programs. The findings have supported much of what was explored in the literature review and has also challenged some studies. The exploration also uncovered a relevant afterthought in the role of the NDIS in the industry and what this means for PS workers as well as clients. With the NDIS soon to be fully rolled out in SA these findings constitute a timely, small-scale contribution to the local evidence base but may also apply in a national and international capacity.

The benefits of PS are many and varied, applying to all areas of the mental health sector. Findings of the report in relation to overall benefits, and with a focus on the recovery process, social engagement and self-care and perceptions both reflected and supported studies of Campos et al., (2016) and Foster et al, (2016). There was unanimous agreement amongst all representatives that PS is a highly effective tool in the recovery process for mental health issues but should not be utilised as a stand-alone method. Rather, it is most effective as an add-on to traditional methods and should be included in the recovery process to complement other necessary services and support. Two large benefits were identified in the representatives' narratives, the first of which being that social engagement is at the forefront of addressing mental health issues, as was implied by O'Connell, et al. (2017). Building meaningful relationships and establishing mutual rapport with clients are essential building blocks of the recovery process and opens the lines of communication from an early stage. Secondly, the value of the lived experience is beyond description; having that understanding allows for support to be provided in ways that are not possible between clinician and client, and PS workers are able to spend time with their clients. These benefits are significant in that they highlight the achievements of PS and its capacity to make a difference in a way that is not otherwise possible.

The majority of representatives agreed with suggestions made by O'Leary et al. (2017) that technology-based approaches to PS are an effective complementary tool that can provide a life-line and increase the extent of outreach support, particularly to the younger generation. This correlates with findings in the literature review describing technology-based approaches as effective. Technology-based approaches, particularly online seem to be developing as something of a necessity in SA as Centrelink is slowly integrated with MyGov in an online setting, but funding is scarce. The approach does require close monitoring and should be incorporated with a PS worker as an element of the recovery process. This is due to the vulnerability of people, technophobia and the safety implications associated with a lack of knowledge and the episodic/unstable nature of the illness. The work of DHC and their implementation of technology bears a likeness to that of Brunette et al. (2017) which resulted in undeniable success. Report findings show that PS is effective in this area as it provides support and encouragement for learning, and PS workers are those who are going to close the gap between the need for clients to engage online, and their ability to do so

Stigma is the largest barrier experienced in mental health, and with significant impacts on South Australians who live with it, as well as the services which provide support. Findings extend beyond the work of Vandewalle (2017), adding discussions of workplace and internal stigma and supporting arguments surrounding the media. Stigma is practiced and experienced by so many, in numerous ways and sadly is present in clinical support. Workplace stigma is both direct and indirect, making many people unsure whether or not to disclose their illness for fear of discrimination. Disclosure often results in little or no work opportunities as these people are feared to be unreliable. Programs run by organisations such as DHC focus on workplace stigma, changing the misconception that people with a mental illness are unreliable employees. With such programs in place, stigma has decreased. Internal stigma is commonly the first stage of stigma that a person will experience. It may be the biggest challenge for some and is commonly propelled by external factors such as a workplace environment or the comments of others. Media stigma is potentially the most damaging as it is the creator of community attitudes toward mental health in general. The misconception that all criminals have a mental illness does little to shed a positive light on the concept of mental health; instead it builds the fear. Over time stigma has been measured by organisations like LWB and shown to have decreased with the continued implementation of PS alongside other approaches. As argued by Davidson et al. (2006), stigma in its many forms hinders and sometimes prevents recovery from a mental illness; the fear of being mistreated, misunderstood or worse, ignored, prevents a large number of people from seeking help. These findings support and reflect the work of Vandewalle et al. (2016) and highlight the important role that PS has to play in the reduction of stigma, and the value of their experience that they can share with others.

Risk comes in many forms to both those who live with a mental illness and PS workers who aid recovery. Risks can be mitigated with the implementation of PS as the sharing of lived experience allows for others to manage their illness and its impacts. As argued by Naslund et al. (2016), being aware of the potential risks means that PS exercises ‘mindfulness’ as a rule to keep them aware of triggers and re-traumatisation without stigma. The two largest risks associated with mental illness were identified outside of the explored literature and extend what was already known. The first major risk is the prolonged illness that some may suffer because of barriers like stigma. The second is the concern that there will not be enough services to cater for the need and demand of so many people. Successful programs like ‘Crisis Respite’ as suggested by Karen McCulloch from NN have been closed, based only on a lack of funding, and have left people with no alternative to assist their continued recovery, mainly because they do not meet the requirements for other programs. These findings suggest that the biggest risk to mental health support is not implementing PS as an aid to recovery.

Contrary to the findings of Mead, Hilton & Curtis (2001), the concept of PS in general is not in its infancy. It is, however, the recognition of PS as an effective tool to aid recovery that is considered ‘infant’ and this is a response which was reflected unanimously from all representatives. Findings do suggest, akin to that of Davidson et al. (1999) that continuous research is a necessity if the goal is to increase engagement in PS in SA, but also exceed beyond this argument to suggest co-design as an effective element of further research. Close collaboration with, and consideration of, people with lived experience of mental illness will positively contribute to future programs, policies and procedures. PS has been proven to be an ideal alternative complementary tool to stand-alone methods of clinical models; but this research needs to be continued to achieve recognition of the lived experience and the important role of PS in management and recovery of mental illness.

Representatives who offered a response relating to the concern of secured funding and the much anticipated NDIS roll-out in SA agreed that while it will provide support to a vast number of South Australians there is still a great deal of uncertainty in the mental health sector. Service support schemes such as the NDIS were not featured in the literature review but arose in the narratives of representatives when asked about the future of mental health services in SA. Representatives from MIFSA and MHCSA explained that the cause of uncertainty arose when subsidies were withdrawn from current programs and used to fund the new scheme which included mental illness as a disability as an afterthought. Consequently, successful programs have since been closed, leaving many South Australians without support. It is predicted that this gap will not be adequately compensated for, with only an estimated 12% of mental illness sufferers set to qualify for NDIS support. Once again, report findings showcase the importance of PS if the goal is to continue and improve mental health in SA.

Recommendations

A number of recommendations can be made, based on interview responses from the key representatives, and broader knowledge of mental health in SA. Broadly speaking, participants demonstrated consensus about the benefit of PS as a recognised form of mental health support, and its goals to improve the mental wellness of South Australians. From this, a number of recommendations for improvements can be made which include:

- **Normalisation:** Increase discussion of mental illness in the community; increase exposure of mental illness and mental health support to the community through positive and true media representations to create an improved understanding and build community support, particularly for psychotic illnesses often associated with poor media representation.

- **Education:** Increase awareness and support at school level, both primary and secondary, to reduce stigma for those who live with a mental illness as well as their family members; an introduction of education programs is suggested to normalise experiences and encourage acceptance in future generations.

- **Collaboration:** More co-design programs, policies and procedures; to offer better targeted support for families and less mainstream mental illnesses, it is suggested that the lived experience be implemented more in the creation of programs and consultations regarding policies and procedures.

- **Evidence-based implementation:** Re-introduce proven programs such as Crisis Respite to extend support outreach.

- **Support:** Increased and continuous Australian Government support in the form of:

- Secure long-term funding to be delivered to ensure sustainable programs and contracts, and that positive results are maintained continuously
- Large-scale research into the impacts of PS and its benefits, both state and national to re-affirm its importance and vitality to a successful mental health support system
- Continued national and state focus on discussions of mental health and support, beyond the duration of the annual Mental Health Week into a regular discussion
- Respect of the role of a Peer Worker across all professions as one to be recognised alongside clinicians and social workers

Conclusion

Mental illness remains a prevalent issue within SA and the reality for many of those who suffer is that it is something that will need to be managed for life – which highlights the need for ongoing support, research and evaluation. It is a debilitating illness that presents itself in many forms and often in the form of episodes. Mental illness heavily affects a person's capacity to live their life in ways that others take for granted. Relationships are significantly impacted, as well as the ability to maintain a career.

This report identifies the perceptions of key representatives on the current status of the mental health sector and finds that while positive results have been produced, it is understood that more can and needs to be done. Stigma against mental health and those who live with it was found to be the biggest barrier. It is experienced in many ways from family, community and in the workplace, leading to a common factor of internal stigma which produces further challenges for the recovery journey, and impacts significantly on a person's life. The biggest risk in PS and mental health support in SA is not related to how safe a client is to work with, but the provision of services to meet constant demand and to ensuring an extensive outreach to all areas.

While it is yet to be officially recognised as an effective approach alongside traditional methods, PS is a proven, successful and holistic method to aid mental health support both internationally and locally in SA. This is reflected in the studies and narratives explored for this report. The benefits of PS are many and varied; allowing people a safe environment, free of judgement and stigma, where others are supportive and open-minded. PS also enables a person to reconnect with themself and allows for a different connection to be developed between peers, founded on understanding and empathy and collectively supported by many key organisations of SA.

Large-scale research and continued strong advocacy are key steps that need to be taken alongside education in normalising the issue of mental illness and creating acceptance in SA.

With uncertainty surrounding the NDIS and the impact it will have for those who live with a mental illness, further research is needed to confirm the positive results identified, rationalise stable funding, and increased use of PS, and to improve the current status on mental health support. Such support will also be vital in extending services to those who will no longer qualify for assisted support, and provide continued hope that a person can live well regardless of their illness.

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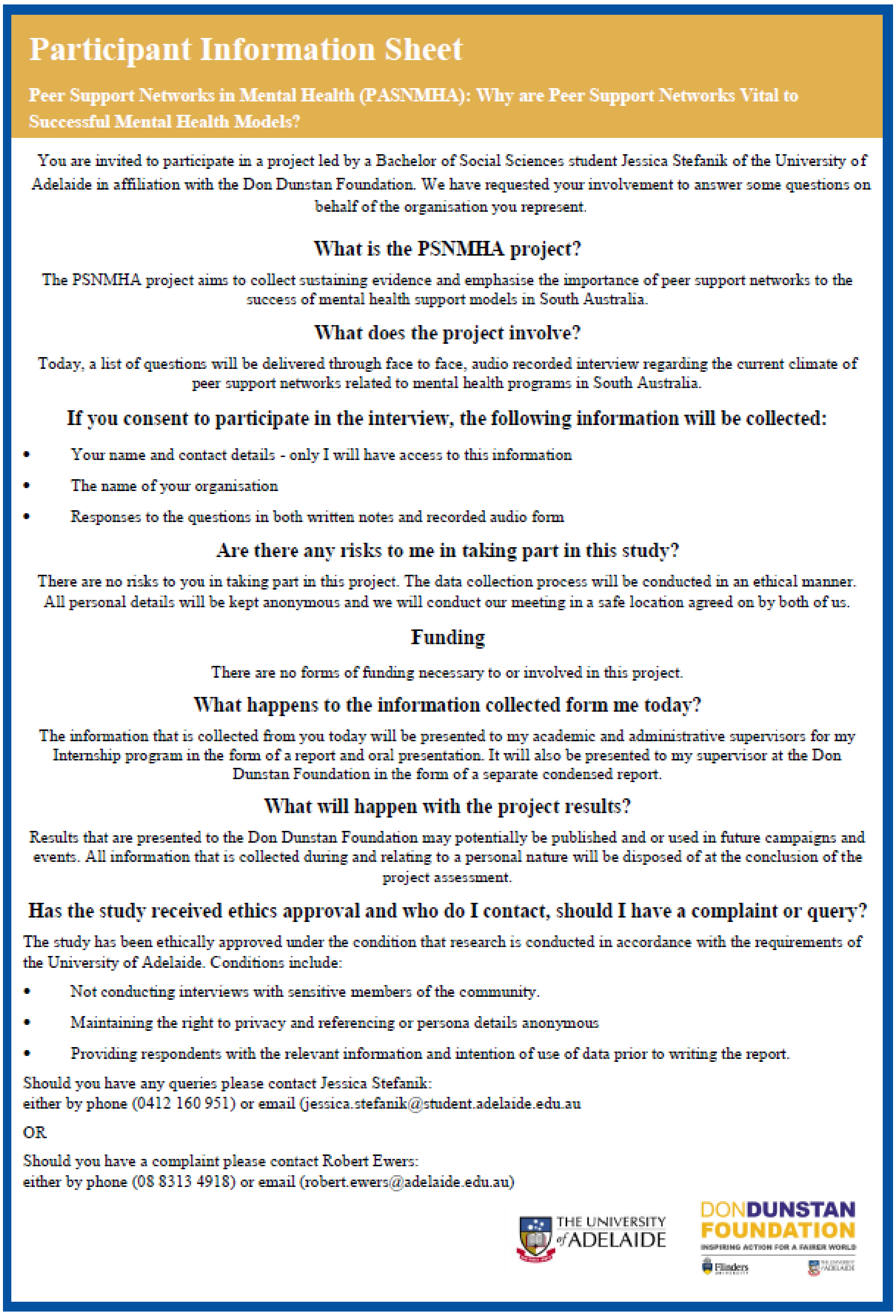
Appendix

1) Information sheet provided to potential respondents via email when requesting interviews



Participant Information Sheet

Peer Support Networks in Mental Health (PASNMHA): Why are Peer Support Networks Vital to Successful Mental Health Models?

You are invited to participate in a project led by a Bachelor of Social Sciences student Jessica Stefanik of the University of Adelaide in affiliation with the Don Dunstan Foundation. We have requested your involvement to answer some questions on behalf of the organisation you represent.

What is the PSNMHA project?

The PSNMHA project aims to collect sustaining evidence and emphasise the importance of peer support networks to the success of mental health support models in South Australia.

What does the project involve?

Today, a list of questions will be delivered through face to face, audio recorded interview regarding the current climate of peer support networks related to mental health programs in South Australia.

If you consent to participate in the interview, the following information will be collected:

- Your name and contact details - only I will have access to this information
- The name of your organisation
- Responses to the questions in both written notes and recorded audio form

Are there any risks to me in taking part in this study?

There are no risks to you in taking part in this project. The data collection process will be conducted in an ethical manner. All personal details will be kept anonymous and we will conduct our meeting in a safe location agreed on by both of us.

Funding

There are no forms of funding necessary to or involved in this project.

What happens to the information collected form me today?

The information that is collected from you today will be presented to my academic and administrative supervisors for my Internship program in the form of a report and oral presentation. It will also be presented to my supervisor at the Don Dunstan Foundation in the form of a separate condensed report.

What will happen with the project results?

Results that are presented to the Don Dunstan Foundation may potentially be published and or used in future campaigns and events. All information that is collected during and relating to a personal nature will be disposed of at the conclusion of the project assessment.

Has the study received ethics approval and who do I contact, should I have a complaint or query?

The study has been ethically approved under the condition that research is conducted in accordance with the requirements of the University of Adelaide. Conditions include:

- Not conducting interviews with sensitive members of the community.
- Maintaining the right to privacy and referencing or persona details anonymous
- Providing respondents with the relevant information and intention of use of data prior to writing the report.

Should you have any queries please contact Jessica Stefanik:
either by phone (0412 160 951) or email (jessica.stefanik@student.adelaide.edu.au

OR

Should you have a complaint please contact Robert Ewers:
either by phone (08 8313 4918) or email (robert.ewers@adelaide.edu.au)

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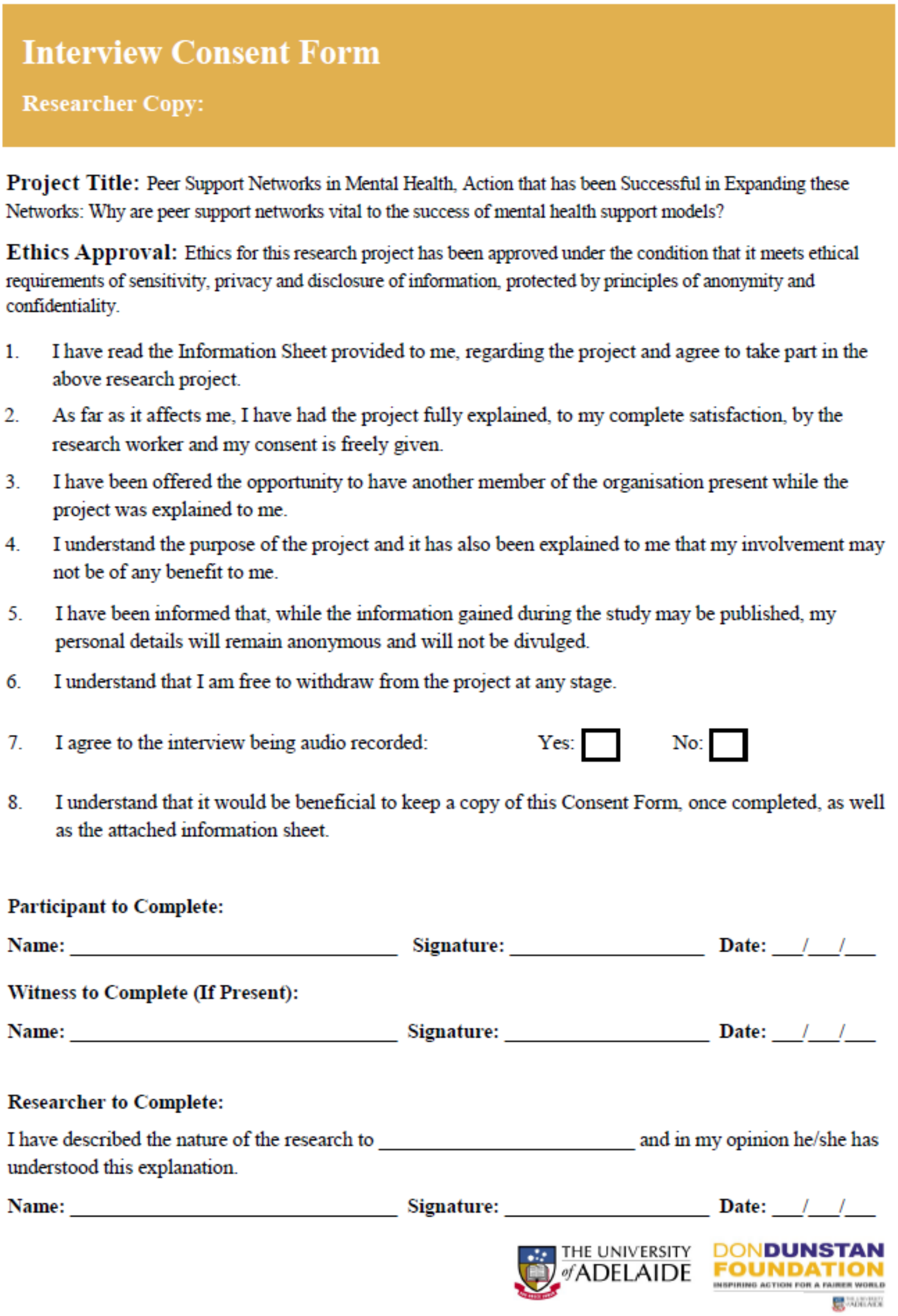
2) Consent form provided to the interviewee for completion prior to audio recording. Researcher and Interviewee copies are identical in content.



Interview Consent Form

Researcher Copy:

Project Title: Peer Support Networks in Mental Health, Action that has been Successful in Expanding these Networks: Why are peer support networks vital to the success of mental health support models?

Ethics Approval: Ethics for this research project has been approved under the condition that it meets ethical requirements of sensitivity, privacy and disclosure of information, protected by principles of anonymity and confidentiality.

1. I have read the Information Sheet provided to me, regarding the project and agree to take part in the above research project.
2. As far as it affects me, I have had the project fully explained, to my complete satisfaction, by the research worker and my consent is freely given.
3. I have been offered the opportunity to have another member of the organisation present while the project was explained to me.
4. I understand the purpose of the project and it has also been explained to me that my involvement may not be of any benefit to me.
5. I have been informed that, while the information gained during the study may be published, my personal details will remain anonymous and will not be divulged.
6. I understand that I am free to withdraw from the project at any stage.
7. I agree to the interview being audio recorded: Yes: ☐ No: ☐
8. I understand that it would be beneficial to keep a copy of this Consent Form, once completed, as well as the attached information sheet.

Participant to Complete:

Name: ______________________________ **Signature:** __________________ **Date:** ___/___/___

Witness to Complete (If Present):

Name: ______________________________ **Signature:** __________________ **Date:** ___/___/___

Researcher to Complete:

I have described the nature of the research to ________________________ and in my opinion he/she has understood this explanation.

Name: ______________________________ **Signature:** __________________ **Date:** ___/___/___

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3) Interview Schedule includes all questions that were asked of the organisation representatives during the interviews; although some were not included in particular interviews or changed slightly for the purpose of who the interviewee represented.

General
How do you define mental illness?
What would you say are the benefits of peer support?
Why does (organisation) employ peer support as a method of aiding people with mental illness?
Are there things that peer support achieve that traditional methods do not?
What are the peer support programs that you employ at (insert organisation name)?
What have you based your peer support network model on?

Benefits
Have there been any significant benefits to arise out of your programs?
How does this fit with the initial goals of the program?
Have clients expressed their views on what has worked in the programs?

Recovery
Do you think peer support benefits recovery? If so, how?
Have you seen examples/evidence of this in your clients' recovery narratives?
Would you say that peer support put an emphasis on the path to recovery more so than traditional methods?

Social Engagement
How important would you say social engagement is in the recovery process?
What have been the benefits of social engagement as an aspect of peer support?

Self-care
When implementing peer support what results have you seen in terms of your clients' self-care and self-perceptions?
Would you say improving a clients' self-care through peer support is an important of achieving positive results?

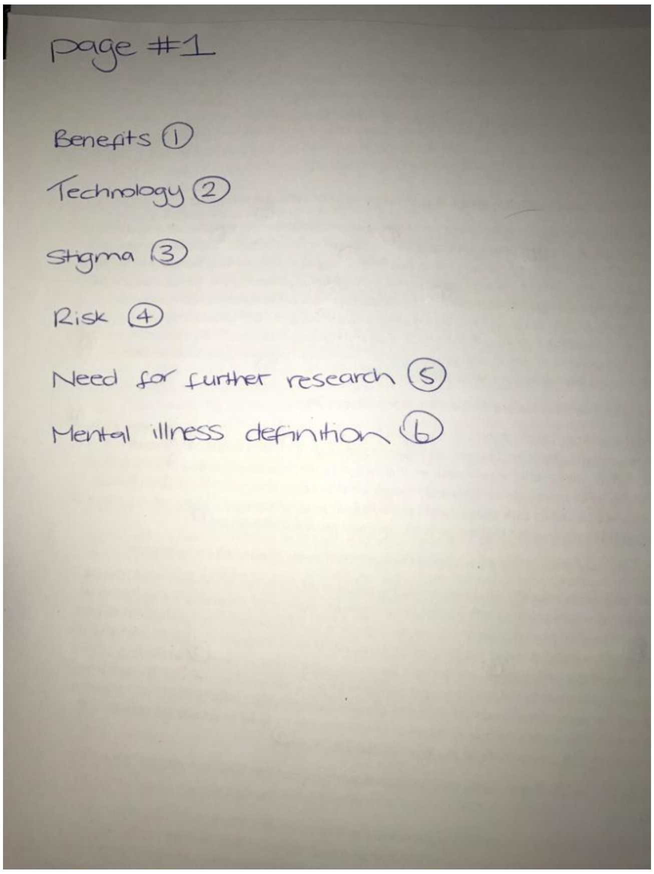
Technology
Have you adopted any technology based programs into your model?
If yes – Has this had an increased impact on benefit and results?
What drew you to incorporate this approach?
If no: What have been the barriers?

Stigma
What are the ways in which stigma is experienced by the clients of your organisation (e.g. public shaming, loss of family support)?
When does it occur? (Are there common experiences that you have encountered during your work?)
Does (organisation) have any programs specifically aimed at reducing and combating stigma?
Would you say stigma is a barrier?
Do you have any suggestions on how stigma is best combated?
Would you say that community awareness and education about mental illness is important?

Risk
What are the primary risks of dealing with clients who suffer a mental illness?
Are risks lessened or mitigated due to the implementation of peer support? If so, please explain further.
Have you found that implementing peer support has reduced the risk of prolonged suffering and potential relapse?
How does Mifsa assess risk when implementing peer support networks?

Questions on Infancy and need for further research
Does Mifsa continue to research best practice and review organisational policy around the implementation of peer support to mental health?
Do you have any recommendations with regard to further research into the implementation of models or certain aspects of peer support that could be adopted by others?
Do you have any final comments or thoughts that you would like to share?

4) Thematic analysis and coding applied to transcripts



page #1

Benefits ①

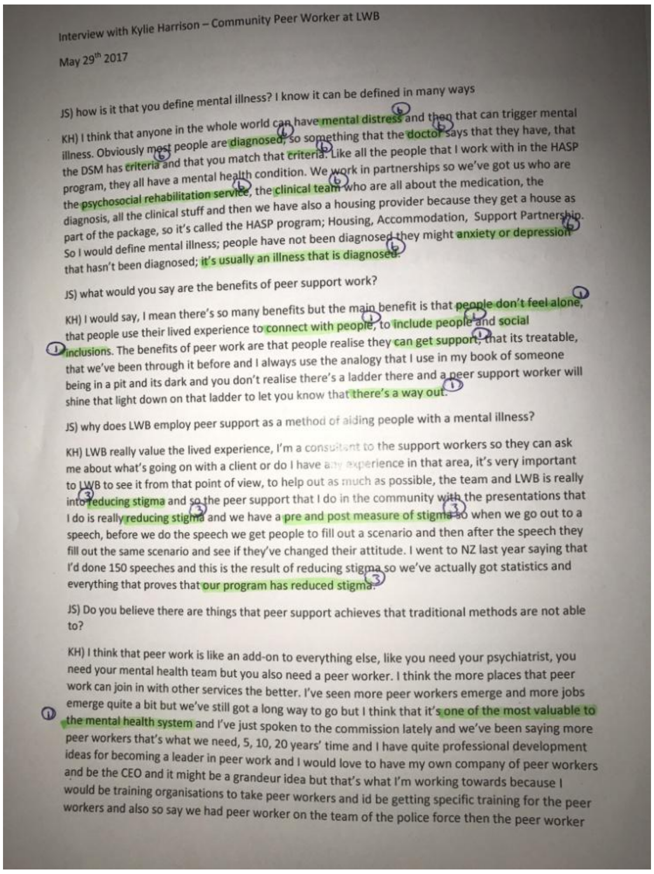
Technology ②

Stigma ③

Risk ④

Need for further research ⑤

Mental illness definition ⑥



Interview with Kylie Harrison – Community Peer Worker at LWB

May 29th 2017

JS) how is it that you define mental illness? I know it can be defined in many ways

KH) I think that anyone in the whole world can have mental distress and then that can trigger mental illness. Obviously most people are diagnosed, so something that the doctor says that they have, that the DSM has criteria and that you match that criteria. Like all the people that I work with in the HASP program, they all have a mental health condition. We work in partnerships so we've got us who are the psychosocial rehabilitation service, the clinical team who are all about the medication, the diagnosis, all the clinical stuff and then we have also a housing provider because they get a house as part of the package, so it's called the HASP program; Housing, Accommodation, Support Partnership. So I would define mental illness; people have not been diagnosed they might anxiety or depression that hasn't been diagnosed; it's usually an illness that is diagnosed.

JS) what would you say are the benefits of peer support work?

KH) I would say, I mean there's so many benefits but the main benefit is that people don't feel alone, that people use their lived experience to connect with people, to include people and social inclusions. The benefits of peer work are that people realise they can get support, that its treatable, that we've been through it before and I always use the analogy that I use in my book of someone being in a pit and its dark and you don't realise there's a ladder there and a peer support worker will shine that light down on that ladder to let you know that there's a way out.

JS) why does LWB employ peer support as a method of aiding people with a mental illness?

KH) LWB really value the lived experience, I'm a consultant to the support workers so they can ask me about what's going on with a client or do I have any experience in that area, it's very important to LWB to see it from that point of view, to help out as much as possible, the team and LWB is really into reducing stigma and so the peer support that I do in the community with the presentations that I do is really reducing stigma and we have a pre and post measure of stigma so when we go out to a speech, before we do the speech we get people to fill out a scenario and then after the speech they fill out the same scenario and see if they've changed their attitude. I went to NZ last year saying that I'd done 150 speeches and this is the result of reducing stigma so we've actually got statistics and everything that proves that our program has reduced stigma.

JS) Do you believe there are things that peer support achieves that traditional methods are not able to?

KH) I think that peer work is like an add-on to everything else, like you need your psychiatrist, you need your mental health team but you also need a peer worker. I think the more places that peer work can join in with other services the better. I've seen more peer workers emerge and more jobs emerge quite a bit but we've still got a long way to go but I think that it's one of the most valuable to the mental health system and I've just spoken to the commission lately and we've been saying more peer workers that's what we need, 5, 10, 20 years' time and I have quite professional development ideas for becoming a leader in peer work and I would love to have my own company of peer workers and be the CEO and it might be a grandeur idea but that's what I'm working towards because I would be training organisations to take peer workers and id be getting specific training for the peer workers and also so say we had peer worker on the team of the police force then the peer worker