



Champions for Change: Report to the Mental Health Commission of NSW

7 August 2015

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Being | Mental Health & Wellbeing Consumer Advisory Group

Being | Mental Health & Wellbeing Consumer Advisory Group (BEING) is the independent, state-wide peak organisation for people with a lived experience of mental illness (consumers). We work with consumers to achieve and support systemic change.

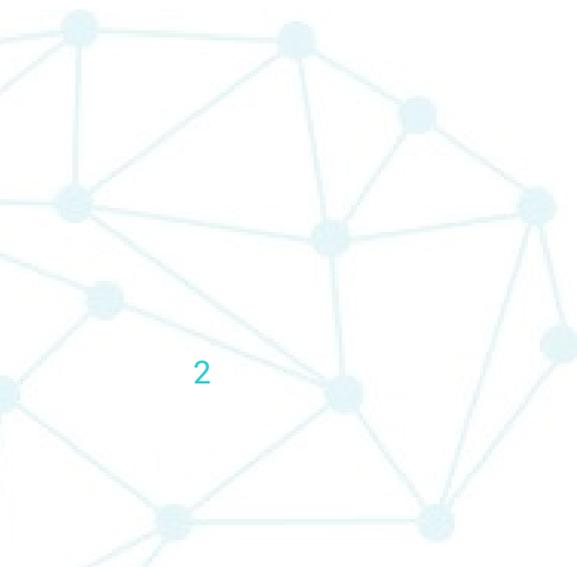
BEING's vision is for all people with a lived experience of mental illness to participate as valued citizens in the communities they choose. Participation is a fundamental human right as enshrined in Article 25 of the International Covenant on Civil and Political Rights (ICCPR). We work from the premise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

Our work is guided by eight principles:

- Principles of recovery underpin all our work
- Recognition of the importance of a holistic approach
- Collaboration and team work
- Flexibility, responsiveness and innovation
- Consultative and participatory processes that have consumers at the centre
- Promoting equity and positive images to address discrimination and prejudice
- Accessible and approachable for all
- Promotion of professionalism and quality practice

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

Find out more at www.being.org.au



1. Executive Summary

This report details the findings of consultations with people with a lived experience of mental illness (consumers), and our recommendations to the Mental Health Commission of NSW (Commission) as a part of the Champions for Change project. The consultations consisted of an online survey with 43 participants, and four face-to-face group discussions with 19 participants.

The purpose of the project was to explore:

- What mental health consumers need in order to influence and become advocates for positive change in mental health reform in their local communities; and
- How the *Living Well: A Strategic Plan for Mental Health in NSW*,¹ adopted by the NSW Government and developed by the Commission, can support local efforts for mental health reform.

Our consultations called for input from consumers who consider themselves to be, or want to be, a champion for change – someone who wants to influence and advocate for mental health reform in their community. For this reason, participants are also referred to in this report as champions.

The findings of our consultations include:

- Many champions are interested in making positive changes in mental health reform, but most could not identify actions that they could personally take.
- Some champions did identify actions they want to personally carry out, and these relate to:
 - Leading mental health promotion campaigns;
 - Collaborating with people to improve mental health and other services;
 - Starting up and running consumer-led initiatives.

There is a lack of opportunities for consumers to be involved in addressing the broad and complex issues underlying mental health reform. Fostering these opportunities would require operational changes across services and agencies to enable genuine collaboration with consumers. The Commission can lead the way by facilitating opportunities for consumer involvement and leadership, and making it easier for people to take actions for positive change.

¹ NSW Mental Health Commission (2014). *Living Well: A Strategic Plan for Mental Health in NSW*. Sydney, NSW Mental Health Commission.

2. Introduction & Background

In December 2014, the NSW Government adopted the *Living Well Strategic Plan for Mental Health in NSW*. The Strategic Plan is a 10-year vision for mental health reform with a whole-of-government approach, and contains 141 actions. The Mental Health Commission of NSW developed the Strategic Plan and has a role in monitoring implementation of the Strategic Plan.

From May to August 2015, BEING coordinated the Champions for Change project, which this report discusses. The Champions for Change project is centred on enhancing the local advocacy efforts undertaken by people with a lived experience of mental illness, and related to mental health reform.

The feedback from the participants in this project shows that there are many consumers who are keen on being involved in mental health reform. Many of these people have experience in advocacy and bringing about positive changes in their community. The experiences that consumers have, including their lived experience of mental illness and experiences in local advocacy are valuable to inform and drive mental health reform. Maximising the potential of champions would help bring about positive changes for successful mental health reform.

This report provides recommendations to the Commission, focussing on the role that we think the Commission can play in supporting the actions champions proposed in their feedback. The Champions for Change project also informs BEING about how BEING can support the positive changes consumers are working to create.

3. What we did and how we did it

For this project, we aimed to gather as much input from people with a direct lived experience of mental illness as possible within the short timeframe of the project. We conducted an online survey using Survey Monkey. We also contacted and supported consumers to facilitate face-to-face consultations with other consumers in their community. For this project, there were a total of 62 participants who indicated that they have a direct lived experience of mental illness.

3a. Online Survey

We conducted an online survey through Survey Monkey. The survey opened on 3 June 2015 and closed on 28 June 2015. We promoted the survey by contacting BEING e-newsletter subscribers, individual consumers and consumer networks. We also promoted the survey through our social media.

The survey received a total of 47 responses. Of those 47 responses, 43 indicated that they have a direct lived experience of mental illness. Four of the participants did not indicate that they have a direct lived experience of mental illness. We excluded the feedback of these four participants from our analysis and this report. Two of those four participants identified as having a lived experience as carers, but not as consumers. We provided their feedback to ARAFMI NSW, the peak body for mental health carers in NSW.

3b. Face-to-face group discussions

We called for consumers to organise and facilitate face-to-face group discussions with consumer champions in their community. There were four group discussions with 19 participants in total. Three of the consultations were facilitated by a person with a lived experience of mental illness. Each facilitator provided us with a written summary of the discussion they facilitated. The four face-to-face consultations were in the following locations:

- Northern Sydney (with young people)
- Inner Sydney
- Northern Sydney
- Western Sydney (with young people)

Note: For the Western Sydney consultation, the facilitator was a young person without a direct lived experience of mental illness

BEING policy staff members were available by phone and email to provide information and support to facilitators, and discuss ideas around running their consultation.

To find consumers to facilitate the group discussions, we called for expressions of interest through our e-newsletter, social media and emails to our contacts. We also made phone calls to consumer networks and organisations to inform them and people in their networks about the project and the facilitator opportunity. Facilitators were offered \$100 for a consultation and up to \$50 for catering.

3c. Barriers to people facilitating a group discussion

A number of consumers and consumer groups, including those specific to Aboriginal, forensic and rural and regional contexts, were interested in holding a face-to-face group discussion for this project, but were unable to do so. We collected some feedback from these consumers and groups about the barriers to them holding a consultation. The main barriers included:

- The short timeframe made it difficult to contact enough people to hold a consultation, especially outside of metropolitan Sydney. A number of people said that they would need more than one month to do the tasks required of a facilitator.
- The remuneration (\$100 facilitation payment, and up to \$50 reimbursement for catering) was insufficient to cover the costs involved, such as the time to organise the consultation, travel and other associated costs.

3d. Analysing the qualitative data

To enable analysis, we exported the responses to the online survey from Survey Monkey into a Microsoft Excel spreadsheet. The qualitative data from the online survey consisted of the responses people had typed into the comment boxes provided. We also had written summaries of the group discussions in Microsoft Word documents. We used thematic analysis to identify core themes and differences in participants' responses. We coded the online survey data in the Excel spreadsheet, and coded written summaries of the group discussions in Microsoft Word.

We then made a distinction between two kinds of responses:

- 1) Responses that were raising a systemic issue and changes the participant would like to see happen without discussing any actions the person could or wanted to carry out themselves to bring about the changes;
- 2) Responses that discussed actions the participant wanted to carry out personally to bring about changes.

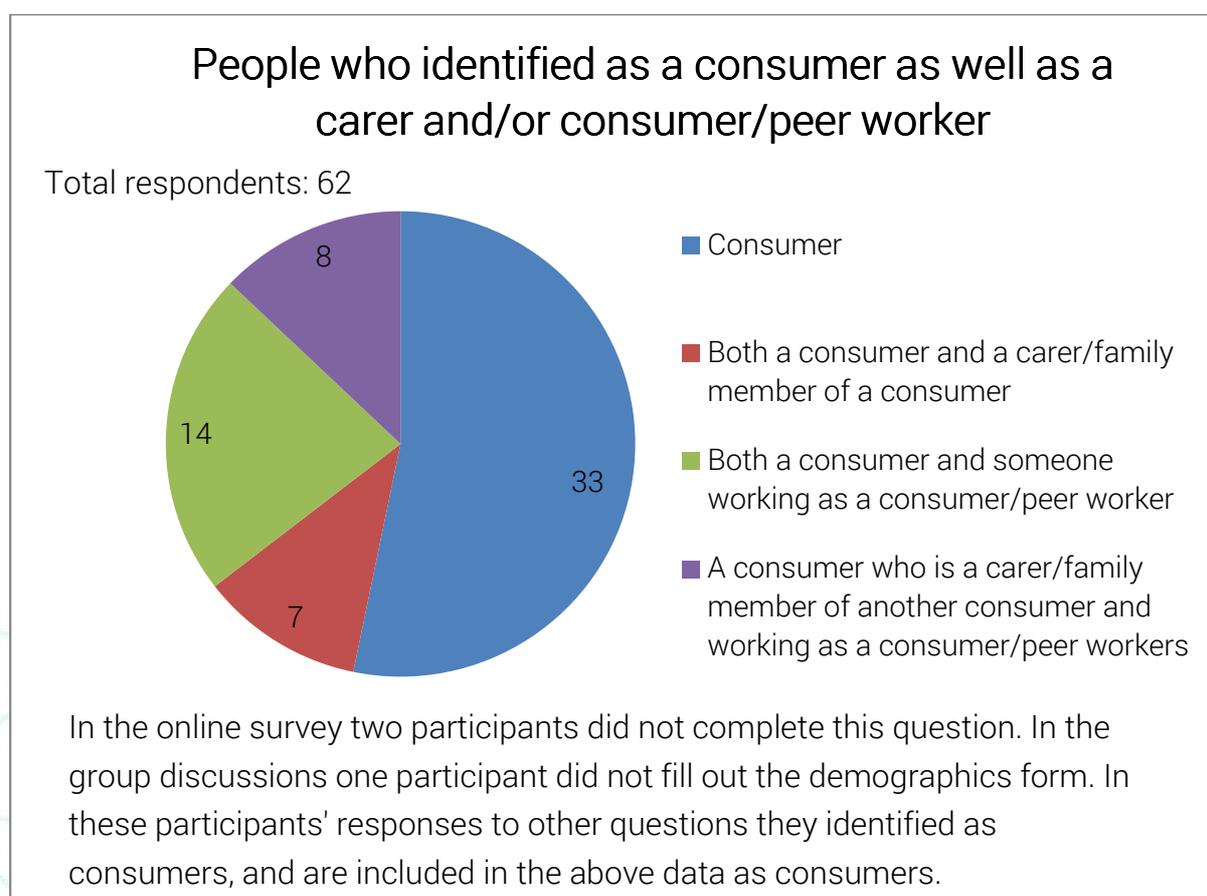
We analysed the data accordingly to identify broader systemic issues, and the actions people personally wanted to take to bring about changes. We could not include everyone's feedback into this report as there was such a wide range of feedback. In line with the aims of this project, we focussed on the actions that people personally wanted to, or could, carry out for positive change.

4. The people who shared their views

4a. Demographics

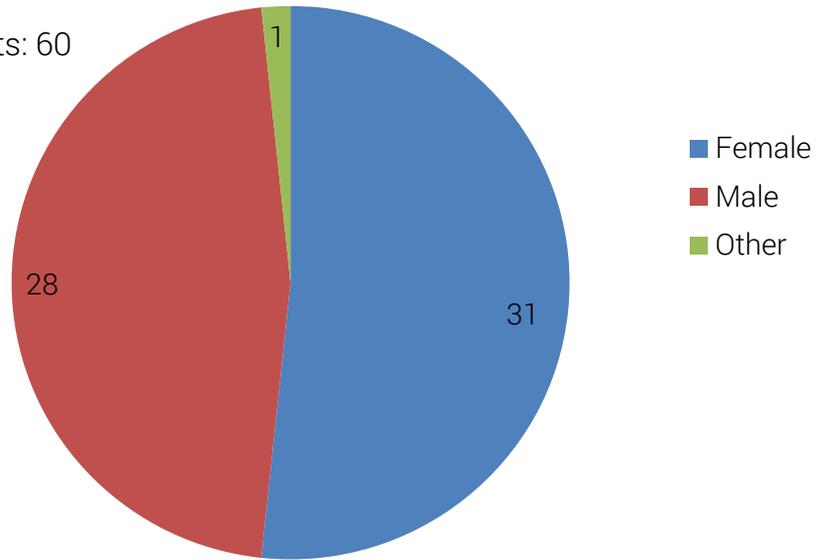
To get a sense of the people we heard from, we asked them nine questions about their backgrounds. This section discusses our findings from these questions. There were a total of 62 consumers who participated in the consultations (either online survey or face-to-face group discussion). Not everyone answered each demographic question. In each chart, we show the total number of respondents for that question.

Of the 47 people who completed the online survey, 43 identified as having a direct lived experience of mental illness. We have excluded the other four responses from our analysis. Two of the responses did not clearly indicate whether the person was a consumer or not. The other two responses identified as carers only, and this data was forwarded to ARAFMI NSW. Nineteen people participated in the face-to-face group discussions and all identified as consumers.



Gender

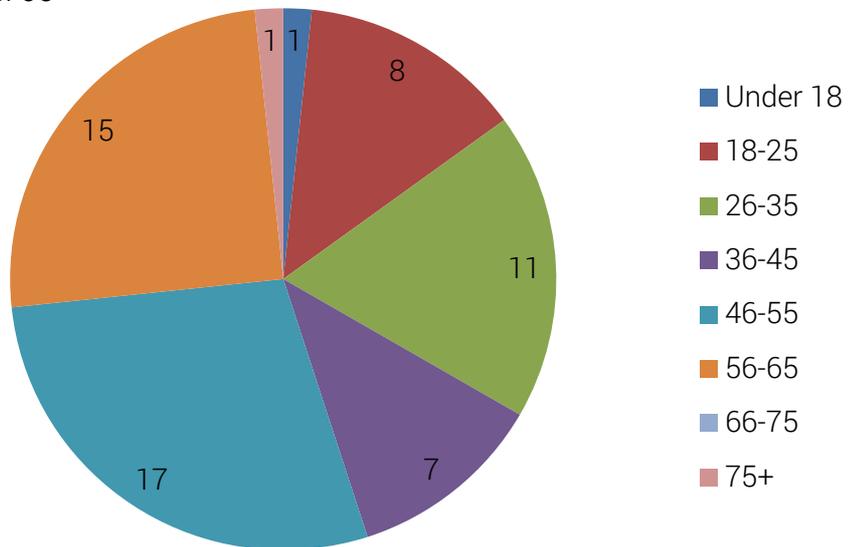
Total respondents: 60



The person who selected the 'other' option identified as a transwoman.

Age group

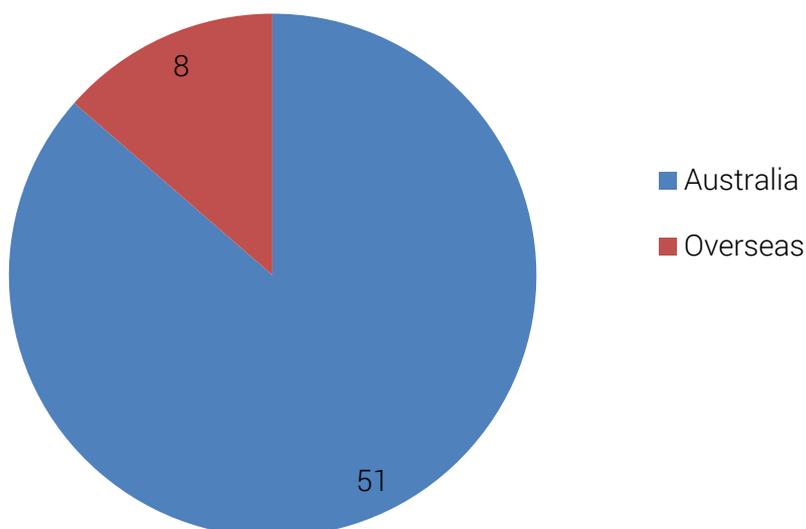
Total respondents: 60



None of the respondents were in the 66-75 age bracket.

Where people were born

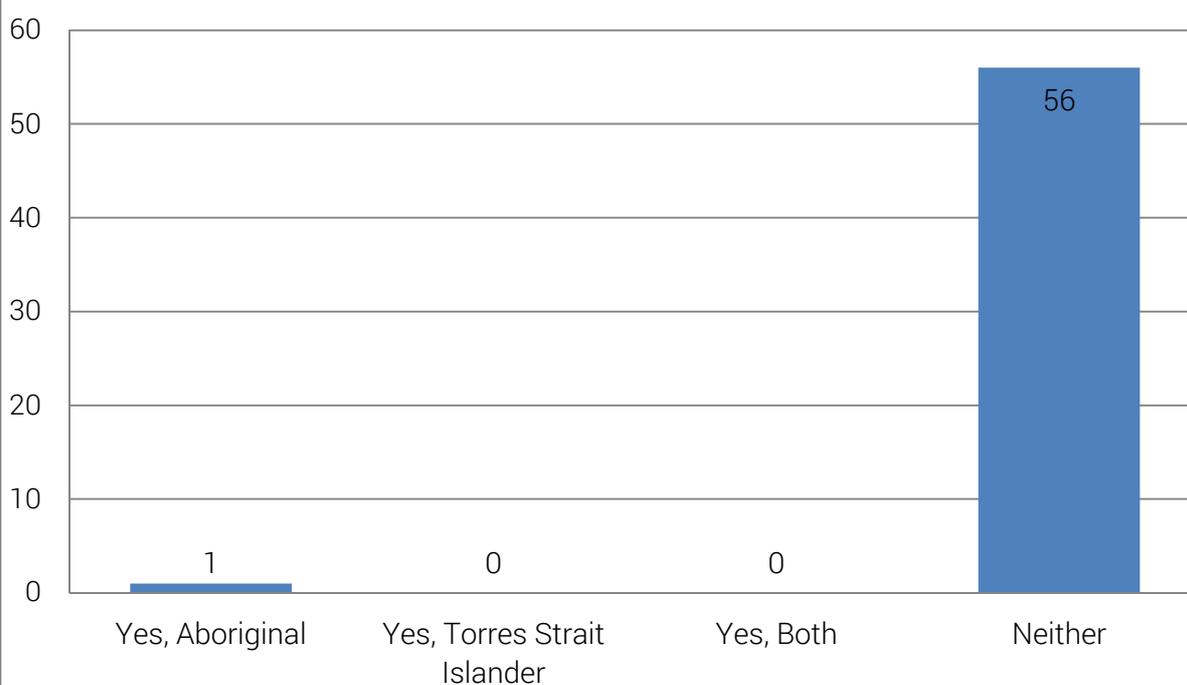
Total respondents: 59



The eight people who were born overseas were from many parts of the world including New Zealand, United Kingdom, Taiwan, Denmark, Egypt, and the Netherlands.

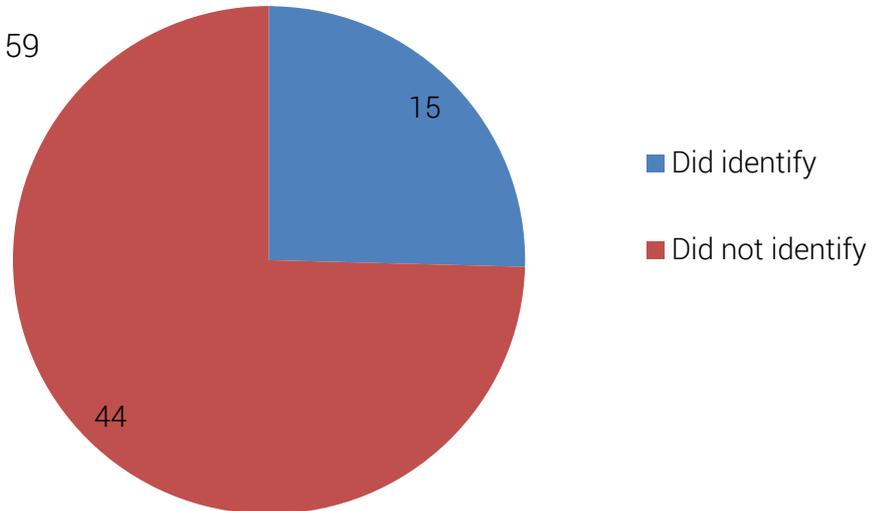
Whether people identified as Aboriginal and/or Torres Strait Islander

Total respondents: 57



Whether people identified as being from a culturally and linguistically diverse background

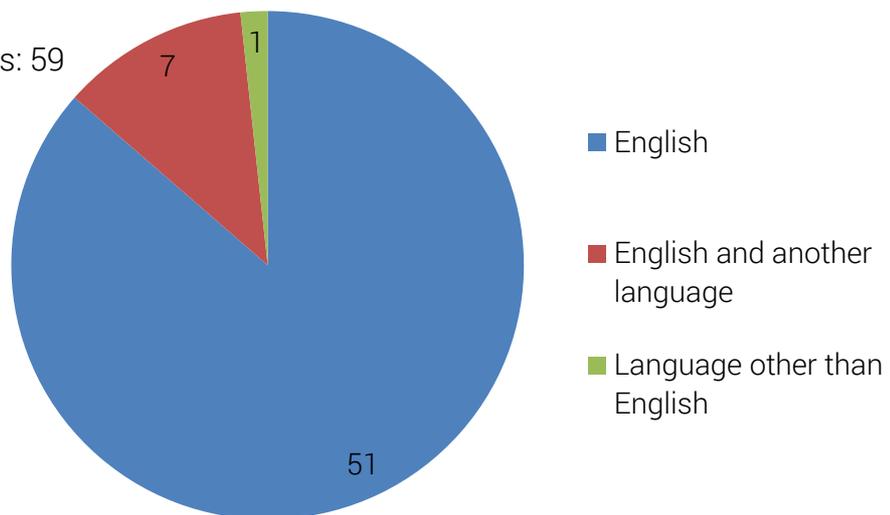
Total respondents: 59



For the individuals who responded yes, there was a range of diversity including Greek, Thai/Chinese, Turkish/Chinese, French, Swahili, Ukrainian, Maori, Armenian and Filipino.

Language spoken at home

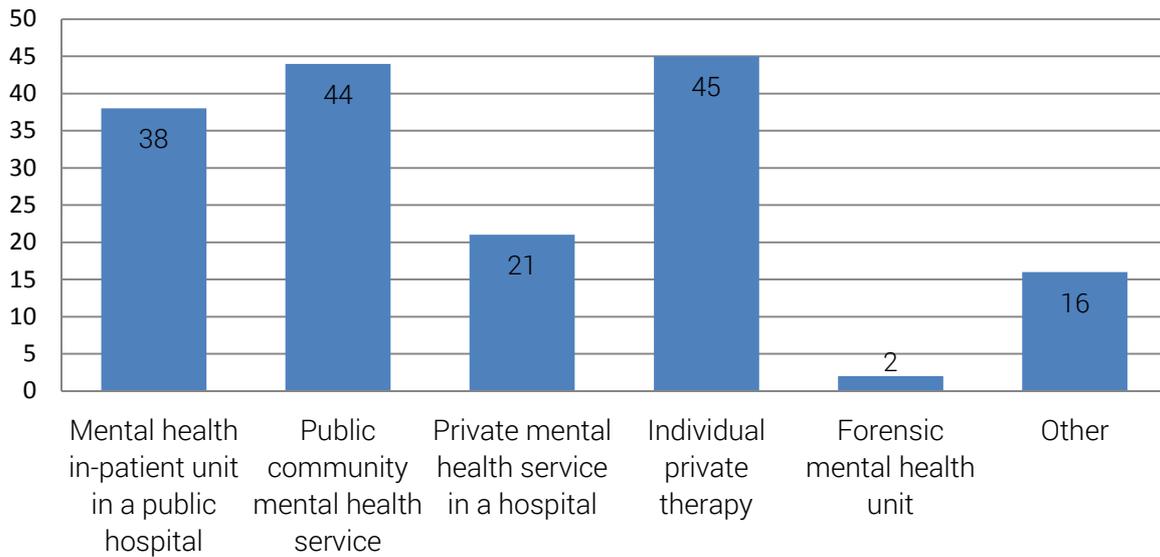
Total respondents: 59



The language other than English was Serbian. The languages spoken in addition to English at home include Greek, Maori, Thai and Mandarin.

Mental Health Services Used

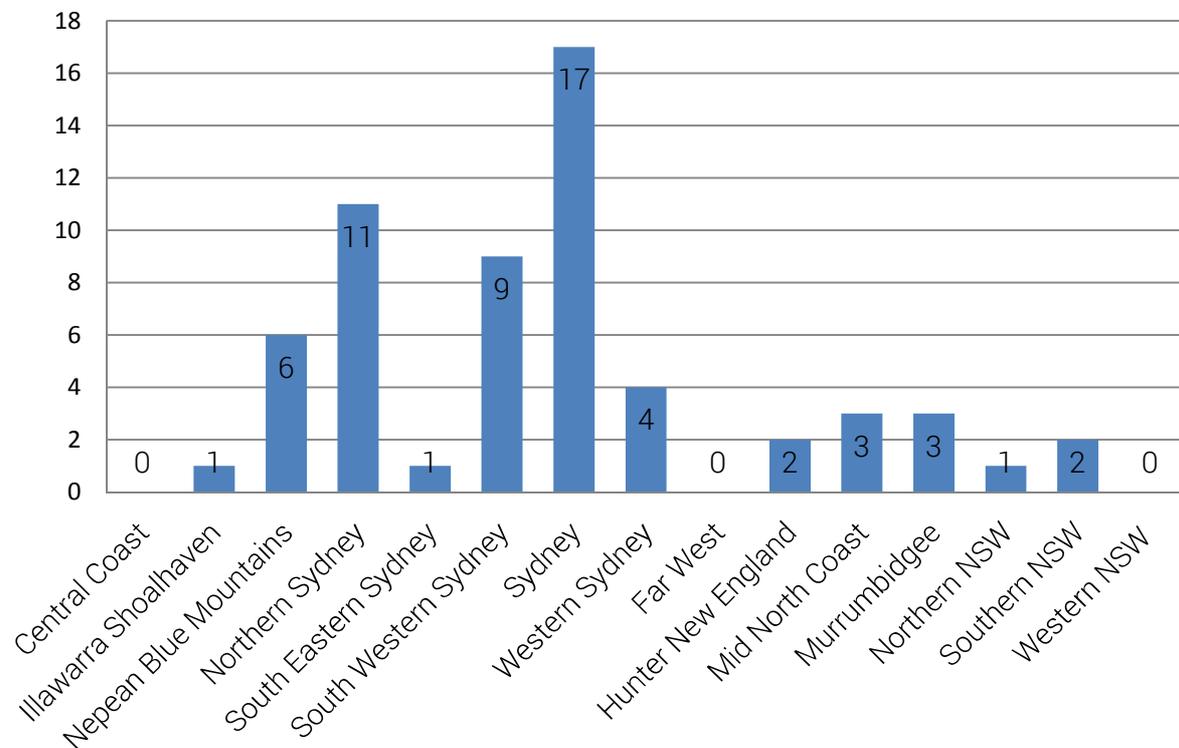
Total respondents: 58



People could select multiple responses to let us know what mental health services they have used. The other mental health services people said they used were general practitioners (GPs) and non-government services.

Total respondents: 60

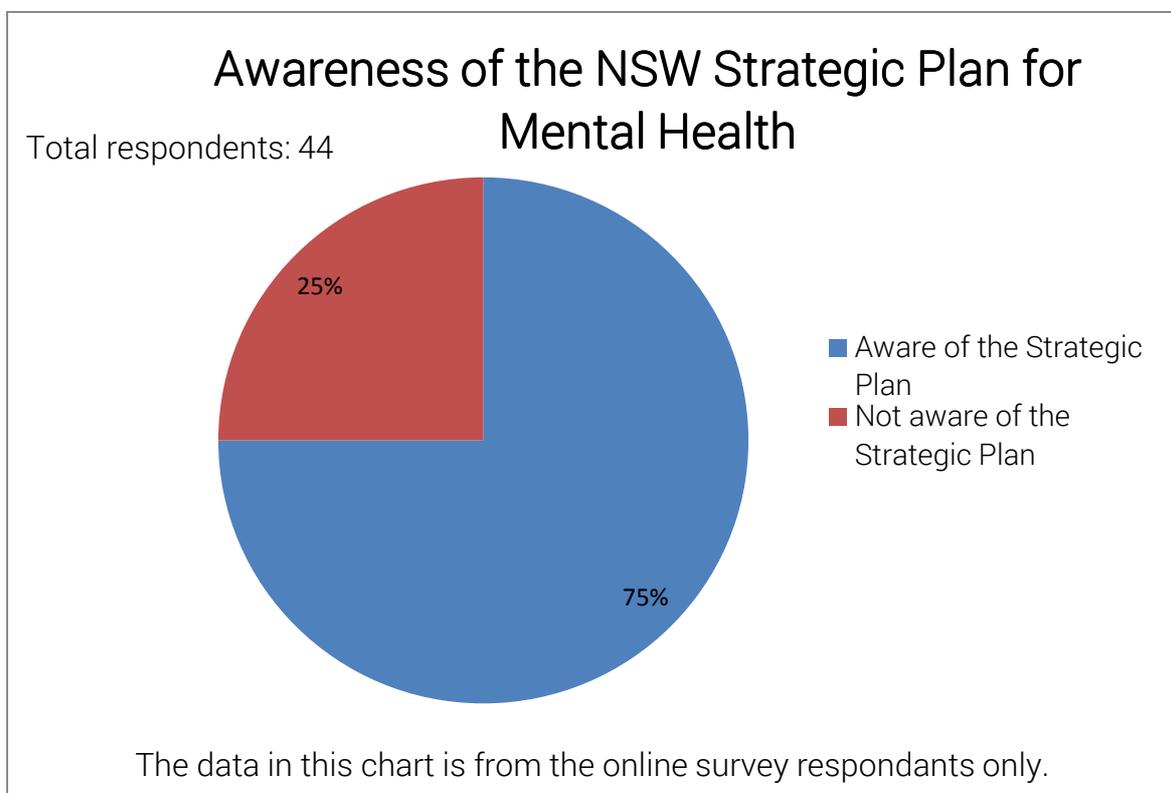
Where people live



4b. Awareness of the NSW Strategic Plan for Mental Health

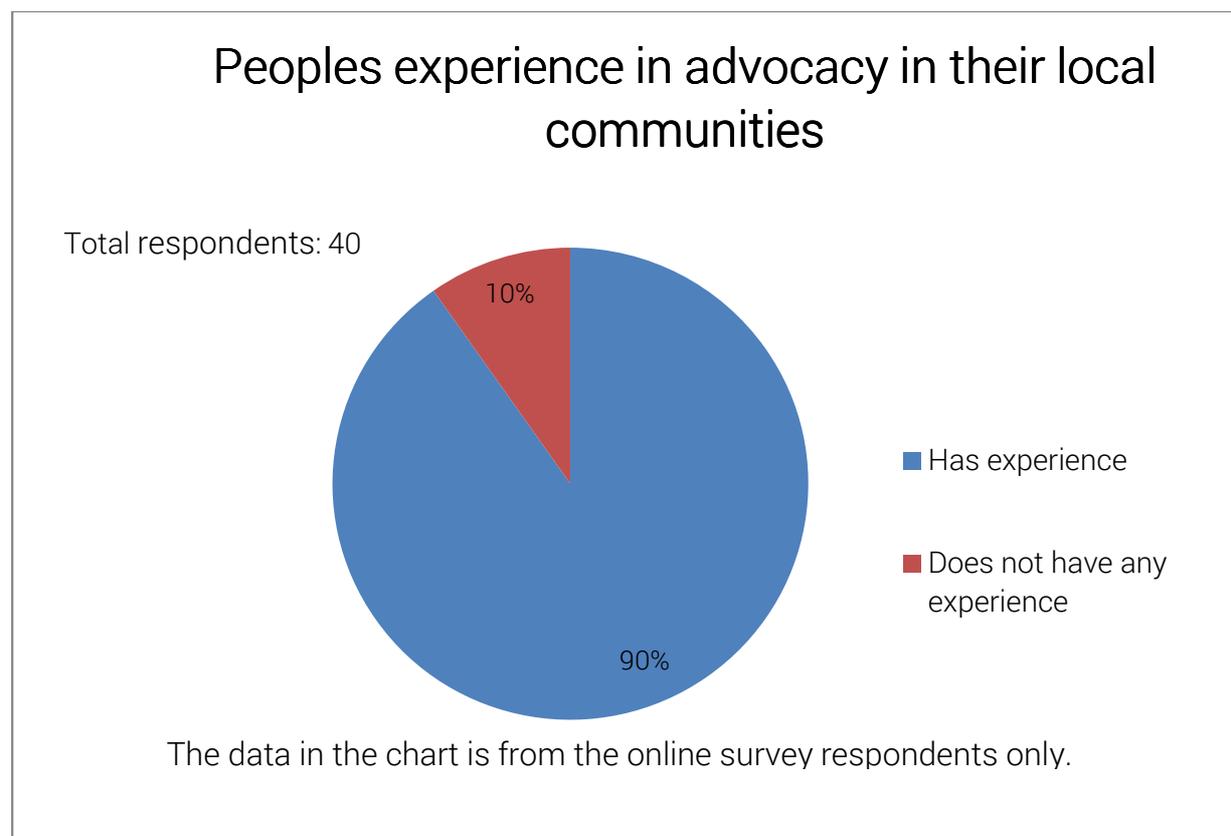
We included a question to find out how many of the participants were aware of the *Living Well: A Strategic Plan for Mental Health in NSW*. In the online survey, of the 44 people who answered the question, 33 (75%) had heard of the Strategic Plan and 11 (25%) people had not heard of the Strategic Plan.

In the face-to-face group discussions it was difficult to determine the number of people who were aware of the Strategic Plan. Overall, most of the participants at the group discussions were aware of and had read parts of the Strategic Plan.



4c. People's interest and experience in advocacy in local communities

The consultations included a question to find out how many consumers have experience in making change in their local communities. In the online survey, of the 40 participants who answered the question, 36 (90%) identified as having experience in advocacy in their local communities. Four respondents (10%) identified as having no experience. In the face-to-face group discussions, the majority of participants indicated that they have experience in advocacy.

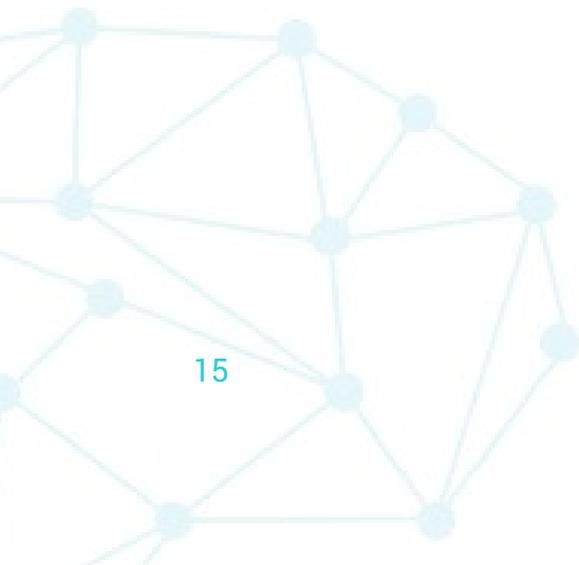
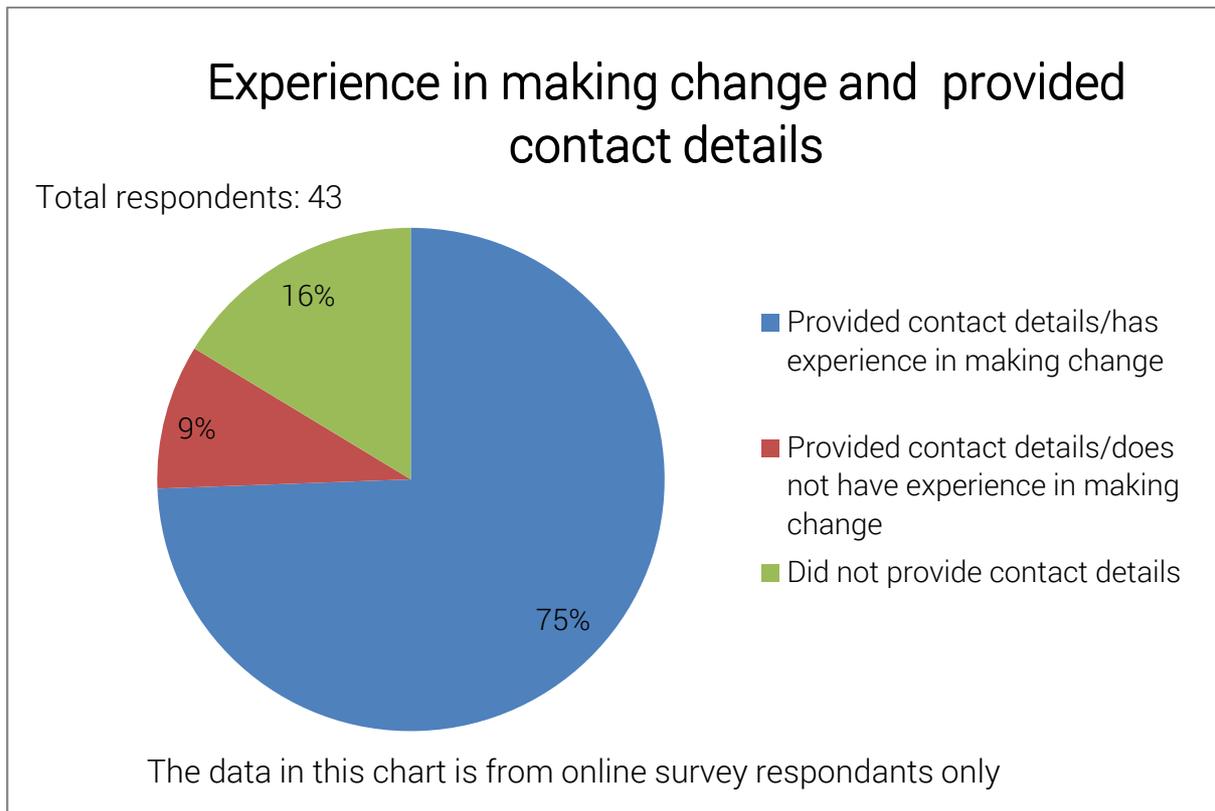


Participants reported a wide variety of experiences in making change in the community. The following table provides an overview of the participants' experience. There was a lot of information about people's experience in making change, and we could not include all of it in the table.

Note: the numbers are approximate due to overlaps and being unable to separate which participant said what in the face-to-face discussion data. We have included the table to demonstrate the broad range of experiences champions have in making changes in their community.

Type of experience	Examples	Number
Mental Health Support Worker	-	2
Mental health promotion/awareness activities	Encouraging people to get involved, telling own recovery story, speaking to the media, being part of mental health promotion events (such as Mental Health Month)	17
Consumer Representatives	A variety of committees, including local hospital boards, health districts and not for profit organisations	7
Participation in community programs	Mental health support groups, school projects, youth run organisations, art exhibitions	9
Consumer Advocate in Mental Health Unit	-	1
Consumer speaker	At mental health forums, presenting at schools	3
Workshop facilitator	Creative writing and drama workshops, Peer Zone Workshops, other	4
Founder of consumer organisation or program	Created support group, consumer advocacy service, projects in decreasing stigma	6
Peer Support Worker	-	1
Undertaking self-training	Individual training and education in mental health and recovery models.	1
Volunteering	-	1

The following graph shows the percentage of participants who have experience in making change and also provided their contact details (name, phone number and email). Of the 43 consumers who answered the question, 32 (75%) provided their contact details and have had experience making change in their local communities.



5. Findings: Steps to positive changes

5a. An overview of this section and the limitations of the findings

The consultations asked people what positive changes they want to make in relation to mental health reform in their local communities. The consultations aimed to find out what actions people wanted to carry out themselves, the barriers they face in carrying out these actions, and their suggestions around overcoming the barriers.

In this section we discuss:

- The concerns people raised which were of a systemic nature, and the changes they want to see regarding these concerns;
- The actions people want to personally carry out, or already are carrying out to bring about positive change;
- What needs to happen for people to be able to personally carry out these actions; and
- What the Commission can do to make it easier for people to carry out these actions.

From participants' feedback we identified three main goals people want to take place. We have organised our findings and recommendations under these goals:

- Promote positive attitudes and awareness of mental health
- Improve people's experience of services, including mental health services
- Strengthen consumers' influence over mental health and other services

In most of the feedback collected, participants raised systemic issues and changes they would like to see happen without discussing any actions they want to, or could carry out themselves to bring about the changes. For example, a participant discussed the need for more collaboration across mental health and housing services, rather than what the participant would like to do to make this change happen. The systemic issues participants raised generally correspond with those discussed in *Living Well: A Strategic Plan for Mental Health in NSW*.

There was limited feedback about specific actions that people wanted to take, or had tried to take, and the barriers they face to carrying out those actions. The actions that people want to take covered only some of the systemic issues discussed.

It is not surprising that most participants did not immediately recognise what they could personally do to make changes to systemic issues. The systemic issues are so complex and broad that it is difficult for people to pinpoint possible actions, if any, to personally address the issue. Furthermore, many champions have felt or been disempowered before. This includes experiences where champions had only the power to comply with the system rather than change it. We recommend making it easier for consumers to recognise how they can achieve systemic change. For example, BEING is already doing this on a small scale by working with some NGO services and the New South Wales Institute of Psychiatry to provide training and support in systemic advocacy for consumers. This work has resulted in some positive and life-changing outcomes.

The Champions for Change project found that many consumers are interested in being involved in making positive changes in mental health reform. However, champions need more opportunities to be involved in making changes. There also need to be operational changes across services and agencies to make it possible or easier for people to carry out the actions. In this report, we make recommendations on actions the Commission could take to create some of those opportunities, as well as to lead other services and agencies by example to move from a culture of 'doing things for people' to 'doing things with people'.

5b. Summary of findings

From the feedback we collected, we identified three main goals participants want to realise for mental health reform. The following table summarises, under these goals, the key findings regarding overall systemic changes people want to occur, and more specific actions participants want to carry out themselves.

Goal: Promote positive attitudes and awareness of mental health	
Overall systemic changes participants want to occur	<ul style="list-style-type: none"> • More public awareness of mental health and wellbeing • Reduce stigma of mental illness (e.g., in media portrayal)
Actions participants want to take	<ul style="list-style-type: none"> • Participate in consumer-led mental health promotion campaigns This requires: <ul style="list-style-type: none"> ○ Opportunities for consumers to drive mental health promotion campaigns ○ Opportunities for consumers to build skills and networks required to lead promotional campaigns
Goal: Improve people's experience of services, including mental health services	
Overall systemic changes participants want to occur	<ul style="list-style-type: none"> • Increase accessibility of mental health services • Mental health services to respond to consumers with more empathy and a 'whole of health' approach • Other services to improve their response to consumers
Actions participants want to take	<ul style="list-style-type: none"> • Collaborate with service providers, agencies and policymakers to improve the delivery and accessibility of mental health and other services. This requires: <ul style="list-style-type: none"> ○ Services and agencies to foster opportunities for genuine collaboration with consumers ○ Opportunities for consumers to build skills, knowledge and relationships required to work with services and agencies to make changes
Goal: Strengthen consumers' influence over mental health and other services	
Overall systemic changes participants want to occur	<ul style="list-style-type: none"> • Increase the reach and appreciation of consumers working in mental health and other services • More consumer-led organisations and initiatives
Actions participants want to take	<ul style="list-style-type: none"> • Start up and be involved in consumer-led initiatives relating to mental health reform. This requires: <ul style="list-style-type: none"> ○ Opportunities for consumers to start and run their own initiatives ○ Resources for consumers to start-up and run initiatives (e.g., funding, training, advice)

5c. Promote positive attitudes and awareness of mental health

What's the issue?

Participants said they want there to be more awareness of the importance of mental wellbeing and less stigma and discrimination around mental illness. To raise awareness of the importance of mental wellbeing, participants want there to be increased training and educational opportunities for the wider community. One champion gave the example of free Mental Health First Aid courses. Another champion suggested changes to the NSW educational curriculum so that people develop awareness and knowledge about mental illness and wellbeing at a younger age.

“Teach kids in schools about mental health, mindfulness, and basic psychology and neurology, so they have a greater understanding of their minds and development”

– Survey participant, 2015

Some champions highlighted that the media can have a significant influence on people's perception of mental illness, and that the media's portrayal of mental illness is often inaccurate, negative and does not include consumers' views. Champions also reported stigma and discrimination from some services staff and the wider community as a barrier to positive attitudes and awareness of mental health.

“Mental illness is only reported as justification or reason for crimes”

– Survey participant, 2015

What changes do champions want to make themselves?

The champions want to see mental health promotion done differently. Currently, it is generally organisations that run the mental health promotions we see in NSW and nationally. Feedback from the participants indicates that people with a lived experience of mental illness need to have more control over the promotion of mental health and the portrayal of mental illness. For example, people want to share positive experiences of mental illness and services, including positive recovery stories. One champion, who has run a project to show the hopes and dreams of people living with mental illness, wants to see more light-hearted campaigns to tackle the stigma and discrimination around mental illness.

People want to be able to play different roles to drive mental health promotion. Some participants want to speak publicly and be ambassadors for promotions. There were also participants who would not feel as comfortable publicly disclosing their lived experience of mental illness. They would prefer to contribute to mental health promotion in other ways, such as by providing input to promotion strategies and ideas.

What do people need to make these changes?

There need to be more opportunities for people with a lived experience of mental illness to promote mental health awareness and breakdown stigma and discrimination. The opportunities need to be flexible and present various roles for people. Opportunities need to allow the person to decide how they want to contribute, and to what extent.

“Please don’t rule me out, because I may not ‘cope’. I will only do if I can - don’t make that decision for me please???”

–Survey participant, 2015

To enable meaningful participation, people need to have enough time to put together their ideas, discuss their ideas and be heard. Some of the champions pointed out that they have other priorities to juggle in their lives, including managing their own mental health. As such, tight and inflexible project timelines can prevent consumers from participating meaningfully in any mental health promotion campaigns or strategies.

Champions would like more opportunities to build their capacity to undertake more significant roles in developing and delivering mental health promotions. Some examples people gave included having the opportunities to improving their skills in writing and delivering speeches, and talking to the media, or writing proposals to pitch their ideas. There also needs to be support available for practical aspects of running a campaign, such as funding for the campaign, and any necessary travel costs.

Working on a mental health promotion campaign can be demanding on a person, including emotionally and psychologically. For example, a consumer publicly speaking about their experiences with mental illness may face discrimination or other negative responses. To provide support for these aspects, people have suggested having a mentor and/or advocate. For example, BEING staff supports consumers to speak at events, such as forums by government agencies. We offer supports, including to help the person organise their ideas, or to discuss any issues they come across, and they

can take up the offer if they want to. Champions also suggested having support from a team of like-minded people, which would include other champions.

“Become part of a team to found a vision and walk forward challenging pre-existing notions, definitions.”

– Survey participant, 2015

What can the Commission do?

To improve mental health consumers’ ability to promote mental health awareness and tackle stigma and discrimination around mental illness, we recommend the following actions:

1. The Commission to create a range of opportunities for people with a lived experience to lead and participate in mental health promotion campaigns.
 - The opportunities should:
 - Be flexible and allow people time to contribute effectively;
 - Ensure people can contribute even if they do not want to publicly disclose their lived experience of mental illness; and
 - Include various roles people can be involved in.
2. The Commission to consider funding consumer-led mental health promotion projects.
3. The Commission to advocate for organisations to have consumers lead the organisation’s mental health promotion campaigns.
4. The Commission to fund an initiative to establish a formal and coordinated network of consumer champions.
 - This would create a support system and an important source of resources for consumer champions. Consumer champions can contact other champions for support when they face challenges in their advocacy, or want to collaborate on actions for positive change.

5d. Improve people's experience of mental health and other services

What's the issue?

Access to mental health services

People want access to mental health services to improve. This includes making the mental health system easier to navigate. Some participants also said mental health services need to be more affordable, particularly, mental health specialists such as psychiatrists. People also want services, such as outreach and psychiatric services, to become more available. For example, have longer opening hours and increase the number of services. This will decrease wait times so people are better able to access services when they need them. In line with the Strategic Plan², people want more community-based services, including follow up support after hospitalisation.

Two champions specifically said they want increased access to appropriate services and trained staff for people with eating disorders. The Strategic Plan highlights a lack of services and appropriately trained staff for people with eating disorders.³

The delivery of mental health services

To improve mental health service delivery and people's experience of mental health services, participants want to change the way services approach care and treatment. Many participants said that services put too much emphasis on the clinical and medical models of mental health. Those participants said they want to see services run with a more holistic and recovery based approach. Some participants said staff need to be more empathetic, to collaborate better with other staff, to actively listen to each consumer, and to focus on the person's 'whole of health', including physical wellbeing. One champion said there needs to be a set of standards for services to implement to make sure services are recovery-oriented. Another participant said for recovery based service delivery to happen there needs to be a higher ratio of staff to consumers.

"Treating the person as human, not a disease"

– Survey participant, 2015

² *Living Well: A Strategic Plan for Mental Health in NSW*, 'Providing the right type of care' pp 55-63.

³ *Living Well: A Strategic Plan for Mental Health in NSW*, '7.4 Eating Disorders' p. 92.

The delivery of other services

To improve mental health consumer's experience of other services, champions want there to be an increase in the level of collaboration across service providers, government departments, and agencies. This includes increased opportunities for interagency partnerships between mental health services and non-mental health services. Participants also want to see an increase in mental health education of people working outside the mental health sector, in particular for health professionals, such as emergency department staff and general practitioners.

"...organisations acknowledging that Mental Health is everyone's business"

– Survey participant, 2015

What changes do champions want to make themselves?

Champions want to work with services and government departments to improve the accessibility and delivery of mental health services, as well as other services. Some champions identified specific issues that they want to work with services and agencies to improve. These issues vary across champions. For example, one champion wants to improve the accessibility of mental health services for people with eating disorders in their community. Another champion wants to lead initiatives in mental health services to help people to look after their physical health. The issues champions want to address are informed by a number of factors, which may include their own experiences, their geographical location, and their perception of their community's needs.

What do people need to make these changes?

There needs to be a greater number and variety of opportunities for people with a lived experience of mental illness to collaborate with service providers, agencies, and policymakers. As discussed in the Strategic Plan, while there has been some progress to strengthen consumer engagement in services and agencies, this is underdeveloped and at times tokenistic.⁴ Feedback from participants highlight that consumers still lack opportunities to work with services and agencies whereby they can really influence and drive change in those services and agencies.

Many people want to collaborate with services and agencies to make changes but do not know how to go about it and who to put their ideas to. Making changes in services and agencies also often involves processes specific to the inner workings of each service and agency. These processes are difficult for outsiders to navigate.

“Difficulty identifying key people in services and government departments”

– Survey participant, 2015

“Unsure where to start especially with government departments... [need] chances to liaise with organisations about improving services”

– Survey participant, 2015

To work with services and agencies to make changes, champions need opportunities to build the skills and knowledge required to work with the change-making processes. Participants also reported a lack of support to deal with the various stresses and challenges that they may come across in working with services and agencies (e.g., the power structures and power imbalances within those settings).

Services and agencies need to change the way they operate to enable genuine collaborate with consumers. For example, they need to make sure champions understand their processes, and have the necessary resources to collaborate, such as remuneration for the person's time. They would also need to fully engage with champions' feedback and take concrete actions to implement changes.

Greater opportunities for consumers to work in various roles in services and agencies would help them gain the organisational knowledge and experience that is crucial to making positive changes. Advocates could also benefit from a mentor and/or a team of other champions that could relate to their advocacy experiences and provide advice.

⁴ *Living Well: A Strategic Plan for Mental Health in NSW*, p. 47.

What can the Commission do?

To foster supportive opportunities for champions to collaborate with service providers, agencies and policymakers, we recommend the following actions:

5. The Commission to facilitate opportunities for champions to connect with and build relationships with service providers, agencies and policymakers.
6. The Commission to encourage and guide organisers of existing networking opportunities for service providers, agencies and policymakers, to make the opportunities accessible for consumers to participate in a meaningful way.
7. The Commission to create paid and voluntary roles within the Commission that are specifically for people with a lived experience of mental illness.
 - Through these roles, consumers can develop their professional networks, and organisational knowledge and skills, which people cannot get from educational training alone.
8. The Commission to work with other organisations, including public, private and non-government organisations, to create similar work experience and employment opportunities.
9. The Commission to provide more opportunities for consumers to co-design the Commission's policies, projects and other initiatives.
 - The opportunities would need to provide appropriate training, systems and policies, resources and leadership for people to collaborate in genuine partnership with the Commission. The opportunities would need to ensure appropriate support for people. These could be secured in processes and organisational requirements, such as in the key performance indicators (KPIs) of the manager or the organisation.

5e. Strengthen consumers' influence over mental health and other services

What's the issue?

Champions want to strengthen the power of consumers to improve mental health and other services. To do this, participants want to see an increase in the reach of consumers who work at services. Participants want an increase in the number of consumer-identified roles across various levels of seniority, in different departments, and all kinds of organisations (e.g., non-government, private, government). One participant, who works at a service and not in a consumer-identified role, wants all services to be more encouraging of staff to disclose their lived experience. Champions also want to increase the number of consumer-led organisations and initiatives.

Some participants said that barriers to strengthening the consumers' influence include the prejudice of staff at services towards consumers, and the lack of understanding about the benefits of consumer-identified roles to services. A small number of participants said that these roles are not valued by services. A champion who works in a consumer-identified role at a service said that while peer support roles are being increasingly acknowledged, this has not been backed up by funding.

“There is an acknowledgement of the benefit of our participation. However, this is not matched with the commitment to financially support the growth of the peer workforce in the public sector”

– Survey participant, 2015

What changes do champions want to make themselves?

Some participants want to start up their own initiatives, including organisations and services. For example, one champion wants to start a bipolar peer support line run by people who have a lived experience of bipolar. Champions want to start up their own initiatives for similar reasons that most people start up not-for-profit organisations or social enterprises, such as to meet a need that is not being met adequately or at all. For example, a champion would like to start up a day-to-day living program because there is not one available in their community, and they think there is a need for one.

What do people need to make these changes?

People with a lived experience of mental illness need more opportunities with appropriate support to start up initiatives of various sizes. Some champions have already had experience in starting some smaller consumer-led initiatives, such as one-off projects or peer-support groups. They need support to start up larger scale initiatives, such as not-for-profit services, social enterprises and wide-reaching promotional campaigns. At the same time, there also need to be opportunities and support for people who want to start smaller-scale initiatives.

Participants said they need help with the logistics of starting up an initiative. People want to be able to get funding for their initiative, which could involve finding grants, connecting with philanthropists, and writing up proposals. To start their own initiative, people need professional advice (e.g., a participant wanting to start up a peer-support line for people with experience of bipolar disorder wanted to know what kind of insurance they would need to get, if any). People also need support to help them deliver the initiative (e.g., if it is a peer support service, they would need support to develop the right skills to deliver the service).

“Business support for consumers wishing to start organisations”

–Survey participant, 2015

In addition to operational support, people need support to deal with the demands that starting up an initiative would place on them as an individual. Starting up an initiative is often time-consuming, and many of the participants have to juggle other commitments in their lives, such as having a full-time job or carer responsibilities. Starting up and running an initiative can also be stressful, and add to the work people put into managing their health, including their mental and physical health.

“I am prepared to work in an agency to help people with psycho-social disabilities in a day to day living program in [Western Sydney location] where there is not one, but, I think they are expecting a lot from consumers who have their own challenges”

–Survey participant, 2015

The supports people would need are similar to the supports required for starting up businesses and enterprises. There are existing examples of efforts to boost entrepreneurship opportunities for consumers and other people. It would be useful to consider these examples when developing opportunities and supports for consumers to create and run their own initiatives. One example of support for entrepreneurs is Rise Asset Development, a charity in Canada. Rise Asset Development provides low

interest small business loans, training and mentorship to support people with a lived experience of mental health and addiction challenges who are interested in pursuing self-employment.⁵ The charity was created jointly in 2009 by a tertiary school for business management and a mental health and addiction teaching hospital. The hospital provides support for participants' health needs. The business school links people to training and mentoring opportunities. Rise Asset Development offers different programs to tailor more to people's needs. For example, its Group Lending Program suits people who would feel more comfortable starting an initiative as a group. The program forms groups of 3-6 entrepreneurs and provides them with a small business training program. It connects them with mentors and industry experts in the community. The program also encourages members of the group to motivate, support and learn from each other.

Champions in NSW would benefit from supports similar to those that Rise Asset Development provides. The supports would have to be adapted to the types of initiatives the champions want to start – for example, by connecting people who want to start community or non-profit initiatives to funders, philanthropists and grants, instead of providing small business loans.

What can the Commission do?

To enhance the ability of consumers to innovate and run initiatives that relate to mental health reform, we recommend the following actions:

10. The Commission to develop opportunities for people with a lived experience of mental illness to start and run their own initiatives relating to mental health reform.
 - The Commission would need to ensure people can get the support they need, including training, help with securing funding, and support for dealing with the stresses on the individual.
11. The Commission to consider existing strategies used to cultivate entrepreneurship and adapt the strategies to foster consumer-led initiatives for mental health reform.
12. The Commission to consider offering seeding grants for people (individual consumers, groups of consumers, consumers in partnership with organisations) to start consumer-led initiatives relating to mental health reform.

⁵ Rise Asset Development Website (accessed on 20 July 2015): www.riseassetdevelopment.com/about-us/

6. Summary of recommendations

1. The Commission to create a range of opportunities for people with a lived experience to lead and participate in mental health promotion campaigns.
 - The opportunities should:
 - Be flexible and allow people time to contribute effectively;
 - Ensure people can contribute even if they do not want to publicly disclose their lived experience of mental illness; and
 - Include various roles people can be involved in.
2. The Commission to consider funding consumer-led mental health promotion projects.
3. The Commission to advocate for organisations to have consumers lead the organisation's mental health promotion campaigns.
4. The Commission to fund an initiative to establish a formal and coordinated network of consumer champions.
 - This would create a support system and an important source of resources for consumer champions. Consumer champions can contact other champions for support when they face challenges in their advocacy, or want to collaborate on actions for positive change.
5. The Commission to facilitate opportunities for champions to connect with and build relationships with service providers, agencies and policymakers.
6. The Commission to encourage and guide organisers of existing networking opportunities for service providers, agencies and policymakers, to make the opportunities accessible for consumers to participate in a meaningful way.
7. The Commission to create paid and voluntary roles within the Commission that are specifically for people with a lived experience of mental illness.
 - Through these roles, consumers can develop their professional networks, and organisational knowledge and skills, which people cannot get from educational training alone.

8. The Commission to work with other organisations, including public, private and non-government organisations, to create similar work experience and employment opportunities.
9. The Commission to provide more opportunities for consumers to co-design the Commission's policies, projects and other initiatives.
 - The opportunities would need to provide appropriate training, systems and policies, resources and leadership for people to collaborate in genuine partnership with the Commission. The opportunities would need to ensure appropriate support for people. These could be secured in processes and organisational requirements, such as in the key performance indicators (KPIs) of the manager or the organisation.
10. The Commission to develop opportunities for people with a lived experience of mental illness to start and run their own initiatives relating to mental health reform.
 - The Commission would need to ensure people can get the support they need, including training, help with securing funding, and support for dealing with the stresses on the individual.
11. The Commission to consider existing strategies used to cultivate entrepreneurship and adapt the strategies to foster consumer-led initiatives for mental health reform.
12. The Commission to consider offering seeding grants for people (individual consumers, groups of consumers, consumers in partnership with organisations) to start consumer-led initiatives relating to mental health reform.

7. Conclusion and next steps

The feedback we collected through this project highlights that many consumers are interested in being more actively involved in mental health reform. Many of the participants already are active in bringing about positive change in their communities. They would like to be even more active, but face barriers and lack opportunities to do so. Right now, the power to make changes relating to mental health reform is still mainly in the hand of agencies, service providers, policymakers and Government.

Drawing on the full potential of consumers who identify as champions would result in more effective mental health reform. To do this, service providers, agencies and Government need to provide more opportunities for genuine collaboration with champions, including opportunities for consumer leadership. These opportunities need to facilitate consumers to get the skills, knowledge, partnerships and resources necessary to make the positive changes they want. In this report we have made recommendations whereby the Commission can lead services and other agencies by example. We hope this project helps to pave the way for greater consumer involvement and leadership in mental health reform.

Appendix

Champions for Change Survey Questions

1. To improve the mental health and wellbeing of your communities, what are the top three things you would like to do to improve services and government departments?
2. Are there any barriers to you doing these things? If yes, please describe the top three barriers.
3. What are the top three things that might help you overcome the barriers you identified in Question 2?
4. Do you have any experience in making change in your communities?
 - No, I don't have any experience.
 - Yes - Please briefly tell us what you did and what the results were.
5. Are you aware of the NSW Strategic Plan for Mental Health?
(This is formally known as 'Living Well: A strategic Plan for Mental Health in NSW 2014 – 2024')
 - Yes
 - No

Please fill out your details below if you are happy for BEING to contact you further about your ideas. We won't share your identity with anyone outside of BEING without your permission.

Name:

Phone/mobile number:

Email:

Please tell us a little bit more about you. These questions are optional and help us better understand your views.

1. Are you a: (Please select as many as apply)
 - Consumer (*person with a lived experience of mental illness*)
 - Consumer/peer worker (*consumer working in a designated role to support other consumers in a service*)
 - Carer/family member of a consumer (*your feedback may be shared with ARAFMI which advocates for carers, family members and friends of consumers*).

2. Are you:
 Female
 Male
 Other, please specify: _____
3. How old are you?
- | | | |
|----------|---------|---------|
| Under 18 | 36 – 45 | 66 – 75 |
| 18 – 25 | 46 – 55 | Over 75 |
| 26 – 35 | 56 – 65 | |
4. What is your postcode? _____
5. In which country were you born? _____
6. Do you identify as Aboriginal or Torres Strait Islander?
 Yes, Aboriginal
 Yes, Torres Strait Islander
 Yes, both Aboriginal and Torres Strait Islander
 Neither
7. Do you identify as being from a culturally and linguistically diverse background?
 Yes, please specify: _____
 No
8. What language(s) do you speak at home? _____
9. What types of mental health services have you used? (Please select as many as apply)
- Mental health in-patient unit in a public hospital
 - Public community mental health service
 - Private mental health service in a hospital
 - Individual private therapy
 - Forensic mental health unit
 - Other, please specify: _____
10. How did you find out about this survey?
- BEING email
 - BEING website
 - Social media
 - Friend/Family
 - Workers at a public mental health service told me about it
 - A non-government organisation told me about it
 - Other: _____