



# **VOICES FOR CHANGE**

## **2014**

# **VOICES FOR CHANGE**

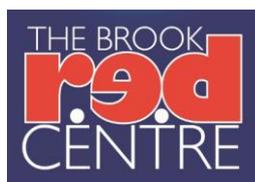
## **2014**

**TALKING TO MENTAL HEALTH CONSUMERS ABOUT  
HOW THEIR VOICES CAN BE HEARD**

**Thank you to the North Brisbane PIR Innovation Fund for supporting us to bring people with  
a lived experience together to share their voices & knowledge.**

**and**

**Thank you to all of the amazing people who shared their voices, time, energy, and passion  
with us for this project.**



## SUMMARY

In mid-2014 Brook RED, a peer operated mental health service, met with a total of 131 individuals with a lived experience of mental illness (consumers) from the North Brisbane region as part of its Voices for Change consumer consultation project funded by the North Brisbane Partners in Recovery Innovation Fund. This was achieved by holding a two day forum (97 attendees) and four focus groups (34 attendees). The consultation focussed on identifying how consumers can be better engaged to inform the mental health system and the project was designed and overseen by a six member steering committee of consumers from varied backgrounds.

At both the forum and focus groups, consumers were very enthusiastic to share their views and expressed a strong desire to be a part of improving our mental health systems. Discussions were focussed on gaining a clear picture of what consumers want and need when it comes to having their voices heard and two main themes emerged from the consultation:

- It can be challenging to get an opportunity to use one's voice; and
- Consumers want to skill themselves up so that when they do get the opportunity to use their voices they can ensure they do so as powerfully and influentially as possible.

This report provides an overview project, specific feedback from consumers on when they do and don't feel heard and what they would like to see more of, and a set of five recommendations for strengthening consumer voices.

This project has demonstrated the sincere desire that consumers have to be a part of the solution when it comes to systems change in the mental health system and has identified a clear pathway forward for consumer engagement on North Brisbane. Brook RED was honoured and felt very humbled to join with the passionate and insightful group of consumers who made this project possible.

## PROJECT BACKGROUND

The Partners in Recovery program has the objective of improving system responses and outcomes for people who experience mental illness and the North Brisbane Partners in Recovery Innovation Fund 2013/2014 identified the consumer voice and collaboration as action areas for projects. Brook RED is a peer operated mental health service and this positions the organisation to uniquely understand the perspectives of consumers and of service providers when it comes to consumer engagement.

Both consumers and service providers are highly motivated and committed to working together to create better processes and outcomes in the mental health system, but sometimes it can seem challenging to move forward into collaboration. The Voices for Change project was designed to help strengthen the bridge between wanting to work together and actually doing so; a bit of a road map approach.

The project was positive in its intent and was designed to look at what is currently working and how these strengths can be built on. There are already a number of excellent examples of consumer engagement happening in North Brisbane and the project wanted to bring the stories of these successes into one room so that themes could be found, ideas shared, and some best practice tips for engaging consumers could be collected from the consumers who know best what works. Following consultations with consumers, it was intended that the findings would be shared with the North Brisbane PIR partnership and mental health services in North Brisbane (and other regions) so that they may support better and more consumer engagement in future.

## APPROACH AND PROCESS

North Brisbane was, to some extent, new terrain for Brook RED (which primarily operates in South Brisbane) when we undertook this project and our first step was to connect with a group of peers in North Brisbane and work with them to guide the project. A collaborative six member consumer steering committee was established – Hongi Pugh, Consumer Representative from Communify; Viktoria Sollmer, Consumer Representative from Neami; Fran Dagostino, Peer Support Worker at Footprints; Shane Martin, Principle Policy Officer at Queensland Mental Health Commission; Erin O'Shea, PIR Peer Liaison Officer at Brook RED; and, Tyneal Hodges, Peer Development and Training Coordinator at Brook RED – and met regularly to shape the project. Additional assistance in navigating in the area was provided by Metro North Brisbane Medicare Local and by the Metro North PIR Consortium Partners.

Promotion of the project was probably the single most important component of the project because getting consumers to attend was critical to hearing their perspectives and tapping into their expertise. Metro North Brisbane Medicare Local and PIR Consortium Partners, Queensland Voice, and consumer champions and peer workers supported us to promote the event and connected us with their consumer networks. The project's two-day forum was attended by 97 people (the majority of whom were consumers) and 34 consumers attended follow-up focus groups.

The forum was held on 28 and 29 May in New Farm and was a mixture of presentations, a panel, and workshops. A list of presenters and panel members can be found at the back of this report.

Workshops to collect consumer perspectives were framed around seven questions:

- What skills, knowledge, and experiences do you need in order to have your voice heard?
- Who do you want to hear your voice?
- When have you felt heard?
- When have you NOT felt heard?
- What would have helped you to feel heard?
- What are we doing that gets in the way of our being heard?
- If you had the power to change one thing in the system, what would it be?

A photobooth, voice wall, collective journal, evaluation form, and one-on-one and small group conversations were also used to collect information.

In July, four focus groups were held with consumers who had not attended the forum. The focus groups were organised and hosted by Open Minds, Richmond PRA, Footprints, and Communitify and provided additional perspectives, allowed the sharing of forum findings, and also allowed us to gain a sense of how generalisable the findings of the forum were to a broader population of consumers. The focus groups felt strongly that the information gathered at the forum was consistent with their perspectives and experiences.

Organisation and collation of collected data for this report was performed by Brook RED in consultation and review with the project steering committee. The themes that emerged from the workshops and focus groups are reported in this document under the section titled What People Said and we have made a list of five recommendations (under the section titled Recommendations) that we believe will support the hearing and strengthening of consumer voices.

Feedback from the forum was positive with forum attendees reporting an average score of 4.8 out of 5 (5 = strongly agree) when asked if they would attend a similar forum again and an average score of 4.3 out of 5 when asked if they felt the forum topics were relevant and important to them. The comments below describe what the project has meant to some of those involved:

Thank you so much for the invitation, hospitality, respect, equality given to all and the wonderful goodie bag and help with transport.

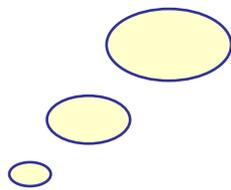
Thanks heaps for a great forum. Great validation & information. I really appreciate how much thought and effort went into organising this event. Love to see another one held again soon!

Good fun and feeling the power of speaking up and being heard. YAY!

I thought it all was profitable to connect with so many groups and individual people, who could relate with mental health issues, where the rubber meets the road.

I found it enjoyable relaxing, supporting, informative & satisfying. Just a little of the content & context was absolutely new to me... much to be learnt and put into place from Day 1 of this conference. Well worth it. I did the right thing to attend this.

I would love to see this happening annually so seeds planted can grow and the ball can keep rolling. I would also love a safe group to learn skills for storytelling and listening and using our voices. Thankyou to Shane, your contributions were very valuable to me.



This was so helpful – networking was important for me today.

## LEARNINGS

Brook RED has learned a great deal about hearing consumer voices from undertaking this project. Aside from the knowledge gleaned about consumer perspectives, we also learned a few things about undertaking a project such as this. Specifically, event promotion, forum structure, and maintaining momentum are areas that we now have a better understanding of.

**Event promotion** – We received wonderful support in connecting with North Brisbane consumers, but did find it challenging to communicate with consumers in the region. With no clear hub for communicating with consumers in North Brisbane, we would allow more lead time for the word to spread in future: we found that communications about the project had an organic quality to it and that it did travel but took more time than anticipated to do so. That said, this project has allowed us to develop a mailing list of North-side consumers and connections with North-side peer champions that would facilitate future communication.

**Forum structure** – Overall, feedback from the forum was positive but improvements could have been made to the structure of the forum. A number of consumers indicated that we had too many presentations on day one and too many workshops in day two; they would have liked a more mixed and integrated approach. Consumers would also have enjoyed more time to connect with each other in a less structured format because they rarely have this opportunity.

**Maintaining momentum** – There has been a lot of interest in keeping the connections made and conversations started in the project going. The importance of connecting with other organisations to ensure momentum isn't lost has been invaluable. Open Minds, Richmond PRA, Footprints, and Communify have agreed to be "Peer Champions" and use the questions from our forum as a tool to engage with their consumers groups. They have also used some of the themes collated from the workshop to explore solutions and opportunities for their own peer groups to self-determine new approaches and ideas in capacity building at a grass roots level. The comments below provide a sense of how important it is to keep the process active:

Feedback from those in attendance was very positive. Having someone follow up on the forum and have an open discussion really reinforces the sense of being heard. The detailed findings you shared prompted some great discussions and I think gave us all encouragement moving forward, knowing that there are a number of things we can do to bring about change.

- Daniel Baddiley, Communify

I just wanted to take this opportunity to thank you and let you know that the people I have spoken with were impressed with the discussions and actually like the idea of this happening more often as a joining and sharing opportunity.

- Toni Rielly, Richmond PR

# WHAT PEOPLE SAID

ABOUT BEING HEARD AND USING  
THEIR VOICES FOR CHANGE



## Q. What skills, knowledge, and experiences do you need in order to have your voice heard?

- **Communication skills** – general stuff like choosing the right words; being able to know when to speak up; knowing how a meeting is run; knowing the jargon or being able to ask when we don't
- **Managing emotions** – learning how not to take things too personally; keeping cool when we hear upsetting, frustrating, frightening things; being able to show feelings in appropriate ways that will make people listen and not shut down; being able to feel like if things went poorly it doesn't mean we are inadequate
- **Education & training resources** – knowing about the system, getting the training that workers get so we're on the same page; experience so that we can get better at using our voices
- **Advocacy skills** – knowing how to put your case forward; knowing how to "get in the door"; negotiation skills; knowing our rights clearly
- **Resources & support** – access to information; mentoring/debriefing so that we can practice using our voices and get feedback and support when we do



## Q. Who do you want to hear your voice?

- **The whole mental health system** – policy makers; NGOs; workers; hospitals; doctors; psychologists and psychiatrists; police and courts; housing providers and all the other services; anyone and everyone who makes choices about people with mental illness
- **Government** – every level and everyone involved in it because we are everywhere we are people so every aspect of government should be listening to us
- **Peers** – other people living with mental illness so we can support each other
- **Media** – newspapers; reporters; the people who are shaping the public image of who we are and are often getting it really wrong
- **Family and friends** – our loved ones; carers; our parents; children; brothers; sisters; partners; our friend including the ones we have lost because of stigma
- **The education system** – from primary through high school; TAFEs and universities
- **Local communities and the general public** – pretty much everyone because everyone is involved in mental illness
- **People who judge** – people who don't understand and judge from a place of ignorance, intolerance, and misunderstanding



## Q. When have you felt heard?

- **When people listen with empathy** – when they show that they "get it" or have been there, too or just try to understand from our perspective; when they just sit with us instead of trying to solve or fix us
- **When I have support** – it really helps when you can have someone with you who you trust; sometimes it helps to have an advocate or witness with you as people sometimes act differently to you then and you get better outcomes
- **When there is reflection about what we've said** – you can tell people are genuinely listening when they ask questions and work to understand the message you are giving
- **When I am validated and listened to** – acknowledgment can go a really long way; when people listen like we are telling the truth; just taking us seriously... these are our lives
- **When the person listening is non-judgemental**
- **When there is a sense of equality** – when it feels like we are working together as a team
- **When people show they have heard us by taking action and following through** – actions speak loudly; you can tell people are listening when things change



## Q. When have you NOT felt heard?

- **When the system gets in the way** – when the needs of the system are more important than our needs; when people are too busy saying what they offer to listen to what it is that we actually want
- **When there is a lack of understanding** – when people just aren't listening or just can't be bothered to understand or even try to; when people think they know the answer before we even give it; when there is judgement
- **When there is a lack of action** – even though people say they have heard us it shows if they don't take any action; actions speak louder than words; feeling heard makes you feel like someone actually cares; if you care, you follow through on your promises
- **When there are power issues** – when there is a power imbalance; when we are forced to do things; when we will be punished if we don't do the things the way someone else wants us to; when people think they are the experts in our lives; when people think they know more about our mental health than we do
- **When there isn't a connection** – when there hasn't been time to build a relationship; when it just isn't a good fit; when there is no empathy



## Q. What would have helped you to feel heard?

- **Resources and education** – people listen better when we know what we're talking about so information is important; knowing what they know would even things
- **Equality** – it would make a difference if we know that we had an equal say or that our perspective was valued; it would be great if we were working together because sometimes it feels like we are pulling in different directions
- **A good relationship and connection**
- **Understanding and validation** – sometimes it is okay to let us know that things really are difficult, painful, or overwhelming; a bit of understanding and acknowledgment really helps; validation won't make us worse it will just let us know you're listening
- **Respect** – being treated like a valuable person; being spoken to like an intelligent adult; telling us why you think certain things; being honest with us when you see things differently than us; asking for our input; being asked for our perspective
- **Confidence and skills** – sometimes it is difficult to be brave and say what we need and want to say; sometimes we don't know the right words or how to say them; for so many reasons we sometimes just let misunderstandings go and don't make sure we are heard



## Q. What are we doing that gets in the way of our being heard?

- **Lack of communication skills** – the right words, the right people to say them to; being able to disagree without it being seen as argumentative or aggressive
- **Lack of speaking skills** – knowing how to make a point; negotiation skills; not getting caught in the points that aren't so important; focusing on the big win, not the little one; how to tell our stories our own way
- **Lack of self confidence and self-esteem** – sometimes we just shut down; sometimes we think that other people actually are the expert because we've lost faith in our own judgment; if you haven't been able to make your own decisions or have your own opinions in while it can be very confronting to start again
- **Managing emotions** – it is easy to become angry, disappointed, offended, or frightened and then logic kind of leaves and is replaced with emotions and we don't get our message across
- **Lack of systems knowledge** – sometimes we don't understand the whole system; sometimes we are talking about the right things to the wrong people or the other way around; it is difficult to know why things are the way they are and why it is so complex



**Q. If you had the power to change one thing in the system, what would it be?**

- **Training and education** for people who work in mental health
- **Education** about mental health for consumers
- Make things **less clinical**
- Policy and government would **listen more** to the people who mental health impacts
- **Peer support** would be more available and we would have a choice to pick a peer to work with if we wanted
- The framework and values of the system would be more about **recovery** and about us as people
- There would be more opportunities to **get help in the community** so that we wouldn't have to wind up in hospital or lose our children, connections, jobs, or families
- Access to more **alternative therapies** not just medication
- **No waiting lists or eligibility criteria** that makes you get worse before you can get help
- More **hope** and belief that we really can recover



## RECOMMENDATIONS

### 1

#### **Hold regular consumer forums to find out what we think is and isn't working.**

Consumers identified that currently there is no real collective consultation occurring with them. Consultation is happening in pockets, but consumers would like it to happen more frequently and on a larger scale. Consumers reported that it is extremely valuable for them to be able to network so that they can learn from one another and also provide a more representative perspective when they are engaged. Consumers were very positive about the forum format and would value a mix of informative presentations and skills development activities at future forums.

### 2

#### **Support us to build skills so that we can contribute to the best of our ability.**

Consumers expressed a strong desire to be included and informative in the design of the mental health system and were clear that they take such a role seriously and want to contribute to their full potential. Consumers identified up-skilling and training in areas that would help them to engage as a need that isn't being met currently and in particular they identified a desire for training in the following areas:

- Developing consumer leaders
- Communication skills
- Understanding and navigating the broader mental health system and context
- Understanding how to work with multiple stakeholder interests and priorities
- How to use your story to effect positive change
- Managing the emotions that come with sharing your story and advocating for change

Consumers further expressed that this training should be delivered by others living with mental illness where possible as this would be inspiring and also serve to help make the training most appropriate to the consumer audience.

### 3

#### **Create a collaborative of those who want and need to hear consumer voices.**

Consumers expressed a desire to be part of changing the system as a whole and were keen to find a forum that will allow them to communicate their messages to many at once. Consumers felt that while there will always be a place for engaging with single workers, agencies, or policy-makers, there may also be efficiencies to gain by having everyone listening at the same time. Because the system is multi-faceted and complex, consumers feel that it is difficult to make any major change when you are being heard by only one component of it at a time.

### 4

#### **Help to develop a network of peer leaders.**

Consumers would like to see each agency/organisation/program have its own peer leader/champion/representative that collects information from other consumers and then meets on a regular basis with a network of other peers so that their information can be shared and that emerging themes can be explored.

### 5

#### **Create a one-stop information exchange for consumer engagement.**

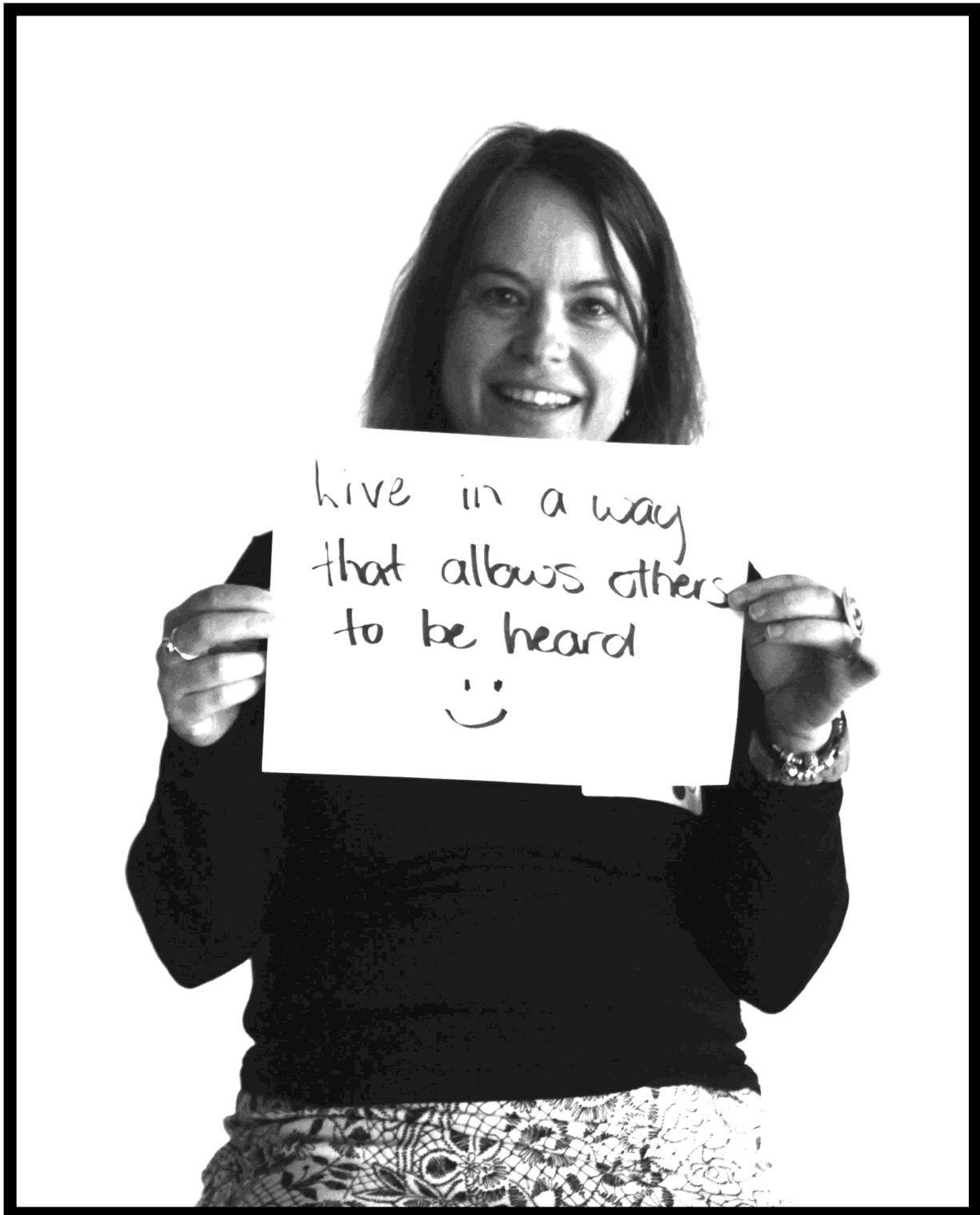
Consumers identified that they find getting information about engagement opportunities extremely difficult and the system increasingly confusing to navigate. Overall, consumer actually felt that opportunities to have their say exist but that it is just really difficult to find those opportunities and often involves more serendipity than anything else.

Consumers feel that the Queensland Voice is a good resource, but doesn't quite aggregate all of the opportunities to have your say. Consumers would like to be supported in developing a sort of one-stop information exchange so that they miss fewer opportunities and can spend time engaging instead of sifting through information sources.

## Forum Presenters and Panel Members

Thank you to the generous and inspiring individuals who gave presentations and took part in our panel:

Sharon Vaughn	Psychologist and Consultant
Shane Martin	Principle Policy Officer at Queensland Mental Health Commission
Helena Roenfeldt	Consultant and Teacher
Teresa Fawcett	Consumer Representative at Greater Metro Brisbane South PIR
Melody Edwardson	Director, Sector Development at The Queensland Alliance for Mental Health
Flick Grey	Mental Health consumer Researcher, Consultant, and Trainer
Noel Muller	President at The Queensland Voice
Mark Pearson	Peer Support Worker at Communify
Jenny Speed	Consumer Activist
Larry Stapleton	Regional Manager at Richmond Fellowship Queensland
Erin O'Shea	PIR Liaison officer at Brook RED



# **VOICES FOR CHANGE**

## **2014**