

Participant experiences and expectations of The Way Back Support Service (TWBSS), ACT

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Acronyms

| CATT | Crisis Assessment and Treatment Team |
|-------|---|
| DBT | Dialectical Behavioural Therapy |
| ED | Emergency Department |
| HCCA | Health Care Consumers' Association Inc. |
| TRec | Transitions to Recovery |
| TWBSS | The Way Back Support Service |

Acknowledgements

The participants' strength and resilience in the face of enormous challenges is truly impressive. Their willingness to share their stories will benefit others, and we sincerely hope life continues to improve for them. Each and every one of them is an amazing and capable person with so much to offer!

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Key messages

The Way Back Support Service is a suicide prevention program that provides traumainformed, non-clinical support to individuals after a suicide attempt. Woden Community Services, in the ACT, became a trial site for TWBSS in August 2016. Health Care Consumers' Association was asked to interview people who had used TWBSS and associated services following a suicide attempt. The consumer stories will be used to help

- inform service improvement within TWBSS, and
- contribute to the TWBSS evaluation.

What we learned

- The principles of trauma-informed care safety, trust, choice, collaboration and empowerment are embedded in the design of TWBSS and exemplified by the Support Coordinators.
- Participants were unanimously positive about their experiences with TWBSS.
- TWBSS is hiring the right people with the right skills as Support Coordinators.
- TWBSS is providing a service that is not provided by other existing services.
- Several important shortcomings in associated services came to light through the interviews.

What this means for TWBSS in the future

Retain the trauma-informed focus

All the participants described numerous examples of care that were imbued with the trauma-informed approach. This is clearly central to the program's success.

Continue providing non-clinical support

This type of support does not appear to be available elsewhere in the health system and was greatly valued by participants.

Expand the program's flexibility

The program's flexibility in meeting the needs of participants is one of its great strengths. However, the timing for entry to and exit from the program need more flexibility to cater for outliers.

Routinely gather consumer stories

Consumer stories draw attention to what is most important from the participants' point of view and what needs to be done better. It also provides strong evidence of the program's success.

How we went about it

Nine, in-depth, qualitative interviews were held with people who had completed the TWBSS. Participants were invited to highlight the most important elements of their experience. We analysed the interviews against the principles of trauma-informed care and produced a diagrammatic representation of their health journey.

Executive Summary

Background

The Way Back Support Service is a new suicide prevention program that aims to help people discharged from hospital after a suicide attempt. It delivers one-on-one, nonclinical care and practical assistance. Its purpose is to connect participants with existing health and social services in their community and provide encouragement and support in the first few months after leaving hospital.

The Way Back Support Service was developed by Beyond Blue and trialled in three locations around Australia, including the ACT. It has been operating from Woden Community Service since August 2016. In the context of an evaluation conducted in 2018, Woden Community Services decided it wanted to hear from program participants. Health Care Consumers' Association was asked to interview people who had used TWBSS.

Aims

The research sought to elicit the experiences of consumers who have used TWBSS and other services following a suicide attempt.

The overall intention is to use the consumer stories generated

- to inform service improvement within TWBSS, and
- to contribute to the TWBSS evaluation.

Method

The research was designed to minimise any harm to participants. We were particularly mindful to minimise the risk of re-traumatising them. The Real People Real Data approach was used because it prioritises the issues that are important to consumers. TWBSS Manager approached all past participants to identify those who were willing to share their stories and the researcher conducted in-depth interviews with each. Participants were offered support during the interview and support was also available immediately after each interview. Some participants took the opportunity to read their transcripts and highlight the elements of their story that were most important to them. These were used to develop a diagrammatic representation of their journey immediately before and throughout their time with TWBSS. The interviews were also analysed against the principles of trauma-informed care – safety, trustworthiness, choice, collaboration, empowerment.

Participants

Seven women and two men participated in the interviews. Five of the women were under the age of 30 and another was the mother of children under ten years of age. The remaining three participants were over 50. Only one participant wished to have a support person present through the interview and support was needed by two participants post interview.

Findings

The data was exceedingly consistent, with most interviews providing evidence of all the research findings. We are confident that further interviews would have yielded similar results.

Abundant instances of the trauma-informed approach to care were identified. All participants talked about the Support Coordinators and TWBSS Manager in the same favourable tones, using the same or similar terms. It is clear that the staff of TWBSS combine humanity and professionalism. They were uniformly seen as

- trustworthy and reliable,
- non-judgemental,
- easy to talk to and be with,
- gentle, and
- validating.

The essence of TWBSS is non-clinical care and practical assistance. The following strategies were all employed by Support Coordinators and the Manager:

- Ensuring safety
- Encouraging well-being
- Helping with goal and priority setting
- Making and keeping appointments
- · Exploring treatment and other options with participants
- Using physical activity
- Promoting the benefits of helping others

TWBSS participants were unanimously positive about their experiences with the program, and all were grateful to have taken part in the program.

All participants indicated that around the time of their suicide attempt or during their time with TWBSS they were ready to take their life in a different direction and TWBSS assisted them to commence this journey. While this sense of readiness was expressed in different ways, it is likely to be central to the program's success. These interviews cannot tell us about the program's success with TWBSS participants who are not yet ready to accept the support offered by TWBSS. However, we must bear in mind that one of the consequences of trauma is that it "affects the way people approach potentially helpful relationships".¹

The 12-week structure of TWBSS seems to work well for participants. Their preferences vary with some meeting weekly and others being happy to meet every two to three weeks. Similarly, some maintain regular text or phone contact between meetings, while others choose to leave contact to the scheduled meetings. The framework provided by regular meetings encourages participants to continue addressing their needs and issues, rather than surrendering to the difficulties.

The program's qualities reflect the trauma-informed approach. Knowing that support is available helps relieve participant anxiety, and the regular meetings provide continuity of care, engendering a sense of security. Crucially, TWBSS offers participants an alternative vision of their future. The program's flexibility and the non-clinical support are valued, in part, because they are provided nowhere else. Underpinning all interactions is the Support Coordinators' commitment to the participants. This commitment is central to ensuring safety and establishing trust.

The research also explored other services that participants received over the same period. In general, the CATT and ambulance service were well regarded. However, the young women all found the experience of ED extremely difficult and several felt they were left worse as a result. Their experiences of the Short Stay Mental Health Unit, the Adult Mental Health Unit, and Ward 2N were similarly unpleasant and potentially unhelpful. Interestingly, the two older participants who both used an emergency department had a more positive experience. Likewise, their experience of the Short Stay Unit and the Adult Mental Health Unit was considerably more beneficial. Only three participants were seen by hospital-based mental health works, but their experiences were consistently positive.

Recommendations

Increase flexibility and discretion

| | Recommendation 1: | Individuals are able to enter TWBSS when they are ready to embrace the process, even if this occurs sometime after their suicide attempt. timeframe. |
|---------|-------------------|---|
| | Recommendation 2: | On first contact, potential participants are asked for the details of, and consent to contact, a trusted individual – not necessarily their next of kin – who will |
| | | be in regular contact with them, and have a sense of what circumstances might suit the potential participant, and know when they might be ready to enter TWBSS. |
| | Recommendation 3: | Support is provided by TWBSS if the participant does not have sufficient community support upon completion of the program. NB The support may be less regular and intensive. |
| Contin | ue gathering data | |
| | Recommendation 4: | All participants who complete TWBSS program are invited to share their lived experience – through the process described in this report – to improve the service. |
| | Recommendation 5: | The information gleaned through interview are regularly reviewed and incorporated into the service, where appropriate. |
| Share v | what we've learnt | |
| | Recommendation 6: | The findings in this report are used to improve TWBSS. |
| | Recommendation 7: | The findings and process of arriving at them are shared widely. |
| | Recommendation 8: | Beyond Blue consider rolling this method of research and |

feedback across all services nationally.

Background

What is The Way Back Support Service?

The Way Back Support Service (TWBSS) is a new suicide prevention program that aims to help people discharged from hospital after trying to take their own lives. It endeavours to connect people with health and community services, and other social networks that might assist them and keep them engaged during a period of high risk and vulnerability. After an initial meeting, Support Coordinators deliver one-on-one, non-clinical care and practical assistance.

The Way Back Support Service was developed by Beyond Blue and trialled in three locations around Australia. Since 2014, the sites have received approximately 1,500 referrals. TWBSS has been operating from Woden Community Service since August 2016.

How did the research come about?

TWBSS in the ACT is guided by the Governance Group and informed by the Stakeholder Reference Group. ACT Health and Beyond Blue commissioned two research projects associated with TWBSS.^a Nous Group was engaged to consider how to improve emergency department (ED) processes and the Australian National University focused on developing outcome measures for the program. The Stakeholder Reference Group noted that neither was really asking about the participants' experiences and felt this was an oversight that needed rectification. Consequently, Woden Community Services agreed to fund the project and this amount was supplemented by the Nous Group to expand the project.

Who was part of the research team?

The research was a collaborative undertaking by two organisations. Health Care Consumers' Association provided the research expertise and Woden Community Services provided essential insight and knowledge about TWBSS, in addition to recruiting and supporting the research participants.

Health Care Consumers' Association

- Dr Kathryn Dwan, Manager, Policy & Research
- Dr Sarah Spiller, Policy Officer
- Darlene Cox, Executive Director

What did the research aim to achieve?

The research sought to elicit the experiences of consumers who have used TWBSS and other services following a suicide attempt.

The overall intention is to use the consumer stories generated

- to inform service improvement within TWBSS, and
- to contribute to the TWBSS evaluation.

- Woden Community Services
 - Prue Gleeson, Manager, Mental Health Transitions
 - Zoe Ryan, Support Coordinator

^a We use the acronym TWBSS when referring to the service that operates from Woden Community Services. When referring generically to the service we will spell it out in full.

How did we approach the research?

We employed qualitative methods to elicit consumer stories. An interview is a great way to gain an in-depth understanding of someone's experience: what happened to them, how they felt about it, and what they would change if they could. It is also a practical method for collecting consumer experience data that can improve decision-making.²

We chose to use The Real People, Real Data³ method developed by Consumers Health Forum, because it was developed explicitly to prioritise the issues that are important to consumers. The method has three major phases:

- 1) Identification of key stages that people may experience as they navigate their health and the health system:
 - Receiving assistance immediately after the suicide attempt
 - Referral and transition to TWBSS
 - Support from TWBSS and other services
 - Transition from TWBSS
 - Life after participating in TWBSS
- 2) Semi-structured, qualitative interviews with individual health consumers about their experience of these stages in the context of their patient journey.
- 3) A three-step analysis process that involves
 - asking participants to highlight what they feel are the most important positive and negative elements of their experience,^b
 - creating a Health Experience Wheel, which concisely presents key experiences in a person's narrative of their patient life journey, and presents emotional high and low points in this journey, and
 - evaluating the wheel and experience narrative against the principles of Trauma-Informed care.

Ethical clearance to conduct the research was granted by the ACT Health Human Research Ethics Committee (ETH 11.17.266).

What were the ethical considerations?

People who have experienced trauma in their lives are at risk of being retraumatised. Therefore, we took great care in designing the research. The interview schedule and recruitment strategy were developed collaboratively with Prue Gleeson, Manager of TWBSS.

A priority of any researcher is to do no harm. Therefore, the researcher undertook training in understanding and responding to trauma offered by Mental Health Coordinating Council.⁴ The interview process was subsequently altered to reflect the principles of trauma-informed care and practice (see <u>The importance of trauma-informed training</u>).

As with all research, we ensured that potential participants were provided adequate information and support, and that they were able to give their informed and voluntary

^b Not all participants chose to read their transcript and indicate which parts they considered to be the most positive and negative. In these cases, the lead researcher and one other researcher from HCCA independently coded the interviews to confirm reliability.

consent. The researcher verbally worked through the information and consent form before participants were interviewed. Participants were also reminded that they could withdraw at any time.

Interviews were conducted in a neutral, comfortable space at the Woden Community Service offices in Woden. All participants were asked if they wished to be accompanied by a support person of their choice. We also ensured that a Support Coordinator was available immediately after the interview should the participant need to debrief.

With the participants' permission, the interviews were recorded and professionally transcribed. The participants understood that their interview would be de-identified and un-attributable to them.

The researchers felt it was important to thank the participants for their time and effort in contributing to the study. At the end of the interview participants were offered a \$50 voucher, which was redeemable at a shopping centre located in multiple places across Canberra. The participants did not know that they would be offered the voucher, so it was not an inducement. Two participants declined the offer, the others were pleased to accept.

Finally, participants received a personalised thank you letter and a two-page, doublesided summary of the findings in plain English (Appendix). This demonstrates respect for participants and acknowledges their valuable contribution both to the research and TWBSS.

How were participants recruited?

All past participants of TWBSS, who were thought to be eligible for the research, were contacted by TWBSS Manager between 25 May to 31 August 2018. Nine were interviewed. See Diagram 1 for the numbers of people contacted, those who considered participating, and their ultimate decisions.

One person was referred by the Crisis Assessment Treatment Team and so did not meet the participation criteria of having used the emergency department. Six people considered participating but choose not to. Their reasons included

- being under too much stress,
- being too physically and mentally unwell,
- feeling they would find it difficult to talk about their experience,
- feeling it wouldn't be good for their mental health, and
- being prevented by other commitments.

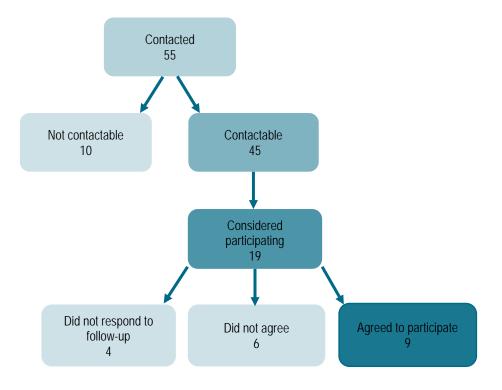


Diagram 1. Recruitment process

Who were the participants?

Seven women and two men participated. The gender balance is unsurprising as women are much more likely to participate in health research than men.⁵ Five young women (i.e. under 20 years) participated. One participant was the mother of young children, and three participants were older (i.e. 40-60 years). A third of the participants had partners, the rest were single.

We had planned to interview eight participants. However, a short way into one interview it became clear that the participant was still in a very vulnerable state. As outlined in the ethics proposal, the interviewer sought the participant's permission to close the interview, put it to him that she felt he was still in a highly vulnerable state, and asked if he would like to speak with a counsellor. The participant agreed to speak immediately with the TWBSS Manager. He subsequently re-entered TWBSS and made good progress. Because of his initial involvement he was invited to re-interview upon completion of TWBSS. The subsequent interview revealed that he did not meet the eligibility guidelines, because he did not use an emergency department, but the researcher decided to continue given his willingness and the uniqueness of his trajectory. This allowed the researcher to explore avenues that were not covered in other interviews. The interviewer also explored his reasons for agreeing to participate while unwell. A precis of each participant follows.

- Participant A is a young woman who lives with her family in a small town in rural NSW who did not understand her struggles. She became depressed and over about two years she was "in and out of hospital" in both NSW and the ACT. After approximately three suicide attempts, she was admitted to the Adult Mental Health Unit and from there referred to TWBSS. Half way through TWBSS she presented to the emergency department and she was admitted to the Adult Mental Health Unit, after which she completed TWBSS.
- Participant *B* is in her early 20s. She has a challenging relationship with her family who do not understand her mental health issues. Her housemate at the time had issues with alcohol that fuelled her own. After she called the Crisis Assessment and Treatment (CAT) Team she was admitted to the Short Stay Mental Health Unit, from where she was referred to TWBSS.
- Participant *C* is an international student studying at an ACT university with the support of an Australian Government scholarship. A significant traumatic loss triggered depression. She sought assistance from her university's counselling centre, who eventually referred her to the CATT. The CATT assessed her at home and took her to hospital. While she was in hospital, she was referred to TWBSS.
- Participant D is a single woman who has previously used the TRec [Transitions to Recovery] Program. She was referred to TWBSS while in hospital after attempting to take her life.
- Participant E revealed to his manager that he had attempted suicide the previous evening. His manager immediately referred him to the CATT, who subsequently referred him to TWBSS. At that time, he had not been ready for TWBSS and withdrew from the program very early on. He subsequently returned and completed TWBSS.
- Participant F's attempt to take his life was interrupted by his wife. She drove him to Calvary Public Hospital^c Emergency Department (ED) and was able to stay with him throughout his hospital journey. He was visited by the CATT, transferred to Canberra Hospital, and chose to stay in the Short Stay Mental Health Unit for a few days. From there he was referred to TWBSS.
- *Participant G* works as a personal carer. She has social anxiety and a problem with alcohol. She was sharing a house with someone who didn't understand mental health issues when she attempted to take her life. She was contacted by the CATT after her time in ED and they referred her to TWBSS.
- Participant H is a young woman undertaking a higher degree at a local university. She has a good relationship with her mother and partner, but a difficult relationship with her father. She suffers from depression and anxiety. An event prompted her to attempt suicide. However, her partner was able to call an ambulance and her family accompanied her to Calvary ED. From there that she was referred to TWBSS.

^c Hereafter referred to as Calvary

Participant I is a young mother with young children and a supportive partner. She has always suffered anxiety and depression. How well she manages it depends upon her circumstances. She was struggling for some time before being taken to Calvary ED in an ambulance. She was in Ward 2N for a couple of weeks before being referred to TWBSS.

The findings

How reliable is the data?

The evidence presented in the following sections is based on nine interviews with past participants of TWBSS. International research has established that major themes emerge through qualitative analysis within six interviews and that saturation occurs within 12 interviews.⁶ We confirm that the major themes had emerged by six interviews and none others arose in the following three, indicating that data saturation had been reached.⁷ This assured us that further data collection would yield similar results and serve to confirm emerging themes and conclusions.

Where possible we use the participants words verbatim. They are usually presented in italics and the entire quote indented. The bolding in the quotes was placed there by the author to emphasise the point being made. It does not represent an emphasis made by the speaker.

How are the principles of trauma-informed care enacted?

Until an individual is safe physically and emotionally from violence and abuse, recovery is not possible.⁸ The relationship between trauma and the development of mental health conditions, co-existing difficulties and complex psychosocial problems has been known for almost 30 years. The challenge for services is to be aware of this and respond appropriately.⁹ Trauma-Informed Care and Practice offers a framework for providing services to individuals who have experienced trauma.¹⁰

Different services and researchers use slightly different definitions of trauma-informed care. We follow the Mental Health Coordinating Council¹¹ in considering the key principles of trauma-informed care and practice to include

- safety,
- trustworthiness,
- choice,
- collaboration and
- empowerment.

These principles do not exist independently of each other. Therefore, quotes demonstrating one principle may also incorporate elements of others. We chose quotes that best demonstrate the principle under discussion. We also attempted to include a number of quotes from each participant to demonstrate the reliability of our findings. The following sections demonstrates how TWBSS enacts the key principles trauma-informed care.

Safety

The Support Coordinators are committed to ensuring both the physical and emotional safety of participants. The first meeting is always a sensitive event that routinely is well handled by Support Coordinators. Participants provided many accounts of the Support Coordinators' warmth and respectful engagement on their first meeting.

The first meeting I had with my Support Coordinator... I was so nervous. She just sat there, and it was like talking to one of my friends. She just was fully listening to everything I said. And it wasn't like a psychologist setting. It was just having coffee. (Participant B)

That [first meeting] was awkward. It was awkward, but the connection was there. (Participant E)

Safety planning always plays a big part in early days of TWBSS, but there are other ways that Support Coordinators ensured the safety of participants. One participant describes a simple suggestion that helped him maintain his physical safety.

I reckon I'm reasonably intelligent ... [but] she asked me to explain how I'd set up [the means to take my life]. And she said ... "Have you got any of the [material still] in the house?" ... And I said, "Yeah, I have." And she said, "Just get rid of it." And I never would have thought of that. So that's what I did. I got rid of all that stuff. (Participant F)

Emotional safety is as important as physical safety and the following quote exemplifies how the Support Coordinators ensure that participants feel emotionally supported when facing challenges. In this example, a Support Coordinator first warns the participant that she might find it challenging to complete an anxiety and depression checklist.^d However, she also reassures the participant that she can ask for help and made it clear that she will be available to support her afterwards.

The first time she explained to me how "This can be quite confronting, basically, how to fill out the form, how you're feeling today ... So just take your time with it. If you need help, we'll be here for you after it." And then I mean that was hard to fill it out, but then to know that she could be there for me afterwards that was great.

(Participant G)

Trust

Trust nurtures feelings of safety, while its absence undermines one's sense of safety. Building trust is an essential step in the process of working with participants because participants' experiences have left them suspicious and sceptical of the health system, in general, and mental health services in particular. While describing what appealed to her about TWBSS, Participant I explained that previous interactions with health care professionals had eroded her trust.

I guess the difference is it [that The Way Back program is] in my home... rather than meeting in a public space. And ... at that stage my anxiety was terrible still ... I'd lost a lot of confidence ... in my dealings with psychiatrists and psychologists ... There's a trust element there that I, I kind of am wary of. (Participant I)

^d Kessler RC. *Anxiety and depression checklist (K10)*. Beyond Blue at <u>https://www.Beyond Blue.org.au/the-facts/anxiety-and-depression-checklist-k10</u> (Accessed 16 January 2019).

She wasn't the only participant whose past experiences of the mental health system were not positive.

Because of [my] past mental health, it does take me a while to warm up to a new mental health worker. (Participant A)

Support coordinators always try to establish a connection with participants and build trust before exploring in any detail the issues leading to the participant's involvement in the program.

She didn't touch an issue that was very sensitive for me that day. She tried to build trust first and tried to make me comfortable. And then when she knew that I was comfortable, that is when she started discussing the issues, how she can help me. ... That built trust and it made me comfortable with her. (Participant C)

Given they met on fewer than 12 occasions it is extraordinary that one participant was on the cusp of revealing the trauma he experienced 50 years previously, for the first time in his life.

Oh, it was very comfortable with her, yes. ... In the second or it might have been the last interview I had with her ... I didn't quite get there, [but I] actually nearly gave her the information that I've never given anybody. (Participant F)

Support coordinators are quick to identify ways to connect with each participant. In the following case, the Support Coordinator recognised the approach that would work best with Participant E.

I think the trades have got a ... very straight forward approach to things. I think when my Support Coordinator saw that in me, he ... clicked and's gone "Okay well this is the way he's going to approach it."

Consistency and maintaining boundaries is also an important part of how Support Coordinators build a sense of trust with participants. This is discussed in more detail under the Support Coordinators' qualities.

Choice

Choice as a principle is self-explanatory, but it is particularly important in traumainformed care because it gives the participant a say in what happens, it leads towards collaboration, and it builds a sense of empowerment. Participants are able to determine where and when they meet, and how contact is made. One participant chose TWBSS precisely because she perceived she could become involved to the extent she felt comfortable.

I liked the terms [TWBSS offered], like, I could see... how it went ... It was a commitment ... for three months, but if I felt like ... I didn't need it or want to do it any longer, I didn't have to do it for three months. I could ... have phone calls rather than in person, if that's what I needed to do and ... we could arrange it ... to suit the person, ... It just didn't seem as overwhelming or as confronting as some other programs. It felt like something I could actually get benefit from without being, I guess, frightened of it. (Participant I)

Flexibility is also an element of choice. This is discussed more under <u>Qualities of the</u> <u>program</u>, but is also displayed in the way Support Coordinators respond to an individual's needs.

Then the Support Coordinator came to my house again. She did ask, did we want to meet at a café or something, you know, and I was still like, "No, I'll avoid those places." So that she actually came around. (Participant G)

Even though the offer was made to come to me or a different situation, personally I couldn't do that. I just didn't feel comfortable in doing that, so I needed somewhere else to go. (Participant E)

In the context of trauma-informed care, choice is not just about a range of options – although these are central to TWBSS – choice also implies the absence of pressure and the presence of support, as explicitly stated by the following participant.

She made it really comfortable. She just basically explained that the service was here not to put pressure on me or anything, just to help me. If I have appointments and stuff I need to go to, they can take me. If I just want someone to talk to, it's just like a conversation that I can have. They were going to take me through, give me some tips and stuff on how to better cope with things. (Participant B)

Collaboration

Collaboration supports consumers and leaves them feeling that someone has really listened to what they wish to accomplish. True collaboration requires the service and its staff working "with" rather than doing "to" or "for" consumers. The following two quotes exemplify how Support Coordinators work with participants while ensuring their safety.

The safety plan, she didn't give it to me and say, "This is what you have to do. Go and fill this." No. We did it together. (Participant C)

He saw ... I was going "Whoa! ... What's going on here? ... What's this mean?" and he said, "Oh, you right with that? What question are you up to?" which was good at the time ... I had to do a bit of thinking and that was a bit difficult for me at the time – I do remember that. But my Support Coordinator, he, sort of, prompted me, and the prompts were obviously appreciated. (Participant E)

Support coordinators also accompany participants to appointments, when needed. This can simply involve driving a participant to an appointment or even prompting them to ask questions while there. Examples of this are discussed in more detail later under <u>Help with</u> goal and priority setting.

All the participants commented that they were pleased to be interviewed because they wished to give something back to the service, which had helped them so much. Some even refused the small gratuity we offered after they'd completed the interview. They strongly expressed the desire to help the service in any small way they could without payment. This is a strong signal that the participants felt sufficiently empowered to draw on their own resources to improve the service.¹²

One of the reasons why I wanted to come in [and be interviewed] was so it will help someone else down the track; if you know what I mean? (Participant G)

The inclusion of lived experience representatives on the Governance Group (n=1) and Stakeholder Reference Group (n=2) signals the collaboration underpins TWBSS. In fact, it was the Stakeholder Reference Group that insisted the voices of participants were heard as part of the service evaluation.

Empowerment

Empowerment is poorly defined in the literature. However, most agree it is a social process that helps foster the capacity to implement change on issues of importance to an individual. Empowerment focuses on a participant's strengths and skills, while acknowledging the difficulties and challenges they face.¹³ The following quote reveals how Support Coordinators demonstrate belief in the participants' strength and abilities.

She would always ask ... "What have you done [this week]?" And she'd always tell me that "Remember that you are amazing and that you can do well." That really helped me, and it was something positive. So, I would sit each day when it's tough and say, "You know what Participant C? Remember that you are amazing. You can do this." (Participant C)

Another way Support Coordinators nurture the participants' strengths is through encouraging and reinforcing their decisions. This includes even small steps towards wellbeing (see <u>Encourage well-being</u>). They also foster belief in the participants capacity to implement change. Participant B had attended an Alcoholics Anonymous meeting but had felt discouraged by others to return. Her Support Coordinator reassured her that it was her decision to make. She also restated the reasons Participant B had for choosing to attend.

My Support Coordinator really encouraged me to keep going [to AA]. We'd talk about it and ... she'd just reassure me that I'm there for the right reasons and I'm there for myself. Why should it matter what anyone else says? And that was enough for me and I was like, "Hell yeah!" (Participant B)

When participants act on decisions they have made based on their goals, they are taking control over their lives. For instance, Participant G indicated at an early meeting that she enjoyed exercising and would like to use a gym regularly. Without further assistance she implemented her plan.

She would ask me questions like, "What do I like to do other than drink?" You know, I said I wanted to get back into the gym ... I really like to exercise, ... but she didn't really help me get back to the gym. I did that on my own.

(Participant G)

Empowerment emerges from the program's focus on the participants' strengths, which are numerous. The participants' decision to take part in this research demonstrates that they felt they had something to offer. And it seems unlikely that three months earlier they would have felt they had much to offer a health service.

Participant E not only has managed to turn around his own life, he has wrought cultural change in his workplace. This required him to acknowledge the power he possessed in his everyday work life. His story is explored later in Scenario 1.

What qualities do Support Coordinators bring to TWBSS?

Across the nine interviews, all past and present Support Coordinators and TWBSS Manager were mentioned in the same favourable tones, using the same or similar terms. This consistency demonstrates that TWBSS is hiring the right people with the right skills and qualities.

Above all else the Support Coordinators combine humanity with professionalism. They are

- trustworthy and reliable,
- non-judgemental,
- easy to talk to and be with,
- gentle, and
- validating.

Humanity and professionalism

The combination of humanity and professionalism is essential to the success of TWBSS. It ensures that participants are treated with the respect they deserve and the understanding they need. The Support Coordinator's approach is captured eloquently in the following quote.

It's his profession to deal with people like me, so he also has a lot of expertise he can share with me to help me. But at the same time ... [he had] human stuff, like integrity and ... just warmth. ... He's a nice person. (Participant I)

The Support Coordinators draw upon a suite of strategies (also see <u>What strategies do</u> <u>Support Coordinators employ</u>?), while consistently emanating warmth and kindness. Conversations can be challenging but Support Coordinators are skilful in conveying information while maintaining rapport.

It was a chat, but in that chat she interweaved ... topics that related to the issues I had, and ... she was very good at that ... She'd bring in things like family, sporting interests and then it'd come back to [the issues I had] – Yeah, she was very good at doing that. (Participant F)

It could just be a normal chat between two people, rather than – it's difficult to explain. It was okay to just have a chat. I didn't feel that I always had to be talking about what was going on with me, and she was able to somehow cleverly incorporate that all together. (Participant D)

He laid it out really well and explained it very well and spoke to me about different parts of it. Yes, it was just explained pretty well. (Participant E)

Their professionalism was evident in the way Support Coordinators maintain clear boundaries, while never sacrificing amiability. All the participants referred to the likeability of their Support Coordinator, but none mistook it for a friendship.

She was just nice to talk to. ... I know it wasn't a friendship, but the way she was, kind of, so approachable and open ... she was, yeah, just really nice.

(Participant H)

Support coordinators also display acute insight. Here a simple insight was able reinvigorate a participant's interest in life.

I think she identified what the problem was, what my problem was. I just needed to get out and start doing things that I used to enjoy or start doing new things. She identified that, and that really helped me to get out and to start living again. (Participant C)

Trustworthy & reliable

The Support Coordinators are adept at building trust, despite trauma potentially undermining participants' capacity to trust.¹⁴ The participants repeatedly expressed their initial anxiety around joining the program, with the first meeting proving particularly stressful. Yet very quickly participants felt comfortable being themselves, and this speaks to the Support Coordinators' skill.

I'm not very good at talking to people, so it was ... having somebody there that you could actually say how you were really feeling, rather than having to put on a front for everybody else. (Participant D)

I was really, really nervous for them to turn up. Like I had to walk upstairs to let them in and I nearly like fell up the stairs 'cause like you know I was having a bit of a panic attack. And then once they come in, they did make me feel quite comfortable. (Participant G)

Reliability is another important quality and is an essential element of building trust. One way reliability is demonstrated is by always meeting appointments.

[She] was this reliable person... [If] she says when to meet and that you are going to meet – and if there is any problem, she would tell me that there is a problem ... She always met our appointments. (Participant C)

In addition, the Support Coordinators routinely prepare participants for what is to come. For example, Support Coordinators prepare participants for potentially stressful periods, be they Christmas with the family or the Support Coordinator's planned holiday.

I think I'd been seeing her for six weeks, and then she went on holiday for a week, which she'd already warned me about the moment we met. ... Then when she got back ... she knew exactly where we had left off but it wasn't like she'd been reading from notes. (Participant B)

Additionally, they explain that completing a given form may prove challenging before handing it to a participant. They ensure that participants are aware when their 12 weeks is drawing to a close. They deliver on any promises they make, such as researching how to join a charity group or locating resources on a treatment that interests a participant.

Non-judgemental

Mental illness carries considerable stigma in our society and the participants are acutely aware of this fact. They were used to being judged and the non-judgemental stance of the Support Coordinators did much to engender trust. In some cases, this allows participants to be more open about their struggles in other situations. My Support Coordinator knew that I had partaken in drugs and stuff like that. I never felt comfortable with that until I started talking to my Support Coordinator ... when I left hospital I was too scared to tell my psychologist. My Support Coordinator, kind of, made me feel very comfortable about it. (Participant B)

Being non-judgemental also allows participants to progress at a pace of their choosing. One participant was unhappy that she had survived the attempt to end her life. Her Support Coordinator did not try to persuade her that it was better to be alive. She simply stood as a witness to this participant's emotions. It seems unlikely that progress would have been possible had the Support Coordinator not acknowledged the participant's reality and been able to refrain from judging her responses.

Easy to talk to and be with

Amiability emerges repeatedly as an important quality of Support Coordinators. The Support Coordinators are sensitive to the participants' psycho-social states and can simply occupy the same space in a supportive way. This allows participants to relax with a relative stranger and to engage to whatever extent they can.

It went well, surprisingly. I felt relaxed then. I remember I compared it to my Counselling sessions. It's more formal and the setting is more formal, but the way we interacted, it was informal and quite relaxing. I was just able to relax. (Participant C)

We would often walk and talk. [It] was a good, sort of, non-threatening way to do things.

(Participant D)

Gentle

Gentleness was a term commonly used to describe the manner of the Support Coordinators and the Manager. I found the word's recurrence genuinely touching, perhaps because one imagines that people with an experience of trauma may not have experienced much gentleness in their lives. Yet they are still able to recognise and respond to it.

I'd be feeling a bit negative about something that happened ... and then, he would ... sort of, turn it around to it being a positive thing. Sort of bringing me back to this space that was a bit more – that could be seen in an alternative way. Just, sort of, gently sort of keeping me there. (Participant I)

She never forced it on me or anything like that. I found her quite kind and gentle actually, the way that she spoke, and that's probably what I needed at that time. (Participant F)

It was presented easily and, in a way, informally is probably the wrong word because obviously you have to follow your procedures to do it, but it was very gentle. (Participant D)

Validating

Support coordinators recognise and accept the participants' thoughts, feelings, sensations, and behaviours.¹⁵ This indicates both acceptance of their current feelings and an understanding of the reasons why they might be feeling that way. Validation can be provided both verbally and nonverbally.

Participant D was unhappy to have survived her suicide attempt and her Support Coordinator was able to be present and nonjudgmental. Participant D also often desired to walk without talking, as elsewhere discussed elsewhere in the report. This willingness to be present and not talk is an example of how Support Coordinators validate the participant nonverbally.

I wasn't comfortable with being out of hospital... I think that was one of the most important things, that that was acknowledged, and it was okay to be in that space. (Participant D)

Some people may mask or otherwise suppress their feelings. Being able to accurately label feelings is an important step towards being able to regulate them.¹⁶ Therefore Support Coordinators help participants recognise that their emotional reactions are normal and help them to understand their behaviour in terms of the history and biology. For instance, Participant E's Support Coordinator explained how his relationship, which was not emotionally healthy, had influenced his thoughts and responses.

It's pretty hard to sit down and explain the nitty-gritty details of the relationship, but he was quite shocked. And he put things back and just sort of said, "But normal people don't do that to other people. It's as simple as that mate." ... I remember him saying it quite clearly, so again that was a different, a different way of looking at it. (Participant E)

Many participants demonstrated the validation they had received throughout the program through validating their own choices. On entry to the service Participant E acknowledged that there was room for improvement in his lifestyle, things like being more active, losing weight, and giving up smoking. However, the program taught him to be "[less] isolated, more determined and more empathetic to myself". This approach helped him approach prioritisation "logically" and make considered decisions about where and how to use his energy. In the following quote, Participant E comfortably discusses his priorities.

I'm still smoking, I've put that actually down on my list to be quite honest. I've just bought a vapour, because a friend of mine used a vapour to give up. And I'm just getting some oils and stuff for it, at the moment. Yes, I've put it low on my list until I get the house sorted and everything like that. I've just sort of gone well, let's do one at a time. (Participant E)

What strategies do Support Coordinators employ?

One of the benefits of speaking with participants is hearing from them what practical assistance Support Coordinators offer. Some types of support, such as safety and goal setting, are explicitly embedded in the program. Others are provided in response to individual participants' needs. The participants mentioned many strategies that can be loosely grouped into seven categories. However, any given strategy usually contained elements of other strategies.

- Ensure safety
- Encourage well-being
- Help with goal and priority setting
- Make and keep appointments
- Explore treatment and other options
- Use physical activity
- Promote helping others

Ensure safety

As discussed earlier under the <u>principles of trauma-informed care</u>, TWBSS addresses both the <u>physical and emotional safety</u> of participants. Safety planning is the most obvious way that Support Coordinators assist participants. It tends to take place very early in the program, usually at the first meeting, and it often involves loading the *Beyond Blue* safety app. Use of the app was variable. For instance, Participant F didn't own a smart phone and a glitch in the system prevented Participant H sending the plan to her partner. Nevertheless, safety planning was well received and at least two participants mentioned returning to their plan at different times.

[The safety planning] was helpful. It helped me identify, the warning signs that I'm going downhill and what I would do when I started noticing those signs. (Participant C)

Participant H noted that the safety plan she developed with TWBSS differed in its orientation from the safety plan she had already developed with her psychologist. The latter focused on how to monitor one's personal safety, while TWBSS focused on how to ensure one's safety by drawing upon the support of family and friends.

The safety plan that I had with my psych was kind of directed at me. Whereas this one is, kind of, in a way it's for me as well but it's – I was writing it for others to see. ... So, my warning signs, you know. ... what [other] people can notice. Participant H

This participant was fortunate in having a very supportive partner and family, so this may explain the difference in orientation. Sadly, few of the other participants were supported by good social networks.

Ensuring participants' safety was not limited to safety plans. The Support Coordinators are also extremely skilled at creating spaces in which participants feel safe.

I do know that we negotiated where we would meet and it would be in a nonthreatening [place] ... So generally, we would agree on a place to meet and then we would often walk and talk. She was a good, sort of, non-threatening way to do things. (Participant D)

Participant F did not recall having a safety plan at such, but he made use of strategies that had been suggested to him when he needed extra support.

They [CATT] seemed to be quite good on the phone. Certainly, after a couple of episodes that I needed to call them, they certainly were pretty good for me ... They certainly were able – not to calm me down but go through a few things where I was able to, well, calm down, I suppose. (Participant F)

This same participant threw out items that he could have used in another suicide attempt on the suggestion of his Support Coordinator.

Maintaining safety appears to remain foremost in the minds of the Support Coordinators throughout the program. They ensure that participants have strategies to stay safe beyond the confines of the program and during emotionally challenging times. All the participants' safety plans were reviewed towards the end of the program. One young woman lived in a rural town with her family who did not understand the challenges she faced, so her Support Coordinator revisited her safety plan before Christmas.

We were just generally talking about how I was going and how I'll be able to keep myself busy and like, because this was early December. What my plans were for Christmas and New Year and how I was going to stay safe. We did another safety plan. (Participant A)

It is interesting to note that safety planning was not to everyone's taste. By her own admission, one young woman did a lot of safety planning, but was quite sure that she wouldn't draw upon it even if she knew it would benefit her.

I said that to my Support Coordinator. I was like, "It's not the most helpful thing but I'll do it." And she's like, "Just as long as you know it's there," you know. But no, I don't find those things helpful at all. (Participant B)

Encourage well-being

TWBSS Support Coordinators focus on maximising participants' sense of well-being, and the "Six ways to well-being" tool was often mentioned.¹⁷ However, it wasn't enough just to go through the process once. Sometimes it is necessary for Support Coordinators to remind and refocus participants.

We were doing the "Six ways to well-being". I would write them down each week and then send them to her. But there was a week or two where I didn't write them. But it, they were in my head. And there was a week where I just hadn't even thought about it. And that was, you know, when I kind of threw myself back into uni and kind of the self-care stuff wasn't as important. So, I guess she just helped me reshuffle my priorities again. (Participant H) Like safety plans, the "Six ways to well-being"^e was something that participants found helpful.

I still have it in my diary and I can't remember what it's called, but I think they do use it a lot. It was very helpful and somewhere in here, I can't remember what it's called. Six ways to well-being! ... so she helped me work out ways to work within that framework. (Participant D)

Another way Support Coordinators promote well-being is to do a needs assessment with participants and ask them to consider what they felt they could do to meet their needs. Simple acts, like getting one's nail painted, could improve well-being.

One of my self-care goals, I guess, early on was to get my nails done. And she asked how that went. And I think I sent her a photo of my hands.

(Participant H)

Support coordinators often text or call asking after the participants, discussing distractions or simply just checking in.

Yeah, she'd send a text most mornings. I responded sometimes, but I'm hopeless with my phone. I really am. (Participant G)

Overall, Support Coordinators act like cheerleaders encouraging participants, celebrating small steps in selfcare and large wins in well-being. The continual validation by Support Coordinators would have been integral in building participants' confidence and self-esteem.

Every time I was seeing her she was like saying, "You're looking so much better. You're sounding so much better." (Participant G)

[The needs assessment was] hard to fill it out, but then ... the last time I met her she pulled ... the same form out, [I completed] and I signed it, and it was just so much better [than the first time I completed it]! ... She basically showed me how much better they were, and I felt better. (Participant G)

Sometimes it was enough simply to plant the seed of an idea. This happens regularly through helping participant articulate their goals, which they then go on to achieve without any other assistance.

Help with goal and priority setting

Goal setting is an important way for participants to navigate the challenges in their lives. Initial goals were simple and often oriented towards selfcare.

I saw her as my behavioural activation coach in a way. So, you know, obviously early on your goals are much smaller. ... And it was nice to have, I guess a, just a focus on, kind of, the basics of the, you know. I think my goals were to brush my teeth and shower every day. (Participant H)

Nonetheless, longer term goals were also discussed early on.

^e The "Six ways to well-being" encourages one to stay active, keep learning, give to others, connect with your community, take notice of others and the world, and care for the planet.

She, sort of, started off asking me, I guess, what I wanted to achieve, like what I wanted to make better, how to get better type of thing. ... I was basically saying, like, "How could I improve my self-esteem?" (Participant G)

Support coordinators help participants to establish and then focus on their priorities. In doing so, they provide an alternative way to view the situation.

One of the biggest worries for me was housing. Now, in talking ... straight-tostraight, face-to-face with my Support Coordinator – the blunt reality sort of hit me ... My Support Coordinator just straight out said, "Well hang on, I rent and there's nothing wrong with that and I don't pay rates, I don't pay all that and therefore, if I don't like the house, I can get up and rent another one." You know, just little things that I've never thought of. (Participant E)

Interestingly, some participants need little more prompting than some to help focus on and articulate their goals. They are able to follow through without further support.

I guess the goals that she was installing in my head that can be done, like you know, like that they can help with putting you in with a ... psychologist.

(Participant G)

Participant G's Support Coordinator explained that with a Mental Health Plan she could receive Medicare subsidised appointments with a psychologist. She also provided a list of psychologists and offered to make and then accompany Participant G to the GP appointment. However, Participant G preferred to do it by herself and negotiated the ensuing hurdles. For instance, the initial general practice did not bulkbill, so Participant G found a general practice who did.

Some months after finishing with TWBSS one participant's goals were still very modest.

I just still think of the 24 hours, so I'm just like, another 24 hours. And at the end of the day when I'm in bed, I'm just like – just another 24 hours. I did this 24 hours, I can do another one... And that – that just goes on every day.

(Participant A)

Support coordinators get participants to focus on small, manageable goals. Participant H decided to get her nails done, Participant C really liked getting active, and Participant A found her list of distractions an integral part to staying positive.

We also did this, like, 5 list thing. So, it's like do something active, do something – and there were a few different categories. And we came up with, once a week, something to do for each of them that I would try and complete before the next week. So, I think that was fun, trying to challenge myself to do [things]. Because ... when I felt low, I didn't want to leave my room. I just wanted to be alone.

(Participant A)

For this participant, another benefit of using distractions was that over time the range of options increased.

I felt like my distraction list was getting bigger. I felt like if something wasn't working, I knew what I could try next. (Participant A)

Goal setting also permeates other strategies. Safety planning essentially includes a list of activities to do when one notices a deterioration in one's mood.

There was a time I had to use those. I would feel I didn't want to talk to anyone. I would feel I don't want to do anything. I just want to sit and not talk to anyone or go out. Then I would know that this is the time that I have to maybe go out and take a walk. When I feel this way, maybe not just sit in my room because otherwise the feelings would get worse. I would know that it's time for me to go out for a walk. (Participant C)

The offer to drive a participant to an appointment is another way Support Coordinators assist people to meet their goals.

Make and attend appointments, and arrange transport

The Way Back Support Service tries to connect participants with existing services, and Support Coordinators maximise the chances of a participant making and attending a potentially helpful service. This is exemplified in the following two quotes.

She was willing to ring up my doctor and make the Mental Health Care Plan for me. It was basically like she was my mind because I was, sort of, all over the shop. (Participant G)

We went to the Women's Legal Service together and I wouldn't have been able to get there and do that on my own... She came with me so that I could remember. She helped me. She was my little memory bank. And also, she took me to the social worker at Centrelink. She got that happening... That was really important because I just was not navigating my way around that very well.

(Participant D)

Support coordinators will also help participants understand the outcomes of medical appointments and meetings.

My mindset at the time was very narrow, very narrow – I couldn't see options – the medical side of things obviously pointed out that. ... [My Support Coordinator explained the consequences of my medical results, like a] normal person with a normal mindset ... I didn't have that at the time. (Participant E)

Sometimes an event suggested by the Support Coordinator addresses an issue of interest to the participant. In this case a lecture on chronic pain was a turning point for Participant E. The Support Coordinator couldn't attend the lecture with the participant as planned, but he successfully presented an opportunity and catalysed the participant's interest.

He offered information [about and] to go to a lecture about chronic pain – That lecture had a massive impact on me – It really did. ... It was all about the mindsets of people with chronic pain or injuries and their recoveries. ... The presentation was brilliant! ... That [suggestion] was out of the blue or something I would not normally do but I was determined to do it and my Support Coordinator gave me information ... that was a turning point for me. (Participant E) On other occasions, attending appointments is more about offering moral support. And participants appreciated the offer even when they choose not to accept.

She'd be like, "Do you want me to come and do an AA meeting with you," or I was going to go to some random drinking responsibly courses. And she was like, "Do you want me to come to that with you?" and I was like, "You know what? I actually don't want you to come with me." And she was like, "That's okay, we'll do something else." (Participant B)

Explore treatment and other options

As discussed, Support Coordinators respond to the interests and informational needs of the participants. Sometimes this entails making them aware of what services are available. Mental health plans, responsible drinking programs, and schema therapy, were all mentioned.

As I spoke, my Support Coordinator assisted. ... If I spoke, for example, about housing, my Support Coordinator would bring up options on that [then], you know, he reinforced it as we sort of spoke further. (Participant E)

On other occasions they would follow up an expressed interest.

I mentioned to her once that I'd been thinking about doing some charity work for, like, Meals on Wheels, that sort of stuff, and volunteering for other charitable organisations that maybe I could help, and she followed up on that and gave me all the information I needed... to do these things. (Participant F)

Use physical activity

Physical activity plays a part in many meetings and for Participant C the physical activities she undertook with her Support Coordinator were pivotal in her recovery.

One thing [I really like] about them [TWBSS] ... – I don't know whether it's the right word but – the informal setting. They're including activities in their service. They don't just come and sit down and talk. We went for tea with my Support Coordinator, went to the Botanic Gardens, we took walks, we climbed rocks. That is different and it's engaging. We don't just talk but you get engaged [physically] also... I had lost hope and I just didn't find interest in anything, so that revived everything. (Participant C)

Being outside was appealing to many participants, even if "outside" meant sitting in a car and looking at the winter environment.

Because I love animals, we went [and] just sat in the car; it was a cold day, so we just sat looking at some horses and I loved that. (Participant A)

Physical activity can be beneficial for elevating one's mood and can be done when a participant doesn't want to speak.

I think some days, I just need it to walk with somebody and not really talk a lot. ... I think being able to get outside and make that being an option was helpful.

(Participant D)

In the preceding case and the next, the participants appreciated the mere fact of the Support Coordinator's company.

We went for coffee, and she says, "Oh, I'll walk you back home." And she walked me all the way back to my apartment in Suburb A, which was a 15-20-minute walk from my car, but she was happy to do that because she was like, "No, no, I'll walk you back to your house." And then she walked all the way back to her car in Suburb B. I was, "Are you sure you're going to be okay?" "Yeah, yeah, of course." It was not out of the way for her at all ... she walked me all the way back to my apartment. It was so nice. (Participant B)

Promote helping others

Support coordinators often encourage participants to find ways of helping others. This strategy also demonstrates the power of each participant to make a difference. Sometimes participants help out family members.

We'd worked out ways where I could be helpful with other people in my family as well as try and make time for myself, which was important at that stage.

(Participant D)

Sometimes they get involved in charity work. Sometimes the help entails looking after animals.

I was having trouble getting out of bed. Especially when I, kind of, took time off uni because it's like I have no reason to. And she was like, "Well, why don't you, you know, be the one who gives Rover" – that's my dog – "give Rover breakfast in the morning?" ... She knew me pretty well by that point, I think, where [she knew] I wouldn't want her to starve so. (Participant H)

Always, helping others is a way of helping yourself.

Yes, that was a big thing that we talked about, by helping others [you're] helping yourself. (Participant G)

What do the participants' experiences tell us about TWBSS?

Success from the participants' perspectives

The Way Back Support Service participants who agreed to be interviewed were unanimously positive about their experiences. Seven of the nine were in a considerably more positive space and they attribute that, in part, to the assistance and support they received through the program.

[TWBSS] made a big difference to me... Well, a huge difference. And as I explained to the Support Coordinator, you know, I probably should have done it 40 years ago. (Participant F)

[Had TWBSS not been there] I wouldn't be as good as what I am now. ... I'd say it's great, yeah, [It's a] really good program. I would say it helps you find your way back. (Participant G)

By combining humanity and professionalism, the Support Coordinators make the participants feel not only supported but special.

[My Support Coordinator] was awesome! In a way, I cannot be more grateful for The Way Back Support Service. They were literally the only people in that emergency, short-term stay experience, any experience in the hospital – they've always been the ones, the only ones that actually made sure you were okay. [They] checked on you and made you feel special. (Participant B)

The participants continue to use many of the strategies imparted by the Support Coordinators. For some that means staying active and trying to eat well. For others it means reflecting on how their Support Coordinator would have framed an event or situation.

I've been doing well. I've been trying to get involved in different activities, especially for a Students' Association. And I've continued with my counselling sessions. I'm still seeing my Counsellor, though it's not frequent. It's monthly now. ARE YOU STILL TAKING THE ANTIDEPRESSANTS? No. YOU'RE POSITIVE WITHOUT ANTIDEPRESSANTS! ARE YOU STILL TAKING THE SLEEPING MEDICATION? No. (Participant C)

I'm eating healthier foods and I've lost about four kilos so far, not much but yes. ... It's been very slow trust me, ... I'm just buying better food really.

(Participant E)

We'd talked about ... some things that actually, you know, that stuck and were helpful when dealing with other situations ... as they arose ... And in that sense, it was valuable, too. So... sort of pausing and thinking, "What would my Support Coordinator think about that?" (Participant I)

TWBSS creates a space for participants where participants can begin to heal.

I think ... taking time off uni and having the Way Back allowed me to ... kind of, take it slow and, kind of, really focus on the basic stuff again. And I think without that I probably would have just rushed it. (Participant H) Participant E not only has managed to turn around his own life, he has wrought cultural change in his workplace. See Scenario 1 (below).

Sadly, two participants continue to struggle with their mental health. Nevertheless, they too spoke well of the program.

The main thing was the acknowledgement ... of the space [where I wasn't happy to be alive] ... I sort of got there in the end, but just to work with that, knowing that, but still being able to begin to plan ahead, I guess. (Participant D)

When asked what might have happened if TWBSS hadn't been offered while she was still in the Short Stay Unit, Participant D replied that it helped her address her feelings of shame and guilt, thereby allowing her to move forward.

I probably would have been a bit lost because I would have felt ashamed too, because I have had lots of Support Services. There's often a lot of guilt around that, so having that there could help mitigate that a little bit. (Participant D)

Several months after the she completed the program Participant A is still only able to take one day at a time. She still avoids "focusing on the big picture" preferring to "see what happens." And yet her support for TWBSS is fulsome.

I'd recommend it to someone. I loved it! I thought it was really good, and it did help me get through knowing that she was there and yeah, it just was helpful at – at the time. (Participant A)

Participant outcomes are captured well in the following quote. While life may not be perfect, it is better than it was and is moving in a positive direction.

I'm not this person I want to be... but I am resembling more of the person that I want to be than previously. (Participant I)

Scenario 1

Since completing TWBSS program, Participant E has instigated significant cultural change in his workplace. The first step was to appreciate his power to influence in the workplace.

It has been a massive change, it really has. ... I really am a key player, so a lot of people look at ... how I react to things – If I walk in cranky in the morning the whole place is going to be cranky.

I've [also] changed my own role a little bit so I'm getting out with the blokes a lot more ... [which means] I've got more opportunity to talk to them.... And they're appreciating it

Additionally, he has modelled more caring behaviour in the workplace.

Well blokes will be blokes. When a guy goes on compo, for example, they'll have a shot, "Oh we've got more work to do. Bludger!" blah, blah, blah, and of course when it comes to me ... I'm just putting it straight back on them. "Oh gee has that happened to you?" "That's a bit rough, poor bloke." "Gees I hope he's getting enough [time off]." "Is he still getting paid?" I just put these questions straight back to them and it seems to stop that conversation almost straightaway and then they sort of go on to "Gees we've lucky we have that cover. We're real lucky to have that cover" and it seems to flow on. ... Then I'm sort of saying to people "Have you checked on Person A lately? Have you checked on Person B lately?" ... "How's he going? He seemed pretty down lately" and I'm almost continually doing that. And what I'm noticing is, it's gone full circle and coming back to me.

Participant E's manager has been very supportive of him, checking up on him throughout his recovery, for instance. So great is the cultural change in the workplace that his manager sought Participant E's permission to showcase the positive changes at a meeting of other managers.

A month ago [my manager] asked me the details and how I got through things and who helped and that ... because, I think, of the cultural change that's happening at my work – He actually made a presentation to other managers using that information – He ... asked me permission [first].

Participant readiness

At some point in interview, all participants indicated that around the time of their suicide attempt or during their time with TWBSS they were ready to move in a different direction. And this sense of readiness was expressed in different ways. One participant had been introduced to dialectical behavioural therapy (DBT) a year earlier, but by her own account she wasn't receptive.

DBT had come up previously at the beginning of last year, and this was not an option. I was not ready for it, and I certainly wasn't mature enough for it, in a sense. After everything that happened, and dealing with my Support Coordinator, my Support Coordinator and I discussed it and I came to this point where I was like, "I think this is the right thing to do. I want to do this for myself."

(Participant B)

Another, talked about reaching a tipping point in her life.

You know for the last 12 years I've had anxiety basically and I've always run away from my problems, so I guess I thought I've just nearly done this to myself. I started thinking of my family and the fact that I can't do this anymore, something needs to change. (Participant G)

While someone else wanted to return to her studies.

I think I wanted to get back on track with my studies. That is one thing that motivated me. I didn't want to see my results and feel bad. I just thought I have come here to study and I can't fail at that, so I need to get well and get back on track.(Participant C)

It is interesting to ponder the degree of success TWBSS has with participants who are not ready or receptive at the point when they are approached by the service. Participant E had withdrawn from the program after 2 weeks because he did not feel he was getting any benefit. Then I asked why he agreed to be interviewed about the service at all.

I think personally I was lucky that I knew I needed help still. (Participant E)

This suggests a degree of readiness, which may not have been there initially. My impression at the time of the first interview was of someone who was completely overwhelmed by his circumstances with few internal resources on which to draw. Therefore, it is foreseeable that for some participants, time must pass or circumstances must change before they are ready to engage with TWBSS.

Finally, Support Coordinators sometimes provide alternatives that persuade participants that there are other possible futures. Quotes supporting this notion can be found in below in <u>Qualities of the program</u>.

12-week structure

The 12-week structure of TWBSS seems to work well for participants and they respond well to weekly meetings.

I think that I really thrive off having that weekly check-in with someone, knowing that someone is there to support me. So yeah, I definitely would have struggled a lot. (Participant B)

I guess just knowing that somebody was there as well, someone that understands you, yep. And then it just helped even with the meetings with her like to get – you know it just helped to talk. (Participant G)

Some are happy meeting every two to three weeks.

Certainly ... between two and three weeks for me worked – worked for me anyway. (Participant F)

Some keenly anticipate the next meeting.

I was always looking forward to our next meeting and thought, okay, an event or something exciting is coming next weekend. By that time, when we met, I didn't – I had lost interest in a lot of things. I was just confining to my room and just didn't do anything. I'd just stay there, but after our meeting, yeah, I was able to go out and started finding activity – finding different activities. (Participant C)

Others appreciate the opportunity to talk or text between meetings.

I was probably still talking to her probably weekly. Not long phone calls. Probably 5-10 minutes and she'd help come up with a distraction or something to do. (Participant A) The weekly meetings seem to provide a framework that encourages participants to continue addressing their needs and issues, rather than surrender to the difficulties of their lives. For instance, it reminds people of distractions (as for Participant A) or motivates them to undertake activities they've committed to at the previous meeting.

I was free to call her or SMS her anytime. ... [But] I didn't ... I just felt that I needed to work hard to get well ... It motivated me. I felt good when I gave her a good report that I've made progress this week, so I felt good and [I] want[ed] that. Even the way she would be excited, it really motivated me. I felt good.

(Participant C)

Qualities of the program

Knowing support is available results in many positive outcomes. It helps to *relieve participants' anxieties*. Many of those interviewed were highly anxious and yet they responded well to their Support Coordinator's manner and the flexibility inherent in the program. People who have experienced trauma often find trust difficult and yet participants reported that safety and trust was achieved. The program, with its regular meetings, provides a *sense of security*, while the *continuity of care* offered by TWBSS addresses safety, builds trust and contributes to security.

When I was in short-term stay, it would have been very hard [to leave hospital] because [outside hospital] no one's there to ask how you are. No one's there to check on you, whereas The Way Back Support Service really did that. I felt like when I went out of hospital, there was actually someone there that was going to support me. (Participant B)

Perhaps most importantly TWBSS offers participants an *alternative vision of the future*.

[It] made me think that maybe I should be going down a different path. (Participant F)

She, sort of, started off asking me, I guess, what I wanted to achieve, like, what I wanted to make better, how to get better. (Participant G)

As discussed under choice, participants value the program's *flexibility*. The Support Coordinators provide *non-clinical support*.

I kind of like that it was in a way, because ... I guess it was just a different way to problem solve. (Participant H)

The non-clinical approach also allows for more informal interactions – chats over coffee, rock climbing, watching horses, for example. Nevertheless, TWBSS is based on an *unwavering commitment to the participants*, and they responded in kind.

What was the nature of participants' experiences with associated services?

While it was not the purpose of this research to assess how well complementary services perform, it is possible to draw some general inferences. However, it is important to understand the data on which it is based. Diagram 2 indicates the number and gender of participants who used each service.

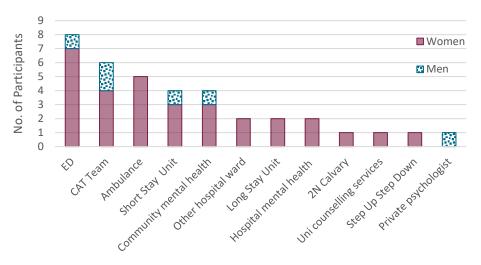


Diagram 2. The number and gender of participants using each complementary service at the time of accessing The Way Back Support Service.

To enter TWBSS one must have attempted suicide. Referrals are accepted from multiple sources including

- emergency departments (EDs),
- the Crisis Assessment and Treatment (CATT),
- the ambulance service,
- hospital-based mental health services,
- · community-based mental health services, and
- general practice.

Participants are likely to have experienced one or more of these services, and their experience of these services influences their recovery and their willingness and capacity to engage with TWBSS. For these reasons we also explored participants' experience of these services.

Ideally, when an individual is in crisis the system works smoothly. In Scenario 2 the community mental health service quickly identified that a young woman was a suicide risk and contacted the CATT. When the CATT weren't able to persuade the young woman to go to ED and it was clear she was in danger, the police and ambulance provided further support. The system worked very well up to this point.

Scenario 2

Participant A had decided to end her life but felt an obligation to cancel her psychiatry appointment booked for later that week. The community-based mental health service asked her why and were concerned by her honest answer. The service persuaded her to come in and talk to the duty officer. To extricate herself, Participant A told them that she would go to a friend's house. The health service called her 15 minutes later and then again. Having established she was still at high risk they asked the CATT to contact her.

I want help but I don't think they're going to help me so ... I was torn whether I go up [to ED] and try. And then they called me again like, five minutes later and they said, "Are you on the way?" I said, "No," because I wasn't. I was just sitting there. (Participant A)

The police then phoned Participant A and an ambulance was called because she had already started to take the medication on which she planned to overdose. Participant A's grandmother was also contacted and met the ambulance at the hospital.

Emergency departments

All the young women (n=5) and the mother of young children who spent time in either the Canberra or Calvary emergency departments were not happy with the care they received. They reported feeling vulnerable and exposed.

I feel uncomfortable. It's just like all of a sudden, all your privacy's gone and you're having someone come in every 5 minutes, "Are you okay?" Or just looking at you and ... – and because where I was, it was a nurse's station so they were just all crowded there. And I was like, this is really awkward. There's like, eight of them there and obviously, there's nowhere else for me to look but forward, and then they're looking at me. (Participant A)

There was little privacy.

Do I really want to sit here in emergency telling someone that I don't know, that I just tried to kill myself, that I want to die, and I know that all these people around can hear me? (Participant B)

Yeah. It was, kind of, weird. ... I felt more like ... I wasn't taken seriously maybe. ... Or you know... like I didn't really belong there, because I was just put in an armchair. ... And I was there the whole time. ... And so it was just odd because I felt like so exposed with the other beds. ... So it was kind of weird like, you know, my family's crying and stuff and I'm crying and there's kind of no privacy. And it just made me feel more like, oh, "I shouldn't be here, I should just go home." You know, "It was a stupid mistake," blah, blah, blah

And participants are acutely aware the of the stigma associated with mental illness.

That's the biggest thing – they make you feel very invalidated. Very invalidated. Your feelings are invalidated. (Participant B)

It's also really bad ... they're waiting for someone to come from mental health because "we're not going to deal with you". ... That's what it sounds like. They didn't obviously say that, but they're like, "Oh, we're just waiting for someone to come for you," and then they'll leave you for like, two hours. (Participant B)

I guess there's this ... pervasive stigma that mental illness isn't really a thing, and ... I, kind of, felt that when there's these ... rows of bed where people are coughing and they're clearly like, physically sick and then I'm kind of just like, chucked there. SO THAT'S HOW YOU WERE FEELING. DO YOU, DO YOU RECALL BEING TREATED LIKE THAT? Oh, not really. I mean, the [ED] nurse was nice to me. (Participant H)

Communication with the patients about what was happening was generally not done well.

I waited in a cubicle and waited for some time in the cubicle there, when they were doing some blood tests. ... The fact that they would just come and take the blood and not explaining that they will test it, and they were going to do anything. They just do what they have to and not say anything to you. (Participant C)

I know there's more important things to deal with at the time [in ED]. I'm not fussy or anything but far out ... I just tried to kill myself and instead, I'm stuck here by myself vomiting into a fucking plastic bag. It's terrifying, but you're not even thinking about it. You're so out of it ... I didn't know what they told me. I didn't know what was going on. (Participant B)

What most seems lacking is a sense that the nurses and doctors cared about their patients.

The hospital, yeah. I think if they could be more attentive. I believe if you bring someone who is suicidal, someone who is hopeless, they just don't need to be left there alone. They feel more alone and it is making the situation even worse. I don't like hospitals. ... If you take me to the hospital and leave me there and not check on me, it makes everything worse. It doesn't help me. ... Just try to make some conversation. Chat with the patient. (Participant C)

Even if I pressed the [call] button, what are they going to do? They'd come over and they say, "You okay? Do you need a new bag?" They're strictly there for that. They're not there to be like, "I'm so sorry that you tried to kill yourself. Here's a pat on the back." It was shit. (Participant B)

Leaving the hospital was highly problematic for most of these women.

I mean yeah, emergency departments don't really treat you that well when you leave. Sometimes, you know like – this isn't the first time this has happened – … sometimes they just act as though … you don't really matter, that you're doing it for attention. (Participant G)

[Discharge] wasn't appropriate. They didn't know whether ... I would be safe when I got home, or not ... They did not hand me to anyone. They just said, "Okay, you can go home." Whether I went home and got on the same thing, they didn't care about that. (Participant C) Participant I's story is told in Scenario 3. It demonstrates a lack of thought or concern about an individual's safety once they are discharged. It also suggests that the staff did not manage a difficult situation well and it resulted in the participant attempting to kill herself again.

Scenario 3

Participant I was taken to hospital by ambulance while her partner stayed at home to look after their three young children. She recalls emerging into a drugged haze and being told she was right to go home. ED rang her partner to ask him to collect her, but he couldn't leave the children, so ED called a taxi for her.

I wasn't wearing any shoes and I was, I think, in my pyjamas and ... I was still really out of it and they gave me a blanket because it was cold. It was winter. And they left me out there waiting for a, a taxi. ... The taxi didn't come, so in my state I walked home. (Participant I)

While it wasn't far, she was vulnerable and alone, and she cut her foot quite badly walking without shoes. On arriving home Participant I was still quite unwell and demanded that the hospital return the medication she had left there. Eventually the hospital gave the medicine to her partner, and later that night she attempted suicide again!

Interestingly in contrast, the two older participants reported positive experiences of both ED and the Short Stay Mental Health Unit.

The CATT

All participants (n=5) who used the CATT spoke positively about their experiences. Participant B called the CATT after she had taken multiple painkillers. She was not seeking help per se, but she wanted someone to know and care for her body after she was gone. Her previous experience of the CATT reassured her that they were a trustworthy service. The CATT team responded immediately and kept telephoning her, while organising the police and ambulance service.

Then I, kind of, panicked and I called the CATT team, and I knew they were like a safe option for me to call the CATT team because I had talked to them when I was younger. I called them, and I say, "I've taken a bunch of Panadol, and I just want someone to find my body safely." And they're like, "This is not okay. We're going to call emergency, where are you?" And I was like, "Oh, no, I'm fine. Don't worry too much about it." They're like, "We're going to call you back, okay?"

(Participant B)

Participant B's counsellor from the university service was growing increasingly worried about her and contacted the CATT. She describes herself now as "happy to be alive", so while she found their calls a "bother" she is grateful that they acted. However, after transporting her to ED, she didn't hear from them again and this left her feeling abandoned. This vulnerable young woman was in a foreign country and the lack of

continuity in the system did not help her state of mind. Nevertheless, the CATT did follow up after she was discharged and that is how she was referred to TWBSS.

[The CATT team] They handed me over and they left. ... I didn't like it because it was – I felt like I was abandoned there. ... I felt very sad and I had expected to, maybe, hear from the CATT team in the morning because they brought me there or for them to say, "We've contacted someone to say that you are in hospital." They didn't ... ask me if I needed to contact someone, even when I needed the night in hospital. (Participant C)

Participant G was also visited by the CATT after discharge from ED and was grateful that they did, in part because that is how she learned of TWBSS.

Someone did come and see me before The Way Back program. I think that was the – like the crisis team. So, when they come and saw me, that was good. ... I was still in a pretty bad place at the time, but then they offered – then they spoke about The Way Back program. (Participant G)

Upon discharge from the Short Stay Mental Health Unit, Participant F was encouraged to contact the CATT straight away should he have any issues, and he did.

I think I rang the crisis centre two or three times, and they were checking on me. ... just to see how I was going, yeah. I never met any of the people there but they seemed to be quite good on the phone. ... [When] I needed to call them, they certainly were pretty good, for me anyway. (Participant F)

ACT Ambulance Service

Those participants who we know used the ambulance service (n=5) were happy with the service they received or did not comment negatively. When commenting positively it was about the manner of the ambulance workers. They were perceived as kind and non-judgemental.

They were really lovely. Yeah, they were really lovely. I think a lady was talking to me and she was just asking me all these questions, and I remember I could not open my eyes at all, but I was very convulsive. I knew my body could not stop shaking or moving or making a twitch, but my eyes couldn't open, so she was just saying, "I'm going to do this now, lovely," and "I'm going to do this," and I'd make some stupid joke and she'd laugh at it and so she was very nice. And I think one thing in that situation is that you, probably, don't want to be judged for while you're in the ambulance, and they don't at all. They don't judge you for being in there for what you're in there for. They're there to help you and they're there to take care of you. I think they go into that situation where even they are going to judge you, and they don't. It's very nice.

(Participant B)

Ambulance workers aren't always pitch perfect, but they demonstrate that they care and that matters to people using the service.

I think he was trying really hard to be supportive and nice, but it just came off the wrong way. ... It was kind of like oh, you know, "You seem like a ... young person with a good partner", you know, ... "What did you do this for?" And, "There's so many reasons to live," and all these, kind of, things, which at the time, you don't really want to hear. ... I just remember having this kind of rolled my eyes moment. (Participant H)

Participant H also learned that one can ring the ambulance if feeling suicidal and was pleased to learn that.

He said that, you know, "If you're kind of ever in this situation again, call us before you take anything, call us before you do anything, and we can still, you know, see someone, get support," and I was like, "Oh I didn't even know that,"

(Participant H)

Short Stay Mental Health Unit, Canberra Hospital

Participants A and B who were in the Short Stay Mental Health Unit certainly felt that the nurses did not care about them.

I was ... not talking too much. And then next minute, they said to me that they're going to try and get a nurse to sit with me. And I was saying, "No." And then they're like, "We have to." They were saying they need to, because they were a bit worried. ... [But] I felt like they were just doing their job because, yeah, the way they said it didn't sound – I don't know. It's hard to explain just ... the way ... it came across. It felt like another thing they just had to do. (Participant A)

It almost feels like it's designed to make you feel worse about wanting to die. It's like saying, "How stupid are you for attempting this," or, "How stupid are you for feeling this way. We're just going to make you feel more isolated and stupid by putting you in this little tiny space, and have people say they're here for you, but they actually just sit in a box watching you," basically. (Participant B)

These young women were at their lowest ebb and were craving some human warmth, but none was provided.

If they'd ask you, I would tell them honestly that I'm not feeling too good. And all they'd offer me was medication. So, then I got to the stage that I was sick of taking their medication. I was like, "This isn't helping me." So, I was just like, "Yeah, I'm fine." (Participant A)

I remember when I was there a couple months ago, and it was my birthday. I'm sitting in there and one of the nurses checked on my blood and she goes, "You know, we're here if you need to talk." And so, then I, kind of, panicked and I went and knocked on the door. I walked out of my room. I stay in my room the whole time because I don't want to go and talk to other people. It's overwhelming. I went and knocked, and I said, "I just want to talk to someone." They came into my room, and I'm like, nervous-crying, if that makes sense. I'm just, "I don't know how I feel. I don't want to go home," and all this stuff. And they go, "Yep. Okay. Thanks for letting us know." And I'm just sitting there half in tears, half having a nervous breakdown telling them that I don't want to go home because I feel like I want to

die, and they're just going, "Okay, we'll come back and check your blood soon." (Participant B)

Participant B was very clear that small things could make a difference.

Just actually go and talk to people. When you're taking their blood, don't just be like, "Have you eaten today?" and when they say, "No," don't answer anything. (Participant B)

When you're in there, it would be so nice that when they come and check your blood pressure and all that stuff, "How are you doing? Are you okay?" Sure, some people are going to be like, "I'm fine, I'm fine," but just taking that time to make that connection with that person would be so helpful. "Have you eaten today? Why haven't you eaten today? You're not hungry? Lost your appetite?" That would be frigging nice to know that they just care a little bit. Sure, there's some people in there that overdosed on drugs by accident and they don't want to kill themselves and they don't really care that they're in there, but there's people like me that all they crave in their life is for someone to love them and take care of them and just show something. Yeah, so definitely, that connection with someone in there.(Participant B)

Ward 2N, Calvary Public Hospital

Participant I was admitted to 2N within 24 hours of her discharge from ED, but her experience was little better.

My parents were worried, because I'd been there for a couple of days and no one had really done anything with me ... And I wasn't in any state to advocate for myself or anything. So, when they came to see me they were a bit ... "She needs some attention" and ... "What's going on with her?" and so, then I got to see the psychiatrist. (Participant I)

As a result of her parents' advocacy she was seen by psychiatrists who adjusted her medication and devised a plan for getting her "back into a better space." She was feeling more confident and felt that the doctors had made a big difference. Unfortunately, her interactions with a nurse were not conducive to a quick recovery, because her physical ailments were being ignored.

I also have endometriosis ... that was a real difficulty, 'cause I'd been having to have a fairly regular prescription for Panadeine Forte and they didn't want to give me Panadeine Forte.

She had spoken with psychiatrist, because she didn't want to be in that situation where she was begging for pain killers. She described one day where endometriosis was causing her significant pain.

There was a really horrible day there where ... I had an argument with a nurse because she wouldn't give me ibuprofen even. And so, I ended up saying, "You can ring the doctor and tell her that the woman with endometriosis is begging for ibuprofen." ... she just glared at me and gave me ibuprofen. And I cried down the hallway and went to bed and at least I got some ibuprofen. (Participant I) Participant I was aware the difficulty nurses faced from patients trying to self-medicate. Nevertheless, she felt that physical symptoms need to be managed and nursing staff should also acknowledge that behaviour they view as difficult is a symptom of mental illness not a reflection of moral character.

It's that thing of being treated like you're just after medication, which I'm sure they come across as well, so it would be difficult for them to navigate that with a genuine, sort of, medical needs and, you know, people who, I guess, are dependent on certain things. But, that's also part of being unwell, like, that – and in a place like that. That's, that's something to accept. (Participant I)

Hospital-based mental health workers

Three participants were seen by hospital based mental health workers, and their experiences were consistently positive. Participant A felt that the mental health worker cared about her as an individual and was willing to listen.

I don't remember much of the conversation with the mental health because I was just all over the shop. I was sick and anyway, I do remember him coming back and always checking on me, and he's just like, "Are you okay? Do you need anything?" ... That was probably the first sign that I felt that someone was actually wanting to hear me and wanting to listen and cared. ... When he comes, he just made me feel good. (Participant A)

This was in stark contrast with nurses in the past who have made her feel she is not worthy of their attention.

Every time he walked past, he would just be like, "Are you fine?" ... [In contrast] I've had people [nurses] tell me in the past also, that you have to be thankful because you don't have a physical illness. ... "There's some people that have physical illness that want to be fine." And I'm like, well, if I could control it, I wouldn't be here. I have better places to be than here. (Participant A)

Participant H's experience at Calvary was similar.

When I saw the Mental Health nurse he was really good. It was just a long time to wait. ... He asked the right questions, kind of, in the right way and let me kind of ramble when I needed to ... [It was] validating. (Participant H)

Participant F was visited in Calvary by mental health workers from Canberra Public Hospital, who were respectful and collaborative.

They made it clear to me it was totally up to me whether I wanted to continue any further, but they would arrange for me to see a psychiatrist at Canberra Hospital [if I wanted]. (Participant F)

Adult Mental Health Unit, Canberra Hospital

Only two participants spent time in the Adult Mental Health Unit. The younger woman seemed to have more issues with the care provided. Indeed, Participant A felt that she had be tricked into admission.

He [a doctor] told me if I take this, you can go. And I didn't clarify where I was going. ... And then I got moved down to AMHU, the Adult Mental Health Unit. ... I had got the impression that if I took it [the medicine], he was going to consider letting me go. (Participant A)

The young woman was in the Adult Mental Health Unit for two weeks, feeling very isolated.

I contacted my Support Coordinator a bit because I wasn't getting listened to by anyone in there and they were just keeping me. So I found I was calling my Support Coordinator and my Case Manager like, between both of them I was – I just had to talk to someone every day. ... I just couldn't deal with it, so I was on the phone to one of them a day. (Participant A)

Another issue of potential concern is that the Unit referred the young woman both to TWBSS and a support line, but the young woman had no memory of this. Conceivably she was told and did not remember. Regardless, the calls from both organisations came as a surprise to her.

There were positive moments for Participant A. She enjoyed the alpaca therapy and the art therapist helped her find a CIT course. Participant A eventually persuaded the Unit to discharge her on the proviso that she wouldn't hurt herself. Unfortunately, the process of discharge and ensuring her safety seemed superficial at best.

Hand over your bracelet. Here's the paper. And – yeah, open the door. I'm out. (Participant A)

Participant D is more positive about the Adult Mental Health Unit. She found it "a very clinical space" but understood that "everyone has to be safe, so it has to sort of be that way." Her assessment of the staff was very positive, and she also appreciated the opportunity to walk to the hospital café daily. However, she felt that the building did not encourage wellness.

The staff were great, but I think the design of the building – even though its purpose-built – is just not conducive to people's well-being. It's just a huge cavern of space that echoes and so if someone's upset, then everybody knows about it. But the staff are wonderful, and they work well within that constraint, I would say. (Participant A)

What did the researcher learn through the process?

The importance of training in trauma-informed care

The training I received in understanding and responding to trauma proved invaluable.¹⁸ As a consequence, I adapted my interviewing technique and employed a range of strategies that are discussed below.

Safety

The research team sought to establish a safe environment for the participants by giving them the option of having a support person present during the interview, if desired. Only one participant chose this option and she did subsequently require support. Difficult issues were discussed with all the participants and at such points in the interview I always asked the participant how they were finding the interview process and gave them the option of pausing or stopping completely. None chose to cease speaking. In the case of Participant E, where I judged that he was in immediate need of help and not in a position to be interviewed, he agreed to me ceasing the interview and to seeking assistance for him. Thus only two participants required support after an interview and that was readily available.

Prior to each interview I sent the participant a short text message introducing myself and attaching a recent photo of myself. I hoped this would enable them to visualise meeting me and lessen any anxiety associated with that. I received no feedback on whether this was helpful. Nevertheless, the Australian Commission for Safety and Quality in Heath Care encourage better communication between clinicians and patients. For instance, the idea of a health professional introducing themselves to the patient is implied in resources covering clinical handover.¹⁹ Furthermore, "Hello My Name is" is a campaign specifically to encourage health professionals to provide person-centred, compassionate care.²⁰ Therefore, I feel confident that this is an appropriate strategy to employ, particularly with people who have experienced trauma.

Trustworthiness

The easiest way to demonstrate trustworthiness is to be clear about what the interview will entail and sticking to the plan. Thus, before each interview I outlined the general flow of the interview. I also explained that while I would let the conversation flow as naturally as possible, I might return to issues to ensure that we covered everything. I also explained that I may be unable to detect if the participant was feeling uncomfortable with a particular line of questioning. I encouraged them to explicitly tell me that they didn't wish to answer that question. However, I reassured them I would only rephrase a question two to three times before moving on.

Being able to build trust in a short period of time is a basic skill all interviewers need. However, I conducted the interviews in a more informal and interactive manner than usual. This was, in part, because it is important to acknowledge existing trauma, and to recognise and affirm the participants' coping strategies.

Building rapport was paramount and I did this, in part, by identifying elements in my life that mirrored the participants' own lives. For instance, if the participant was a dog owner, I talked about my two dogs. When one talked about the importance of getting a good night's sleep, I concurred wholeheartedly. When the participant was a parent, I mentioned my child and shared a recent experience that accorded with her own.

Perhaps most significantly, I shared with all the participants that I experience chronic depression for which I take daily medication. When one participant mentioned her anxiety around being slightly late, I commiserated and joked that in my experience life is quite hard enough without being punctual as well. The participants seemed to respond very positively to my openness.

Thanks, that's appreciated. ... Thank you for making it so easy. (Participant D)

And thank you for being easy to talk with as well and thanks for sharing your things, too. ... That's very, it's generous of you, too. (Participant I)

Choice and Collaboration

Participants were encouraged to talk about issues, only to the extent that they felt comfortable doing so. This provided them with the option of not sharing information if they felt uncomfortable or sharing more than planned if that felt right to them. These options allowed the participants to decide the direction of the interview and thus collaborate in its creation. Qualitative interviews are generally understood to be a creative event (ref).

Empowerment

One way I chose to empower participants was through trust. Whenever, a participant talked about progress they had made, I was sure to acknowledge their success. In the following exchange, the participant had expressed a concern about his perceived dependency on medication to help him fall asleep.

Basically, during the week when I'm working Sunday night to Thursday night – I take it [the sleeping pill] and only at quarter dose, but yes, at the weekends I don't take it at all. I WOULD SAY THAT A QUARTER DOSE SUNDAY TO THURSDAY, WHEN YOU'RE WORKING, DOESN'T SOUND LIKE A HUGE DEPENDENCY. IT SOUNDS LIKE [THE EQUIVALENT OF] A GLASS OF WINE IN THE EVENING. (Participant E)

The importance of empowering participants through the interview triggered me to unambiguously acknowledge how the participants contributed to the TWBSS's improvement by taking part in the interview. I also explicitly sought their suggestions for how the service can be enhanced. This demonstrated the value of both their experiences and their reflections on them.

The importance of debriefing

The Way Back Support Service takes a strength's-based approach, and each interview highlighted for me the participants' numerous strengths. Perhaps this was why I generally felt reasonably positive at the end of each interview. Nevertheless, I did speak with the Manager of TWBSS after each interview. These debriefings tended to be used as opportunities to clarify elements of TWBSS or perceived inconsistencies in a participant's narrative. Two interviews did leave me shaken, largely because the participants were still quite clearly struggling with difficult issues. In these cases I remained in touch with the Manager about the participants' progress, and this served to reassure me that they were being supported. Interestingly, the days I spent writing this report made me aware of how much I had come to care about each participant I had interviewed. This may suggest a need to debrief about the overall research project.

The voluntary nature of the participants' participation

As demonstrated when discussing recruitment, participants felt comfortable refusing to participate. Sometimes this was done simply by not returning calls. But quite often participants were explicit about concerns for their health and well-being and the fact that an interview would disrupt their current life.

The participants who chose to be interviewed generally expressed the desire to give back to the service that had helped them.

I guess when I help people I feel really good, so this was ... one of the reasons why I wanted to come in ... so it will help someone else down the track ... 'cause it helped me, so hopefully by providing my answers and that, it can help somebody else. (Participant G)

Even though I was in a lot of pain this morning – I kind of still am now but it's less – I still wanted to come ... I really wanted to do this because I did think it was helpful. (Participant H)

Participants' self-awareness

The researcher was struck by the participants' deep understanding of themselves and their personal situations. For instance, one participant started the interview by apologising if she stuttered, because she was nervous. However, she was proud of being good at her job as a carer in an aged care facility and knew that she handled certain situations better than others.

It's [not] a struggle with [the people I care for] – more with the staff. ... but lately I've been able to, like, hold more conversations and stuff with the staff. (Participant G)

Another explained why a safety plan wouldn't work for her.

I just find that because of my nature, if I'm in a situation where I'm really angry or suicidal ... I'm going to go out of my way to be in a bad mood. Even if I have that safety plan there ... I'm actually going to go out of my way to not read it, on purpose. (Participant B)

Participants were able to articulate their strengths and give examples of them in action.

My biggest support was work. Now I know that sounds strange, but if I stayed busy ... internally I was sort of satisfied. Don't get me wrong, it's a high-pressure job and that but that's my world. (Participant E)

While some were more articulate than others, all were able to reflect on their experiences in the context of their lives and society more broadly.

I wear makeup ... and *I*, for years ... *I was just hiding it [my depression] from* everyone. Even my partner ... [But] *I* couldn't present as well as *I* wanted to in hospital ... It's just a reflection of how you've been overtaken by the, this disease rather than – it's not your natural self. (Participant I)

What actions would see more people receiving the support they need?

Increase flexibility and discretion

Participants appreciate the flexibility of The Way Back Support Service. That flexibility manifests in the choice the service provides participants in terms of the timing and location of meetings. This helps relieve their anxiety, ensure safety and build trust. It is also present in the way Support Coordinators respond to the needs and wishes of participants, and non-clinical nature of the support. Notwithstanding this flexibility, I believe there is room for more flexibility around entry into the program.

Participant readiness appears to be a significant element in a participant's success with the program. Trauma affects the way people approach potentially helpful relationships,²¹ and this may result in potential participants not responding to approaches from TWBSS immediately after a suicide attempt. As demonstrated through Participant E's story, people may not always be in a position to accept the offer of help immediately. Therefore, I would recommend a greater degree of flexibility around the timeframe in which people can be accepted into TWBSS.

In interview, the researcher explored with Participant E ways that TWBSS could have kept in touch within him during the period he wasn't ready to enter the program. He suggested asking potential participants to nominate a trusted person who would be in regular contact, who would have a sense of what circumstances might suit the potential participant, and when they might be ready. TWBSS could then keep in contact with the nominated person rather than risk bothering the individual repeatedly.

You're not going to affect the people that are just so isolated – Now how do you get to them? Look this might be a really one-off, left-field thing but when you first get the people to come in I would suggest they nominate somebody ... in my case it would have been my boss – use them as a check in as well. (Participant E)

There is also an ethical imperative to continue providing support if the participant does not have sufficient community support on completion of the program. Two participants, on completion of TWBSS appeared to have required ongoing support. Participant D was supported post TWBSS by the Woden Mental Health Team. Unfortunately, little was not available to Participant A, a young woman who lived in rural NSW. Her only support was a psychologist appointment every few months, which required her to return to Canberra.

| Recommendation 1: | Individuals are able to enter TWBSS when they are ready to embrace the process, even if this occurs sometime after their suicide attempt. timeframe. |
|-------------------|---|
| Recommendation 2: | On first contact, potential participants are asked for the details of, and consent to contact, a trusted individual – not necessarily their next of kin – who will |
| | be in regular contact with them, and have a sense of what circumstances might suit the potential participant, and know when they might be ready to enter TWBSS. |

Recommendation 3: Support is provided by TWBSS if the participant does not have sufficient community support upon completion of the program. NB The support may be less regular and intensive.

Continue gathering participant stories

Standard 2 of the National Safety and Quality Health Service²² requires health services to involve consumers in the organisational and strategic processes that guide the planning, design and evaluation of health services. What better way than to ask consumers about their experiences and how the service can be improved?

This report has demonstrated the value of eliciting participant stories and presenting them for consideration by TWBSS for service improvement. Specifically, it has provided TWBSS from a consumer perspective on:

- how the principles of trauma-informed care are enacted,
- what participants value in Support Coordinators,
- what strategies are used to support participants,
- the success of TWBSS, and
- insight into participants' experiences with complementary services.

This data is not gathered systematically through any other process.

The method developed and used in this research has been employed with nine participants, all of whom were happy to engage with the research and were comfortable with the process. The entire approach is explicitly based on the principles of traumainformed care and documented in application eth.11.17.266, which was granted ethical clearance by the ACT Health Human Research Ethics Committee. The risk of harming participants was mitigated, and the response when participants required support post-interview was demonstrated to work as intended.

The skills needed to undertake the interviews with participants are available within Woden Community Services. Ideally, the person doing the interviews would not have had previous contact with participants (e.g. Senior Manager, Mental Health and Wellbeing). The skills to analyse the data and prepare Health Experience Wheels could be acquired with training.

| Recommendation 4: All participants who complete TWBSS program are invited to share their lived experience – through the process described in this report – to improve the service |
|---|
| Recommendation 5: The information gleaned through interview are regularly reviewed |

and incorporated into the service, where appropriate.

Share what we've learnt

Presentations and publications will familiarise health professionals and allied disciplines with a trauma-informed approach to eliciting consumer stories from people who have completed the Way Back Support Service. It may also provide a prototype for the eliciting consumer involvement in similar or aligned services.

Recommendation 6: The findings in this report are used to improve TWBSS.Recommendation 7: The findings and process of arriving at them are shared widely.Recommendation 8: Beyond Blue consider rolling this method across all services nationally.

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Appendix

Summary of findings in plain English

The Way Back Support Service

What participants told us

I cannot be more grateful for The Way Back Support Service. They were literally the only people in that ... experience that actually made sure you were okay. (Participant B)

I've been doing well. I've been trying to get involved in different activities... I'm still seeing my Counsellor, though it's not frequent. (Participant C)

> I loved it! ... And it did help me get through, knowing she was there. (Participant A)

I probably would have been a bit lost [without TWBSS] because I would have felt ashamed.

(Participant D)

Taking time off uni and having the Way Back allowed me to ... take it slow and ... really focus on the basic stuff again. ... I probably would have just rushed it. (Participant H)

> I wouldn't be as good as what I am now. ... [It's a] really good program. I would say it helps you find your way back. (Participant G)

I'm not this person I want to be... but I am resembling more of the person that I want to be. (Participant I)

> [TWBSS] made a big difference to me... a huge difference! (Participant F)

I'm eating healthier foods and I've lost about four kilos so far... It's been very slow trust me ... I'm just buying better food, really. (Participant E)

What participants liked about the Support Coordinators

Humanity and professionalism

He laid it out really well and explained it very well and spoke to me about different parts of it. Yes, it was just explained pretty well.

(Participant E)

She was just nice to talk to. ... I know it wasn't a friendship, but the way she was, kind of, so approachable and open ... she was, yeah, just really nice.

(Participant H)

Trustworthy & reliable

[She] was this reliable person... and if there is any problem, she would tell me that there is a problem ... She always met our appointments.

(Participant C)

Non-judgemental

My Support Coordinator knew that I had partaken in drugs and stuff like that. I never felt comfortable with that until I started talking to my Support Coordinator ... when I left hospital I was too scared to tell my psychologist. My Support Coordinator, kind of, made me feel very comfortable about it.

(Participant B)

Easy to talk to and be with

It went well, surprisingly. I felt relaxed then. I remember I compared it to my counselling sessions [which are] more formal ... But the way we interacted, it was informal and quite relaxing. I was just able to relax.

(Participant C)

Gentle

I'd be feeling a bit negative about something that happened... and then, he would... sort of, turn it around to it being a positive thing... bringing me back to this space that... that could be seen in an alternative way. Just, sort of, gently... keeping me there.

(Participant I)

She never forced it on me or anything like that. I found her quite kind and gentle actually, the way that she spoke, and that's probably what I needed at that time. (Participant F)

Validating

I wasn't comfortable with being out of hospital... I think that was one of the most important things, that that was acknowledged, and it was okay to be in that space.

(Participant D)

What practical strategies worked for the participants

Ensuring participants' safety

We were just generally talking about how I was going, and how I'll be able to keep myself busy... [and] how I was going to stay safe [over Christmas and New Year]. (Participant A)

Encouraging well-being

One of my self-care goals, I guess, early on was to get my nails done. And she asked how that went. And I think I sent her a photo of my hands.

(Participant H)

Helping with goal and priority setting

I guess ... she was installing [goals] in my head that can be done, like ... help with putting you in [contact] with a ... psychologist.

(Participant B)

Making and keeping appointments

She was willing to ring up my doctor and make [an appointment for] the Mental Health Care Plan for me. It was basically like she was my mind because I was, sort of, all over the shop.

(Participant G)

Exploring treatment and other options

If I spoke, for example, about housing, my Support Coordinator would bring up options on that, you know, [then] he reinforced it as we sort of spoke further. (Participant E)

Using physical activity

We went for tea... To the Botanic Gardens. We took walks. We climbed rocks. That is different and it's engaging. We don't just talk but you get engaged [physically] also... I had lost hope and I just didn't find interest in anything, so that revived everything.

(Participant C)

Promote helping others

We'd worked out ways where I could be helpful with other people in my family as well as try and make time for myself, which was important at that stage.

(Participant D)

I mentioned to her once that I'd been thinking about doing some charity work for, like, Meals on Wheels, that sort of stuff, and volunteering for other charitable organisations that maybe I could help, and she followed up on that and gave me all the information I needed... to do these things.

(Participant F)

What we found

TWBSS, ACT

- ensures that the participants feel safe and can build a trusting relationship with their Support Coordinators
- tries to be flexible and provide options to the participants
- works with the participants to ensure that their needs are met
- focuses on the participants strengths and skills, while acknowledging the difficulties and challenges they face
- fosters the capacity of individuals to make changes in their lives that are important to them

What we did and what we plan to do

We spoke with seven women and two men who had completed The Way Back Support Service program in the ACT. Participants were invited to highlight the most important elements of their experience. We analysed the interviews against the principles of trauma-informed care. This means we wanted to see if the participants felt

- safe and able to trust the Support Coordinators,
- that they were given a choice of options to suit their needs
- that the Support Coordinators worked with them as partners, rather than told them what to do, and
- that they were able to make changes in their lives by the end of the program.

We also produced a diagrammatic representation of the participants' journey from the point at which they attempted suicide to immediately after the completion of the program. This is called a health experience wheel. It collects all the main elements of each story on one or two pages.

TWBSS, ACT has already used the participants' stories to improve the local service and hopes to help other Way Back Services around Australia.

Thank to you all who took part in this research!

The participants' strength and resilience in the face of enormous challenges is truly impressive. Their willingness to share their stories will benefit others, and I sincerely hope life continues to improve for them. Each and every one of you is an amazing and capable person with so much to offer!

Thank you also to the staff of TWBSS, ACT for being so generous with their time and thoughts. I believe that the Support Coordinators are models of how to conduct oneself in a health or social service. The research would not have been possible without the extraordinary efforts of Prue Gleeson who worked with me to develop the method and helped me correctly understand the details of the program. Pam also brought her years of experience and insight to the analysis. Thank you also to Pam Boyer who ensured that this valuable research took place. Both Prue and Pam were wonderfully supportive of me throughout, for which I am truly grateful.

Kathryn Dwan Health Care Consumers' Association <u>www.hcca.org.au</u> 18 January 2019