

**Scottish Mental Health Law Review – Stage 3**

**Feedback from VOX Scotland**

**27th May 2022**

1. **Who we are**

VOX is a national members’ led mental health charity. VOX aims to ensure that people with lived experience (PWLE) of mental health conditions are influencing a number of key policy areas by capturing members’ experiences and representing them at a range of groups and networks.

1. **What we did**

To engage with people with lived experience on their views around the law review's recent recommendations:

* We enabled people with lived experience to understand the recommendations (either through our team, or through the support of the law review team).
* We created a safe place for people to share their viewpoints - engagement was via mixed methods, both in-person and online, also person-centred and inclusive.
* We held Lived Experience Discussion sessions with five groups

Lived Experience Discussion Groups were planned with 6 groups. One of those groups didn’t have any participants join us on the day.

Given the emotive nature of the discussion we focussed on reaching groups who already had a sense of belonging and trust.

We reached out to a number of Collective Advocacy Groups and arranged sessions with Advocard, HUG – Spirit Advocacy and Bipolar Scotland. Some collective advocacy organisations were already pulling together a response on this topic and therefore were happy to take forward themselves. We offered support to those groups in order to enable and encourage contributions.

We also reached out and engaged with a number of third sector projects who are providing support to people with lived experience directly, and arranged sessions with the Kintyre Link Club, Oban - New Hope Kitchen and the African Women’s Network (AWN) in Glasgow.

Finally, some of our members got in touch directly with us either through email (4 participants) or by phone (2 participants).

We engaged with 56 participants in total.

**Participant numbers**

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| --- | --- |
| Bipolar Scotland | 10 |
| HUG – Spirit Advocacy | 8 |
| Sharpen Her: African Women’s Network | 10 |
| Oban, New Hope Kitchen  | 14 |
| Kintyre Link Club | 8 |
| Other - Phone call and email  | 6 |
| **Total participants**  | **56** |

1. **Overview/Format of the session**

VOX Scotland aimed to ensure that the discussion sessions were inclusive, and as such should be based on conversations which are meaningful and relatable. We used examples to bring the consultation to life, and we focussed in on three key areas, as agreed with the law review team.

The data collected throughout this engagement process, and the resulting recommendations in turn should be reflective of people's authentic experiences and priorities.

VOX’s manager and VOX’s Development Officer held the discussion sessions, and were supported by the group contact person, while for Oban New Hope we were joined by one of the law review team.

We started by explaining the background and focus of the law review, the change in purpose and then we looked at the following three key areas;

* Human Rights Enablement
* Supported Decision Making Processes
* Autonomous Decision Making

We also found that some discussion areas arose naturally including advocacy and community/social support.

We thanked everyone afterwards, and we offered support if anyone needed it after the conversations, we also provided them with our contact details and informed them that we would send a copy of the final report to them.

1. **Summary of Key Points Raised**

The key points which arose from the discussions we held with participants, focussed around the suggested changes being seen as positive and meaningful. There were however significant concerns raised by participant’s over what would be required in practice to enable these new laws to be implemented effectively.

There was a particular worry over whether resources would be adequate enough for successful implementation of human rights enablement, and worries highlighted around what would happen in practice if human rights assessments were initiated, but the services and supports were not provided in order to realise those rights.

There was also a sense of a “lack of faith” in supported decision making frameworks, and autonomous decision making being put into practice successfully. Participants talked about the foundations which would be required to make the new laws work, such as advocacy, awareness raising, training and practice development, and wondered whether these would be invested in at the levels required.

1. **DISCUSSION SESSION 1 - Human Rights Enablement**

Participants were provided with some examples of how human rights enablement looks at mental health from a broader perspective, and how it includes more than just mental health, specifically, that it takes into account factors like housing, addictions, employment, underemployment and other social inclusion related issues.

It was felt by the majority of participants that the whole person approach is very positive, with most of the participants we engaged with seeing the benefit of enabling their rights from a broad viewpoint. It was felt that if this was put into practice effectively it could lead to significant improvements in quality of life for people who have mental health problems.

Participants provided numerous examples of how they could see where it could make a difference if their lives were looked from a perspective which includes social and economic rights. Participants noted that it could help prevent people falling between the gaps, and it could help many people to move forward from ongoing issues which never get resolved.

*“If you go to the GP they will just give you medication. That won’t help me as I will still be left in the exact same situation with my life at a standstill for years and years, and medication won’t work to fix that” AWN*

*“I actually have the problem mentioned in the example of poor housing, where it is damp and I have just had to live with that. If they did a holistic assessment and looked at my rights they would see how the housing is impacting my mental health and the problems it causes me” AWN*

*“I think it’s a good idea to change it to include these other human rights and to have the human rights assessments”. Oban – New Hope*

It was clear participants felt that this could be highly beneficial to improve peoples’ life, prevent further deterioration in their mental health and support recovery.

Addiction Issues

One area where this approach was felt to potentially be particularly beneficial, was for those who have mental health problems and addictions and/or alcohol misuse. Participants were clear that this was often a form of self-management/self-medicating, and that we need to provide appropriate support for those with dual diagnosis.

*“Gambling addiction then alcohol, drugs. Makes you feel better to start with, but then makes you worse”.* Bipolar Scotland

It was noted that currently people can not easily get effective help for their mental health problems unless they are already able to manage their addictions and/or alcohol misuse, and it was hoped this rights-based approach could challenge this “catch 22” situation.

*“I can relate to the addiction example, having had a cannabis addiction and being refused for mental health treatment but also not getting help for the addiction”. Kintyre Link Club*

It was clear that connecting mental health services with support to address addictions and/or alcohol misuse, was felt to be an area where this broader approach may force a level of accountability within services.

All participants felt that connecting mental health support more closely to housing, employment and other social issues was positive, and furthermore that it may lead to developing new supports which could address specific challenges fundamental to improving lives.

Is Human Rights too broad a concept?

Some concerns were raised over whether Human Rights is too broad a concept. Whilst the idea of looking at the whole person was seen as positive there were concerns as to whether the Human Rights Approach was the right tool to create the change required.

Participants questioned whether human rights captures the complexity and nuances around mental health. It was also mentioned that it can feel like a fight or struggle as it sets a precedence/baseline which in practice is unrealistic at times to defend.

Some of the concerns included the following:

*“I want to know why existing legislation isn’t upholding our rights” Oban, New Hope.*

*“I think there could be another approach, where yes, health as a whole (holistic, physical and mental) is taken into account but not based on people having human rights to everything, and arguing breaching human rights all the time”. HUG – Spirit Advocacy*

*“We talk about mental health like it’s a battle approach but in other countries it’s much more balanced – not what I want and what I deserve – it’s a cooperation between us and them – here’s what’s provided, how can we make it work” Bipolar Scotland*

The main concern around human rights being the framework discussed was whether, in reality, this approach would drive positive change.

Key issue -will there be adequate services and supports to make it happen?

Whilst the general feeling was that human rights enablement could helpfully identify what is needed for the individual from a broader perspective, there was a worry over how this would lead to being able to access the services and supports identified within the human rights enablement framework/assessment.

It was highlighted that currently services cannot provide what is required (before adding the wider factors such as social and economic rights into the picture) and that this makes human rights enablement seem unrealistic and idealistic. The context of the current economic climate and the impact of the pandemic was also mentioned a number of times.

“*If you look at the Patients’ Rights Scotland 2008 you’re supposed to have the choice of how to access your treatment, near me or phone or in person but now covid is used as an excuse and you are not given that choice”* HUG Spirit Advocacy

Significant gaps in services, particularly in rural areas, already impacts on current human rights being upheld. Furthermore, many people are denied a service due to not meeting set criteria. Whilst it is hoped that human rights enablement would lead to new services and supports being developed, the funding and resources which would be required in order to do so being provided in reality was viewed with cynicism and despondency.

*“We’re still having problems with choice and person-centered care, for example with choosing the gender of the clinician or whoever you are going to be speaking to”* HUG – spirit advocacy

*“How much resource does the government have to actually put this holistic human rights assessment and all the things that then people will be entitled to, into practice”.* AWN

*“All (services and supports)are under-funded – need the money to make it work. Same barriers if local services underfunded”.* Bipolar Scotland

*“Highland has now stopped funding addiction services, so if you are assessed and it’s decided you need and have a right to addictions help, where will that help come from?”* HUG -Spirit Advocacy

*“The reality is that mental services are overstretched and don’t have the resources. And especially in rural areas, it’s so hard to see a psychiatrist, a CPN and even your GP”* Oban – New Hope.

*“I spoke to police officers the other day, and even they were saying how ridiculous it is the hoops people need to jump through to be able to get treatment, especially if there is an addiction involved.”* HUG – Spirit Advocacy

*“It sounds great but if you don’t put in the money to fund it up to 200% of what it is now, you’re not even get started”.* Kintyre Link Club

If sufficient funding can be put in place to support human rights enablement and lead to wide ranging support and services, it was felt that it could be a remarkable development, which would have a hugely, positive impact on people’s ability to access what they need to support their mental health.

However, participants raised concerns that it could become yet another assessment to be carried out leading to very little change and taking time away from providing support. The other worry raised was that very high threshold levels to access support may be set, which means it would only apply to a very small number of people. Additionally, that despite identifying key services and supports required to be developed, it simply would not materialise.

“*It’s all very well having the law in place but public bodies just wriggle out of things and don’t take responsibility and funding and resources are blamed”.* HUG -Spirit Advocacy.

Thresholds and criteria for assessments

There was a sense from participants that to make this work it would be expected that a threshold would be set to be able to access support, and this highlighted a number of concerns such as:

* Who decides who is unwell and is it diagnosis specific?
* What if your mental health problems fluctuate?
* What if you are not really in contact with any services or supports?

An issue may arise during the assessment process itself: will the person carrying out the assessment fully grasp how unwell someone is and understand the fluctuating nature of mental health problems?

*“Picking up the point on anxiety, I actually disagree with (the other participant) about that. Anxiety like lots of mental health conditions, fluctuates, where some days you can go out but can’t manage the supermarket and other days you can’t even leave the house. Things change, so wouldn’t all be about having a diagnosis.” Kintyre Link Club*

Other people may need services or support which reaches out to them in order to get an assessment caried out, and participants were unsure how this would work in practice.

*“I wouldn’t go for an assessment, I need somewhere to go for support but don’t want assessment where they diagnose and judge me”* Phone Participant

*“I’m wondering about people who may need an assessment and have rights being breached but they don’t actually come into contact with mental health services to get it put in motion. Important for there to be other ways to get one.”* Oban, New Hope.

Time and resource

Participants asked who would carry out the assessments. It was felt that clinical staff would be unable, and possibly unwilling to carry out these assessments as it would be yet another process which takes away from providing care.

*“I’d be very surprised if they (health care staff) were supporting this as in my experience, on the whole (not every single one, but many) do not want to or aren’t able to take any more time to spend on people to do assessments or consider the whole person” HUG – spirit advocacy*

*“GPs are overwhelmed already, so how will they manage this or who will do it?” AWN*

Workforce and training issues were also mentioned and the importance of it not being a tick box exercise.

*“I wonder how it will work – who would we go to, to write out the (HR assessment) document? If it’s the first person we have contact with who sets it in motion …..a lot of people would need training”. Oban, New Hope.*

Responsibility and accountability

Many questions were asked about who is accountable and ultimately responsible. For example, if something goes wrong, or you don’t feel an assessment is accurate, who is held responsible. What if someone carries out an assessment and someone else does not agree, who makes a final decision?

Upholding Rights

The other point that was highlighted was around relevant processes if they felt their rights were not being upheld.

*“How are individuals suffering from mental health conditions going to enforce their rights?”* HUG – Spirit Advocacy.

It was clear that many people didn’t think they would feel able to challenge any issues around this. Furthermore, they didn’t have support to do so. Many participants talked about the need for advocacy and other support to take forward situations where rights are not met.

It was noted some people don’t have a family member/friend or supporter to help them, and that we have to create a system which acknowledges that for some, social networks have broken down due to complexities around mental health.

It was mentioned a number of times that both individual and collective advocacy need investment to be able to provide support to individuals in having their human rights supported or defended.

Keeping the process live and the need for a review process

Issues were raised around how changes to individual circumstances would be recorded within the assessments. Regular reviews and processes for updating assessments were felt to be essential to ensure it is both an effective and meaningful assessment. The potential for many different people being able to make the assessments raised concerns over how information was shared and stored.

There were also points made around how someone can need help but may not be in the right place at that point in time to seek help.

*“When should an assessment happen?– In this instance maybe it should be when the person asks for it…. when the person goes into treatment is when they’re ready”. Bipolar Scotland*

It was clear that participants wanted readiness to accept help, sharing information between services and organisations, regular reviews, and updates when required to be factors that are thought through in some depth.

Awareness and training of Human Rights Enablement

Awareness of Human Rights Enablement was stated as being crucial to ensure this approach is successful. This awareness raising would need to be within the workforce, through services and organisations, and most importantly within communities. Training was also mentioned as being something which would need to be carefully thought through.

*“It’s a big culture shift with expectations on statutory services and also lots of work on helping people understand what their rights are” Bipolar Scotland*

*I think it will be a lot about awareness, making sure people know about it. And are actually supported, because people don’t know and aren’t supported at the moment to get their rights or get treatment”.* Kintyre Link Club

*“Training is important – peer in particular. Our charity have trained mental health ambassadors and that was really important” AWN*

*“I think it sounds like a good change and will help people but feel the most important thing will be to train the lay people like me – training and understanding and awareness for ordinary people, staff, those who are supporting others and peers will be so important if it’s going to work”* AWN

Awareness Raising should therefore be taken into account in order for this approach to be successfully implemented.

1. **DISCUSSION SESSION 2 - Supported Decision Making**

There was a general feeling that a focus on supported decision-making should be fundamental. There was wide consensus that we need to find better ways to support people to make decisions. It was felt that the support for decision-making at the moment is inadequate, and that there is a lack of understanding of current processes which support decision making, like advance statements.

It was noted that a combination of family members, carers, supporters and a range of professionals and advocates should be involved in supporting a person to make decisions about their care/rights.

Participants felt an approach which brought together professionals and key people that matter to the person was something that has been talked about in the past which should be happening but does not seem to be in practice. They also stated that having laws to enforce it or protect it can only help.

As with the human rights assessments there were concerns raised about the resources which would need to be in place for people to get the support they need to express their wishes, have them respected, have an equal say, and have carers involved properly in conversations where individuals want them to be.

Importance of carers/supporters

Some successful elements of current models of supported decision making were noted. Examples of family members being involved in care was highlighted and seen in general as being reassuring for supporting decision making.

“*Role of carers [is important] mine has a good understanding of what I would want done in situations*” Bipolar Scotland.

*“I’ve been in psychiatric hospital twice and what got me through that, in the way that was best for me, was having my brother as my named person who I trusted”* AWN

However, it was noted that this wasn’t always an option if people did not have family, carers, or supporters.

Advance statements and directives

The idea of advance directives being broader than advance statements was highlighted, and this was felt, in theory, to make sense.

It was noted however that there has never been an appropriate awareness raising campaign on advance statements, and that it has also never been properly embedded within services and systems (with someone who has an overall responsibility for this process). Furthermore, that support to develop an advance statement is not easy to find. Without these prerequisites it is unclear how having a broader remit will deliver effective transformation.

*“The issue we already have with the existing advance statements is that there remains a lack of understanding in the wider mental health community of what they are, who should write one and how to do that. There needs to be more accessible information in a way that people can take ownership of and have the support to write. It’s really not part of the general discussion which is on treatment and services. So education is needed on that and any advance directive brought in”* HUG – Spirit Advocacy.

*“I think this (advance directives) is a good idea – I’m sick of having to explain everything about myself and diagnosis and everything over and over again, especially here with the turnover of staff. It’s good to have an advance statement and the directive but we need support to do them”. Kintyre Link Club*

In relation to the discussion around the importance of support to create advance statements and/or directives, it was noted that not everyone has a family or friend to support them. It was clear that participants all had very different circumstances, and that we need to create mechanisms to be flexible enough to accommodate for these differences.

*“That’s my problem too, I don’t have anyone apart from the people in this group…. It’s difficult if you don’t have family or close friends you can rely on. And I would need support to write it!” Kintyre Link Club*

*“You need time from someone and that personal touch so that it is done right and people’s views are listened to.” Oban, New Hope.*

The need for the process to stay live and change as required was also discussed, there was a concern that if this did not happen that it could damage relationships and not represent someone’s will and preference adequately.

“Paperwork, option of where it sits – individual or hospital – person kept and gave to wife and GP and the hospital kept a copy too. Need that support within 24 hours of person going into hospital.” Bipolar Scotland

*“I think the advance directive seems like a really good idea but would want to make sure it stays useful, like with the advance statement, so that it is reviewed regularly as people and circumstances change”. AWN*

1. **DISCUSSION TOPIC 3 – Autonomous Decision Making**

Participants felt that we should always support people fully before looking at having to step in and decide that someone is unable to make autonomous decisions. It was felt by many participants that there are times when a person who has a mental health problems is unable to make an autonomous decision.

*“when people, including me, are very vulnerable they need someone to step up”.* Oban, New Hope.

Most people felt that it is the relationships with clinical staff, and the involvement of key people which mattered most when someone is unable to make autonomous decisions. This quality of the relationships between staff and patients was mentioned frequently and it was felt that without this no system or process will genuinely benefit an individual, and also that those who know the person best (both clinically and in general e.g. carers/friends) should be involved.

*“The biggest factor is not the law or the wording of the law but the people involved. Good doctors, nurses, social workers, if they’re trying to help then the patient responds. But if you have a great law with good wording but people are under pressure or don’t have the best interests of the patient at heart then it won’t work to help the patient.”.* Bipolar Scotland.

It was difficult to know how this could be built into mental health law but it was felt to be so important that it should be highlighted.

Distribution of power

Many participants felt that power should be more equally shared between a group of individuals e.g. named person, psychiatrist, key staff, the person themself, advocacy and relevant supporters of the individual.

*“I wonder who else could be involved positively in determining if someone isn’t able to make their own decisions – who is deemed appropriate? A social worker – especially adult support protection, or a carer? Community Mental Health team/CpNs/advocacy? There are a myriad of people involved in decisions and could potentially pave the way for people to be admitted to hospital – detaining them. From the point of view of refusing treatment or admission to hospital, who is involved is important”. HUG – spirit advocacy.*

The majority of people did feel that professional support from clinicians was important.

*“Main thing that makes me feel better if shaky is seeing a professional – reassuring for me even just for 5/15 mins – that’s what makes it so frustrating for people to wait so long to see someone when they know it would only take a few minutes to help. If feeling shaky - down or hypo/hyper need help not to let that get worse”* Bipolar Scotland

Whilst the involvement of clinical staff was seen as very important, there was also a need to ensure that wider involvement takes place, and it was noted that usually the depth of knowledge carers and friends have is vital in understanding the full picture of someone, particularly in relation to wider social and economic factors.

*“I think it would be good not to have just one psychiatrist saying someone hasn’t got capacity. It should be a group of people, agreeing that someone needs help with decisions ….and much better if they have a trusted named person”. AWN*

*“I think it should be something like a group of 5 people deciding whether someone needs intervention because they aren’t able to make their own decisions at the time. Not one, make it safer”. Kintyre Link Club.*

A minority of people were unhappy with any intervention against their will no matter who is involved.

*“I have grave concerns about anyone being able to interfere and take control of my decisions and my life. I have a right to be wrong and I want it to be known that I don’t ever want anyone to decide for me. It’s a slippery slope. How would you know when intervention is needed, who can tell that and have the criteria for it?” Oban, New Hope.*

Broadening out the concept of autonomous decision making to include issues such as coercion, controlling relationships or those who had addictions was felt to be a fairly positive step forward but there were some concerns.

It was noted that if you are experiencing domestic abuse there should be a way of enabling and recognizing this within law as impacting on your ability to make autonomous decisions, but uncertainty about the practice and implications of making this happen and where boundaries lie were noted.

*“Makes sense if someone is in an abusive relationship but I wonder how they can intervene and help.”* Bipolar Scotland

There were some concerns about the wider involvement of who can make decisions on behalf of someone, that it could lead to power being used inappropriately. Particularly if someone has a vested interest e.g. financially, and that it may take away safeguards which currently protect your rights.

*I can see good and bad things about this change to widen the law to include more people. I have lived experience of both dementia and a brain disorder. And the worry is that if someone with a vested interest uses their power inappropriately.* HUG – Spirit Advocacy.

Given we were discussing this with people who have mental health problems the discussion mainly remained focused mainly on mental health.

1. **Other key points raised**

Advocacy

Advocacy was mentioned throughout the discussions (although the term wasn’t always used). It was stated a number of times we need to invest to ensure people are supported to access their rights in an unbiased way, some of the points mentioned are summarised below;

Individual advocacy;

* To ensure people get individual support to understand their rights e.g. human rights assessments, supported decision making.
* To support people to articulate and work through their decisions and views on a range of issues.
* To raise awareness of advance statements and directives to individuals.

Collective advocacy;

* to identify recurring issues arising geographically and nationally in relation to mental health law.
* To identify where systems, policies, laws and practice are not working and identify solutions.
* Identify good practice and raise awareness on issues relating to mental health law.
* Promote elements of supported decision making e.g. advance statements and directive e.g. via peer support/advocacy (for example like the work carried out by the Mental Health Network, Greater Glasgow)
* Provide support and campaign/push on human rights issues not being upheld

*“ a significant proportion of people are not having human rights upheld, and not having services they need because the staff are being whipped by their managers to meet targets and only give certain amount of sessions or sessions to particular people. Need an advocacy role (otherwise) they say ‘no you’re not eligible, and can’t have it.”* Bipolar Scotland

There was a strong sense that we need to be able to understand experiences of people directly and to do so we need both individual and collective advocacy to capture people’s experiences in an unbiased way.

Social/Community Hubs

One of the points that participants mentioned a few times was around the need to create spaces where people can come and meet others who will accept and understand them. This came through within all the group discussions.

Validation, connection and peer support were all highlighted and felt to be of importance in making the new laws effective. Without this there were concerns over the ability to raise awareness of concepts e.g. advance statements and human rights assessments, the ability to support lower level mental health needs (if thresholds or specific criteria were identified) and furthermore that social rights may not be easily realised.

There were a number of strands within Social/Community Hubs which participants highlighted as being valuable. The first one was that the contact with others can stop you becoming more unwell and going downhill, mainly through a sense of belonging and validation.

“*this is the difference between life and death for me. Coming here”.* Kintyre Link Club

Secondly, the way it helps people to get more connected and find out what else is happening and link you to other potential support, information and networks.

*“I feel detached from my community, I really need somewhere I can go along to and hear what’s going on”* Phone call

Thirdly, the benefit of peers who truly understand how you feel and can encourage you (whilst also experiencing a sense of meaning from supporting others) was felt to be important.

*“Giving peer support helps me too – encouraging people to get out for walks, be involved in communities, be socializing” AWN*

1. **Conclusions from our discussion sessions**

The changes identified in phase 3 of the mental health law review were felt to be positive in relation to the concept of human rights enablement. Participants felt that including wider factors such as economic and social rights was very promising in terms of direction of travel for mental health law, and it was felt that further development of supported decision making was essential.

It was noted that looking at autonomous decision making from a perspective which takes more than just “mental disorder” as the key criteria made sense, but that it was also difficult to comprehend the impact this could have in practice. The majority of participants felt that the distribution of power (in relation to stepping in when it is felt that someone is unable to make an autonomous decision) should be shared within a larger group of people who know the person, so a full understanding of the person and their needs is captured. Although safeguards around vested interests must be developed.

Finally, the problems and concerns our participants identified were focused around how the new suggestions could be realised, and whether adequate levels of funding would allow the services and supports required in order to make human rights enablement happen. Furthermore, whether supported decision making processes would be invested in appropriately, and finally whether autonomous decision making could be carried out in a way which puts the suggested ideologies into practice.

**Appendix 1**

Participant information

Bipolar Scotland 26th April 2022 - Different geographical areas of Scotland, different age groups and genders.

Sharpen Her: African Women’s Network, Glasgow, 3rd May 2022- Most of the women live in Glasgow or Lanarkshire, most have settled refugee status, while one woman is still in the process of attaining refugee status. The women originally come from Uganda, Nigeria, Malawi, Pakistan, Algeria and Azerbaijan.

Spirit Advocacy Highland User Group (HUG) Law Review Online Session, 11th May 2022- The participants were a mix of genders and ages, and were mostly based in and around the Inverness area.

Oban New Hope Group In-person Session, 12th May 2022- The participants were a mix of nationalities and ages, with the majority of participants being female. Participants live in and around the Oban area and have lived experience of mental health difficulties.

Kintyre Link Club, in person, Campbeltown 13th May 2022- The participants were a mix of ages with the majority of participants being female. Participants live in and around the Campbeltown area and have lived experience of mental health difficulties.