

National Mental Health Consumer Organisation Establishment Project

Consumer Reference Group Monthly Update

September 2013

Fay Jackson, CRG Member



Hello and welcome to our very first monthly update.

Monthly updates are in response to feedback from a few of you, our brothers and sisters, who told us that you were feeling out of the loop with what was going on to establish our new mental health consumer peak body. We are sorry that some of you felt that way, and know that we hear you!

Monthly updates will now be written by one of the Consumer Reference Group. The purpose will be to make sure we keep you updated and informed on all the work and activity going on to establish the new organisation.

The main reason we have not had a lot to tell you is because most of what we have been doing, such as building the constitution, has been really important but for many people not very interesting or exciting (well it sure wasn't for me, but it is definitely important). For example, one of the major things we have been trying to work out is how the new organisation will be registered for taxation and funding purposes. We decided that the most sustainable option is that the new organisation will be a Health Promotion Charity. This option will ensure that we have the best opportunities of acquiring funding through a number of avenues, including taxable donations and government funding.

What we urgently need now is for you to spread the word to all our brothers and sisters across the country. Tell them to sign up and get involved, so together we can show the new federal government that we have a united voice and the new mental health consumer peak body is needed.

We have good representation on the Consumer Reference Group, including Aboriginal peoples, LGBTI representation and people whose first language is not English. However, we need to be more inclusive, and to do so we need to better understanding how we can get our messages to a multitude of people from diverse places and back grounds, including remote and hidden cultures.

Most importantly we need your help to pass on our messages and involve people who do not have access to a computer. Your ideas on what we can do better to engage this group of people would be most welcome.

Thank you in anticipation of your involvement, and please be assured that we are listening to you.

Sincerely

Fay

Additional Information

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Don't forget to encourage your networks to sign up on the [Register your Interest](#) page, to receive all the last information on the Establishment Project.

Upcoming events:

Representatives from the Project Team and CRG will be in attendance at the Canberra Mental Health and Wellbeing Expo. For more information on the expo, [click here](#).

The Mental Health and Wellbeing Expo

When: Tuesday 8th October

Time: 10.00am – 1.00pm,

Where: University Drive South, Building 24 NATSEM Building, University of Canberra, ACT 2601, Australia. Entry to the venue via University Drive South, turn off from Haydon Drive. Campus map <http://www.ucevents.com.au/campus-map/>

Watch this space!

The new website will be live by October 2013. Keep an eye out for a beautiful, user friendly online experience!

Mental Health Week, 6th – 12th October 2013:

The CRG and MHCA Project Team will be involved in various Mental Health Week activities in their local communities. Find out what's happening in your area at <http://1010.org.au/events> , or register your local event on the national database.

MHCA and CRG Face to Face Meeting

The next CRG and MHCA face to face meeting will be held on 7&8 November 2013.

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October 2013

Keith Mahar, CRG Member



I put my hand up to be considered for the Consumer Reference Group because progress is required in relation to mental health. Individuals with mental health issues continue to be unjustly treated, denied access to appropriate support, and end up marginalised and excluded from their rightful place in the community. It is unacceptable to me that in the 21st century people with mental health issues and their loved ones continue to pay such a high price due to stigma, prejudice and discrimination in society; including family breakdowns, unemployment, social isolation, feelings of hopelessness, and suicide.

As recently reported on the 7.30 A.C.T (ABC program), while a political activist in Canada I was diagnosed with bipolar disorder ([link](#)). As a result of my experience in activism, I came to the conclusion that being right is not enough to accomplish social change: power is key. It is my belief that collective action is the only way to effectively accelerate the positive social changes that are needed respecting mental health in Australia.

As Fay mentioned last month, most of the work by the Consumer Reference Group has focused on developing the constitution for the new organisation.

This month the [Mental Health Council Australia](#) Board endorsed important governance related recommendations proposed by the CRG, these are:

- a hybrid membership model, meaning that both individuals (people with lived experience of mental illness) and mental health focused organisations can be members
- a nine member Board: three elected by individual voting members, three elected by organisation voting members, and three appointed by the Board
- a majority of the Board will have lived experience of mental health issues
- a Chairperson with a lived experience of mental health issues and/or who identifies as a mental health consumer.

We are keen to provide opportunities for you to give us feedback on the draft constitution, so keep your eye on the Project website www.mhconsumer.org.au later in November and early December 2013.

It is my hope that the future national consumer mental health organisation will be a catalyst for better outcomes for people with mental health issues by collaborating with existing stakeholders, adopting a community development approach that attracts wide participation, and harnessing the skills, knowledge and passion of people with lived experience, and their families and friends, to work together and achieve changes in the mental health system and Australian society.

In my view issues such as stigmatising language and portrayals of mental illness in the media are important areas where nationally coordinated campaigns by the new national mental health consumer organisation have the best likelihood of being successful and leading to positive change.

I established an online social network a while back for people who are interested in issues related to mental health (it works like Facebook with a billion less users). If you want to talk to me about the Establishment Project online, kindly go to www.mentanet.org to register and participate.

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Upcoming events:

The Consumer Reference Group and Mental Health Council Australia will be holding their next face to face meeting in Adelaide on 7-8 November 2013. They will be tackling big issues around governance, engagement and communication. Local Adelaide based Mental Health NGOs have been invited to a meet and greet with the CRG on 7 November 2013, to learn more about the Project to establish the new mental health consumer peak.

National Mental Health Consumer Organisation Establishment Project

Consumer Reference Group Monthly Update

November 2013

Qin Yi Lily Wu, CRG Member



My name is Qin Yi Lily Wu. I migrated from China to Australia 23 years ago. I have lived with mental health condition since I was 18 years old, with the support of my family, friends, psychiatrists, my managers, my mentors and support networks as well as the benefits of the medications. I have achieved living in a meaningful, productive and satisfied recovery life style in our multicultural society.

I have worked in number of government and non-government mental health services as a Consumer Worker and Peer Support Worker for the past 10 years. I support consumers, especially Culturally and Linguistically Diverse (CALD) consumers, in their recovery journey in the inpatient units as well as community settings. The work has been really rewarding and can sometimes be very challenging. The rewarding part is to see so many consumers staying well in their recovery journey in our multicultural community after the short intervention of hospital stay. The challenging aspects are some consumers, especially CALD, are isolated from the community and slow in their recovery from trauma and distress experiences of migration to, and settlement in, Australia.

The ultimate aims for me to be involved with the Consumer Reference Group (CRG) are to raise a louder grassroots consumer voice, especially CALD consumer voices, at the National level. This is most important in the process of establishing the national mental health consumer organisation.

I have learnt so much as a CRG member. The constitution, legal entity and the Board and membership structures for the new mental health consumer organisation are very new knowledge to me. Sometimes they are very challenging and hard to understand properly. Thanks to the CRG, the Project Team and governance consultant who have all helped me to understand the complex knowledge and information. As a result, I am able to fully participate and contribute to the project.

It is so important that the new organisation will focus on human rights and social justice approaches to mental health consumer issues and interests through system advocacy, from grass roots to national policy. The new organisation will advocate and promote improvements in the care of consumers, especially CALD consumers, and foster consumer and CALD consumer leadership in the mental health sector.

The CRG met on the 7-8 November 2013. The outcomes of the meeting will be included in the next Communique. We will be consulting on the constitution in the coming weeks and these details will be included.

A competition to name the new organisation will be announced in early 2014, so please take some time to get your ideas together.

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Upcoming events:

Constitution Consultation: The draft constitution for the future organisation will be released for comment very soon. Further information will be provided in the communique next week.

If you have any questions or comments please email us at enquiry@mhconsumer.org.

National Mental Health Consumer Organisation Establishment Project

Consumer Reference Group Monthly Update

December 2013

Michelle Banfield, CRG Member



In the busy run down to the end of the year, I have had plenty of opportunities to discuss the importance of the new national consumer organisation and reflect on why I wanted to be a part of the process. I have been a mental health consumer for about 25 years and am at a point in my recovery journey where I realise that bipolar disorder has shaped who I am but by no means defines me. As Keith said in his update in October, stigma and discrimination are still big problems for mental health consumers and I believe a united voice for social change is the way to combat these problems. In my work as a consumer researcher in two university departments focusing on health services and mental health, I am privileged to work with consumers who generously share their experiences and knowledge to help make research more relevant. Lending my own experiences and thinking to shape a strong national voice for consumers is one small way of giving back.

It has been a very busy year for everyone involved in the National Mental Health Consumer Organisation Establishment Project. Thanks to the enthusiasm and patience of the governance consultant, I think everyone on the project team and CRG is now very well versed in good governance! We have wrestled with tricky questions that sometimes turned out to have simple answers, particularly in our commitment to ensuring the new organisation has strong consumer leadership. We have worked hard to find ways of connecting with the broader mental health community as we shape the organisation. We are excited that the draft constitution is now out for consultation. If you haven't already had your say, head over to <http://mhconsumer.org.au/constitution-consultation>. Don't worry if reading an entire constitution is not your thing. We are happy to hear your comments on any part.

There are some big steps for the new organisation coming up early in the new year. The constitution, redrafted to include feedback, will go to the MHCA Board for consideration in February. We will be looking for nominations for members of the first board. However, for me, the most exciting thing is that we will be launching a naming competition. The name of an organisation is such a key part of its identity and can convey a really strong message. I know there are some snappy and inspiring ideas out there waiting to be aired.

On behalf of the CRG and the project team, I would like to wish everyone a safe and happy holiday season. This time of year can be hard for those of us missing loved ones or feeling isolated but I hope that everyone can find some peace and hope as we see in another year.

Best wishes

Michelle

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We hope that your festive season is one bright and full of joy, and look forward to continuing our work in 2014.



National Mental Health Consumer Organisation Establishment Project

Consumer Reference Group Monthly Update

January 2014

Lorraine Powell, CRG Member



A very warm welcome to a new year that is shining with promise and opportunities!

It is a very exciting year for us on the Consumer Reference Group as we are beginning to see the fruits of our labours pay off. 2014 is the year for the new organisation to be launched!

Did you give your feedback to us on the draft constitution? We launched this consultation across Australia, finishing on 17 January 2014, and have received some great feedback, so *thank you* for taking your time to contribute. It is only by hearing from you we can produce an organisation that sincerely reflects the desires, hopes and dreams of so many of you who have waited so long in anticipation of the new organisation.

Since our last update provided by Michelle, the members of the Consumer Reference Group have been very busy undertaking targeted individual consultations also on the constitution. This means that a possible total of 33 people have been directly consulted by us, along with your feedback through the website.

As we commence back after a bit of a break, we are anticipating a huge amount of work during the first quarter of this year. We will finalise the constitution, register the organisation, apply for charitable status, and, most importantly, advertise and appoint the inaugural board and the CEO, phew, it's all systems go.

The process of appointing the board is believed to be vital to the success and integrity of the new organisation. The CRG has recommended a panel be appointed who will consist of a member of the CRG (and it will be a member who is not intending to apply for a role on the board), a representative from the Mental Health Council of Australia, and a person from the Department of Health (the funding body). We have commenced recruitment of these roles also.

All members of the CRG have been required to advise if they have an intention of applying for a board role, this creates something called a conflict of interest, and means these members cannot be part of any discussions regarding the board composition. Our learning in governance delivered by the consultant has ensured we, the CRG, do our utmost to reflect quality governance protocols, and this is one of those times.

Is being a member of the board something you may be interested in? You will have seen in the draft constitution the necessity for board members to have a lived experience, along with other skills. From my perspective, having been a board member with many organisations, it is a very rewarding, humbling and valuable experience, and one I highly recommend. Please

keep your eyes out for the advertising of the board nominations and have a go. We want to embrace diversity and uniqueness of individuals, along with a strong group we can have confidence in, to launch your new organisation.

On a personal note: I have a genuine belief in the resilience and capacity of individuals who live with mental illness. My own lived experience, and using that as a consumer consultant, has enabled me to witness the remarkable tenacity and honesty of people, and it is a humbling privilege to share a person's journey with them. My work with the CRG, along with being sometimes overwhelming, has also enabled relationships to form and flourish in a very real-time experience of peer support. Alone is not strong, and no one can do anything alone. To belong to this amazing group is one of my highlights from 2013 and into 2014. As we see the fruits of our labour grow into an exciting future for consumers in Australia, I am honoured to have been able to serve as part of this process.

2014 is where the rubber finally hits the road for the new organisation. As you get more encouraged and involved, keep a look out for the expression of interest documents if you are interested in applying for the board, and details about the naming competition. Reach out to someone you know and encourage them to be the best they can be, and to sign up to our registered interest list as we need you and your peers to continue to support and grow your new mental health consumer organisation.

Cheers,

Lorraine Powell

CRG Member

Additional Information

The Project Team would like to extend a huge thank you to everyone who contributed to the draft constitution consultation. We received over forty submissions from individuals, advocates and organisations, making the consultation a great success.

To find out more about the Consumer Reference Group or the Project head to the website for more information: <http://mhconsumer.org.au>. The Facebook page will keep you up to date on the latest developments: <https://www.facebook.com/mhconsumer.org.au>.

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National Mental Health Consumer Organisation Establishment Project

Consumer Reference Group Monthly Update

February 2014

Darren Jiggins, CRG Member



The excitement builds as we move closer to the much-anticipated launch of the new National Mental Health Consumer Organisation. The Mental Health Council of Australia (MHCA) team and Consumer Reference Group (CRG) members, like me, are working very hard on all that needs to be done to launch the new organisation. The amount of work to be done in the establishment phase is enormous. However, I have never been more energised working on a project like this one; establishing a new national mental health consumer organisation! I am very proud of the work that our CRG and the MHCA project team have committed themselves to through this very important project, taking each step carefully towards success.

Our constitution for the new organisation sets the foundations for our new organisation and the CRG would like to thank all those people who took the time to contribute to recent consultation. Due to the quality and quantity of the feedback from the consultation, the constitution will need a major redraft, taking more time than anticipated. The CRG will work through the next steps to finalise the constitution at its next meeting in March 2014.

Well, the time will arrive very shortly to begin advertising for, and recruiting directors to the inaugural Board of the national mental health consumer organisation. These Board members will embark on the very important task of setting up the new organisation. Details of Board structure and the role of Board members can be found in our draft constitution on the project website <http://mhconsumer.org.au/constitution-consultation>. I encourage people with a lived experience of mental health issues, and organisations to consider who may best fit the inaugural Board. From my experience working on the inaugural board of 'Flourish', our Tasmanian mental health consumer organisation, this first year will be hectic as the Board sets up the new organisation. The CRG and MHCA have done some of the hard yards to give the new organisation the best possible start, including a constitution that provides a best practice governance framework.

The process to recruit and select the directors for the Board is nearly ready to be finalised. And I am very pleased to advise you all that Lilly Wu has been selected by the CRG as one of three people to represent us on the nomination committee to select our inaugural Board. The other two committee members include a representative nominated by the MHCA Board and another nominated by the Department of Health. Watch this space for details on nominating to the inaugural Board.

I believe the most important decision for the inaugural Board, once selected, will be the selection of the new CEO of the organisation. This person will play a key role in getting the organisation up and running, with all the expectations of the consumer movement awaiting the potential of what this organisation can achieve. Please take

some time to consider if you or any person in your networks would be prepared to take on this massively exciting challenge of setting up our new organisation. With an expectation that the new organisation is a united voice of consumers and will deliver nationally focused programs, this will be no ordinary job.

Along the CRG's journey to provide guidance to the MHCA, we have sought to speak with leaders in the consumer movement nationally. At our next two day meeting in March 2014, we have invited key mental health consumer focused national, state and territory organisations to meet with the CRG and the MHCA project team. We aim to discuss the potential for the national mental health consumer organisation and the benefits it will have for all consumers and our organisations. The outcomes from the day will assist the CRG and the MHCA project team understand the priority program areas that the Board and CEO of the new national mental health consumer organisation need to consider.

We want your ideas to name of the new organisation! 'The National Mental Health Consumer Organisation' (NMHCO) may be a fine name for the new organisation, but possibly not the best. So a working group of the CRG are planning a competition to name the organisation. A consumer organisation named by consumers is what we are looking for. We look forward to the difficult task of choosing from what we expect to be many great names for the organisation, more details to come soon.

The CRG and MHCA project team continue to work towards the launch of an independent national mental health consumer organisation, governed by a fabulous Board, and an amazing CEO and staff willing to step up to the challenge of uniting the national mental health consumer movement. This will benefit every consumer and lead to progressively changing the thinking of every Australian when it comes to living with mental health issues.

The CRG and mental health consumers nationally through the 'scoping study' (<http://www.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-s-nmhcorep-toc>), have voiced their vision for this organisation. This vision challenges us all to boldly break new ground for cultural change, end discrimination for those of us, who like me, face the daily struggle of mental distress, contribute as we can with dignity, and most importantly to celebrate diversity within the Australian community.

Cheers

Darren Jiggins

CRG Member

Additional Information

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National Mental Health Consumer Organisation Establishment Project

Consumer Reference Group Monthly Update

March 2014

Ian Watts, CRG Chair



OK ... It's time to talk about money and other resources.

The Consumer Reference Group (CRG) met in early March. Though it still has many tasks ahead, each of its members can see the critical turning point later in 2014, when the new National Mental Health Consumer Organisation will be launched, and the CRG will hand over the reins to its Board of Directors and CEO.

We are excited that there will be an organisation owned, governed and managed by people with a lived experience of mental health issues, but we are realistic.

It is estimated that 45% of Australians aged between 16 and 85 (45%) will experience a common mental health related disorder over their lifetime. That is 7.3 million people. Each year, 1 in 5 Australians in this age group, or 3 million Australians, are estimated to experience symptoms of a mental disorder; and almost \$6.9 billion, or \$309 per Australian, was spent on mental health related services in Australia during 2010–11.

An organisation that takes true national leadership in changing the way Australian society thinks about mental health issues; that achieves meaningful change in the lives of Australians who experience mental health issues and that boldly champions the contribution that people who live with mental health issues make each day of their lives will take lots of resources to run.

Our organisation will need resources for its external focus on human rights and social justice. It will need resources for its internal focus on providing information, mentoring, educating, and training.

Around the CRG, members imagine an organisation fuelled by a wide range of voluntary contributions as people with a lived experience of mental health issues participate in changing the Australian community. But we know a credible, compassionate and active organisation will also need funding.

We might use government funding, and indeed, we hope that the organisation's start will be underpinned by funding from the federal government. However, I believe that we will need to become independent of government funding because we need to be fearless in our mission and reliance on government funding can bring the perception (or reality) of government influence.

The truth is that it takes resources to build a platform through which people who are often excluded from grassroots mental health and well-being campaigns including Indigenous Australians, people from culturally and linguistically diverse backgrounds, young people, older persons and people with dual disability can be an authentic part of the social movement we envisage.

I imagine you, like the members of the CRG, want our organisation to have sustained and fruitful impacts in policy and research, information provision and exchange, systems advocacy and lobbying. Other organisations that have been successful in these goals have put their minds to the ways to fund their organisations just as much as they have put their hearts and minds into creating programs that make a difference.

I'm asking you to turn your mind to the sorts of motivations people and organisations will have to support the new organisation (either with funding, or with in-kind support). I'm asking you to turn your mind to the various, sometimes innovative, sources of funding that the new organisation might use. I'm asking you to turn your mind to the key decision-makers.

Our new organisation might tap into a large number of people who share our concern and provide a way for them to fund its work. We might want to seek support from some founding sponsors who have been affected by mental health issues and understand the critical voice that consumers must have. Perhaps the new organisation could secure funding for undertaking specific activities, for example community education?

The CRG's role as 'midwife' for the new organisation means that we want it to start out with the best chance of life. We could choose to leave ideas about funding to the new organisation, but we know it will be very busy as it starts.

It would be a mistake for the new organisation to just seek money wherever it can, as that may lead to a compromise of its fundamental culture and mission. Our potential funders are becoming more thoughtful about who and what they will fund.

My request, on behalf of the people on the CRG, is that you start thinking about our future funding strategy now. We know there is a wealth of information in our community, and many people who really understand what it takes to make a national organisation sustainable.

We have a dream ... but, we know it takes cash and other support.

Let us know your ideas!!!

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Contact Us

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You can also call the Project Manager, Jodie Fisher, at the Mental Health Council Australia on (02) 6285 3100 or email jodie.fisher@mhca.org.au.

National Mental Health Consumer Organisation Establishment Project

Consumer Reference Group Monthly Update

April 2014

Lei Ning, CRG Member



After more than a year discussing, debating and negotiating, the Consumer Reference Group (CRG) has almost reached its most important task, which is to establish the Board of the new national peak mental health consumer organisation. The Board members will be selected by a panel which comprises of members nominated by the CRG, Mental Health Council of Australia (MHCA) Board and the Department of Health. It has been a wonderful journey even though at times, tedious. Special thanks to the MHCA and its project team who made this enormous task doable and enjoyable.

Throughout the planning process, one enduring topic was how to safeguard consumer leadership for the new organisation. Consumer leadership is a developing new concept in the mental health sector nationally and internationally. Gordon (2005)¹ foresighted that:

“Consumer involvement makes mental health services more effective. There is now extensive evidence-based support for this position... It is contended that the paradigm shift from consumer ‘participation’ to consumer ‘leadership’ may be more fruitful in realizing the considerable benefits that result from effective consumer involvement in mental health services”.

To participate, people have traditionally had to rely on the goodwill and invitation of others. It was visualised that consumers are equal to others, are the most informed about their needs, and are able to take leadership. Unlike participation, leadership assumes people with mental health problems have the power to set the agenda, make major decisions and control resources (O’Hagan, 2009)². Consumer involvement in mental health services is advancing in a new direction, from passive participation to active leadership, which is a new challenge for all stakeholders within the mental health sector.

Consumer leadership is vital for the success of the new national mental health consumer organisation. As the founding President of the World Institute on Disability - Ed Roberts reminded us that:

“When people come to the conclusion that they have the right to be in the community, to have a say in how that community treats them, they are beginning to develop a consciousness about taking control of their lives and resisting all attempts to give others that control”.

¹ Gordon, S. The role of the consumer in the leadership and management of mental health services. *Australasian Psychiatry* 2005; 13 (4): 362-365.

² O’Hagan, M. Leadership for empowerment and equality: a proposed model for mental health user/survivor leadership. *International Journal of Leadership in Public Services* 2009; 5 (4): 34-43.

The CRG realised that ensuring consumer leadership for the new organisation is a challenge. We cannot take it to be granted. The CRG had numerous discussions to debate various ways to safeguard consumer leadership within the new organisation from drafting the constitution, designing the board skills matrix to setting up the principles for the CEO selection. Those discussions were rigorous, productive and fruitful, and at times intense and emotional. It was a respectful journey for everyone who was involved.

As a member of the CRG, I have learnt a lot from this unique process and experience, and a lot from fellow members. I am proud that the new national mental health consumer peak will be governed and directed by a Board of Directors, a majority of who must have lived experience of mental health challenges. And I am even prouder in the knowledge that the new Organisation will be truly owned by people with lived experience, for people with lived experience of mental health challenges; in short – BY US FOR US.

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National Mental Health Consumer Organisation Establishment Project

Consumer Reference Group Monthly Update

June 2014

Wayne Oldfield, CRG Member



From the beginning, little things.....

As a person of Aboriginal descent and having a lived experience of mental illness, the input I have had into the project to establish the new national mental health consumer organisation has brought me great pride. I have felt accepted, respected and treated with dignity by my peers. The newly formed relationships with like-minded people, along with the sweat and the tears has been immensely rewarding, and at times daunting.

It is hard to believe that it is nearly two years since the project to establish a new national mental health consumer organisation commenced. The new Organisation has taken shape and we now draw close to the finish line. However, not without one more hurdle; securing ongoing funding for the new Organisation.

The 2011-12 Federal Budget Package, *Delivering National Mental Health Reform*, included a five year funding commitment for the establishment of the new Organisation. The first few years of funding was approved for the current Project work (to September 2014). Further funding to support the next phase of the Project, the transition to an independent national mental health consumer organisation, is included in the Federal Budget forward estimates for 2014-2016. However, with the recent change in government there has been no guarantee that this ongoing funding will be available for the next phase of the Project.

The Mental Health Council Australia (MHCA) has submitted a proposal to the Department of Health for ongoing funding for the new Organisation. A special update will be sent out once we have a decision.

One of the challenges we face is that much of our current work is dependent on ongoing funding, in particular recruiting Directors to the new Board and the CEO. Naming of the new Organisation has also been put on hold.

Despite the challenges, we have continued work to make sure we are in a good position to keep tracking toward the finish line. The Independent Nominations Committee, responsible for the selection of Directors to the new Board, has met and is ready to go. Work has also commenced on a strategy for naming the new Organisation. We must be positive and we have to be ready, even though some of these things might happen a little later than we hoped, and despite the funding uncertainty.

The redrafting of the constitution following the consultation has not been without its challenges; mostly it has meant that this work has taken longer than any of us thought. We have learnt that establishing good governance is complex and worth taking the time to get right.

It has been an amazing journey so far and we all hold our breaths in anticipation of ongoing funding. For me it has been a pleasure to have worked this past two years with such a dedicated and diverse group, and one of the most satisfying and rewarding tasks I've been involved in.

A big thank you to the MHCA Project staff and consultants who advised us along the way, and of course all the consumers who have contributed with sage advice and input.

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September 2014

Emily Todorov
Consumer Reference Group Member



My name is Emily, I'm in my late twenties, and an avid advocate for mental health. It has touched my life profoundly. I have bi polar, borderline personality disorder, post-traumatic stress disorder and currently recovering from a long battle with anorexia and substance abuse.

Working as a member of the Consumer Reference Group (CRG) over the past couple years has been a wonderful learning experience for me, and the perfect introduction into the mental health consumer movement. In fact, it is the reason I've decided to pursue a career in advocacy. You can learn so much from your peers and those who have been there before you.

My specific areas of interest involve minority groups, such as young people, the GLBTI¹ community and those living in rural areas where services aren't as easy to access. I began my advocacy journey when I was appointed as a Beyondblue youth ambassador in 2010. Speaking at various conferences and engagements (and appearing on national television!) about my own personal experiences has been invaluable. There is so just much stigma out there. One of my missions in life is to challenge stigma and normalise mental health issues. The truth is many, or most of us, will come across mental illness at some point in our lives.

Being on the CRG has been very positive for me. No longer do I carry the shame associated with a mental illness. I'm proud that I have such wonderful colleagues who I can relate to, and together we are making our mark on the somewhat murky world of mental health. Helping to establish Australia's peak organisation for mental health consumers has had a great impact on my confidence and equipped me with a multitude of skills I never dreamt I would be capable of.

Working with the project team at Mental Health Australia has also been an amazing experience and I've met many learning curves along the way. Governance training was a complex one to tackle, but I now have a clear understanding of the importance of great governance and the nuts and bolts that go along with it. One thing I have taken from this experience is the strong need to have a majority of consumers driving the Board of the new organisation, as well as having many consumers and consumer peak organisations as members. In my view consumers are the real voice of mental health in Australia, and abroad, and the contributions they make are invaluable.

¹ Gay, lesbian, bisexual, trans/transgender, intersex peoples

My vision is for the new consumer organisation to take the lead on community education, policy advice, media awareness and stigma reduction. Stigma has impacted my life in a negative way; it has taken away relationships and my own dignity at times. When I get out there sharing my experiences whether it's to a large audience or my fellow CRG colleagues, my aim is to stamp out stigma, and raise awareness that mental health issues can be part of anyone's life at any time; it does not discriminate.

I also hope that the work of the new organisation will lead to better care and services for mental health consumers, their families and friends. From my experience, peer support workers and advocates are instrumental in changing the mental health sector. I've had many bad experiences in the mental health system. It's my hope that experiences like mine will be avoided in the future; with the help and guidance of mental health consumers, peer workers and advocates.

After living with a mental illness for the better part of my life, every step in my advocacy journey lessens the stigma I feel associated with being unwell. But there is still a long way to go and the new organisation will be the perfect vehicle to help reduce it.

Ongoing funding so the new organisation can start its important work is our biggest challenge. We are hopeful that the National Mental Health Commission's *Review of Mental Health Services and Programmes* will recommend ongoing funding when its report goes to government in November 2014. This will mean that our consumer led Board, and the CEO can be recruited. Most importantly, the new organisation can get on with its important work to transform the mental health sector and reduce stigma.

Additional Information

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National Mental Health Consumer Organisation Establishment Project

Consumer Reference Group Update

December 2014

Consumer Reference Group Members
Darren Jiggins and Lily Wu

This is the last update from the Consumer Reference Group (CRG) for 2014. We decided this update would be brought to you by two CRG members; myself (Darren Jiggins) and Lily Wu. We reflect on what has been achieved despite funding uncertainty, and highlight the importance of your ongoing support to get our organisation up and running.

Reflecting on our journey - Darren



What a journey it's been! I finished up a six month secondment as Executive Officer with 'Flourish' the Tasmanian consumer organisation last year. While working in isolation in rural Tasmania, I was struck time and again by the need for a national peak body. As an individual, I always felt the challenging work of consumer advocacy needed much more support than is currently available. The need to build capacity of, and support for, a mental health consumer organisations was all too clear. There is no doubt that the need for a national mental health consumer peak is as great today as it was when we started the Project back in July 2012.

The *National Review of Mental Health Services and Programmes* by the National Mental Health Commission has created unease and uncertainty across the sector. It has impacted on the establishment of the new organisation, which we had planned to launch in September this year. Without ongoing funding, activities required to operationalise the new organisation, such as recruiting the new Board and CEO, have been put on hold. The Project was given an extension by the Department of Health until May 2015.

Despite the challenges of the last 12 months, there were also inspiring highlights and achievements. The response to the consultation on the constitution earlier this year exceeded our expectations and informed further redrafting of this important document. The Constitution was endorsed by the Mental Health Australia Board at its meeting on 3 December 2014. It is now ready to go and for the new organisation's Board (once recruited) to adopt or alter if it wishes.

The consultation workshop with mental health consumer state and territory peaks hosted by the CRG and Mental Health Australia in March 2014 was another highlight. This was the first time, ever, all state and territory consumer organisations and key individuals met in the same room. It was a great event, galvanising the CRG to work harder on the Project and consolidate the obvious need for a national peak body representing the voice of consumers.

We are all very proud of our hard work and confident all will be ready when the time comes to transition from a project to an operational independent organisation governed by, and for, people with lived experience. We have provided the future organisation with the foundations for the best possible start and positioned it for success in the future. It will be an organisation that is set to change how mental wellbeing is viewed by all Australians.

Calling for your support - Lily



Over the past 12 months I have continued to be a CALD Consumer Advocate and provided grassroots peer support to inpatient consumers. I have also provided support to consumers living in our multicultural community in South West Sydney Local Health District; South East Sydney Local Health District, and a number of non-government organisations in the South West & West Sydney areas. These areas have the largest multicultural communities in Australia.

There is still a strong call from consumers to establish a national peak consumer organisation to ensure our voices and deep concerns are heard and acknowledged at the highest levels, and informing processes that drive mental health reform.

As Darren said, the CRG and Mental Health Australia project team have worked very hard over the last two years, with support and advice from many experts and leading national consumer advocates. We have built foundations and structures for good governance to support the future organisation. We greatly appreciate everyone's support and the community's involvement in this process. Now we need your support more than ever.

Government funding for the new organisation may not be announced until Budget 15/16 in May next year. In this time of uncertainty we need to stay focused, and most importantly stay positive. It is a most crucial time, and we must stay on track so we can launch our peak knowing it has a sustainable and successful future ahead of it.

The delay in funding has been disappointing and disheartening; it has impacted on us all. However, it has allowed us to focus on developing a comprehensive hand-over pack, including a draft governance manual and operational policy templates, to support the new Board and management. We are also looking at options should government funding not be available. Our work includes developing a transition plan that explores other avenues for operational funding to assist the Project transition to an independent organisation.

To ensure our vision for a national mental health consumer peak is realised, ongoing support from you and our multicultural communities is crucial.

We would very much like to hear from you. The CRG are keen to hear your views, thoughts and ideas for the future consumer peak. You can do this by sending an email to enquiry@mhconsumer.org.au or by writing a letter or emailing your local MP.

On behalf of the CRG and Mental Health Australia project team, Darren and I wish you all a happy and restful holiday.

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National Mental Health Consumer Organisation Establishment Project

Consumer Reference Group (CRG) Monthly Update

Lorraine Powell, CRG Member

April 2015



Hi there!

Have a look at this picture- it is taken in Perth, and is something I drive past often.



This is known as a Penrose triangle (http://en.wikipedia.org/wiki/Impossible_object), something which can be drawn 2 dimensionally (see page 2); but challenging to make exist in the real world, in a 3 dimensional space. I find it intriguing that looking at it from different angles provides a completely different shape, despite it being one sculpture, and the 2D picture it arises from.

Over the last two and a half years many people have looked at the responsibilities and work of the CRG from many different perspectives (angles). Despite our consistent efforts to keep our peers and colleagues informed about our role, responsibilities, achievements and challenges, there has been some confusion about the CRG and the Project to establish a national mental health consumer organisation, governed by and for people with lived experience of mental illness.

Initially, each member of the CRG was appointed by the then Minister for Mental Health (the Honourable Mark Butler MP) to advise the Mental Health Council of Australia (now Mental Health Australia) on establishing a mental health consumer organisation. Funding was for the CRG to meet, undertake their work, and to launch the new organisation with an inaugural Board and CEO.

The work of the CRG has always been to undertake the 2 dimensional work. Throughout the Project we provided updates about how we were focusing on building a strong sustainable organisation (a 3D concept). In a 2 dimensional sense this meant capturing in documents (such as the constitution) all of our hopes, dreams, desires, creativity, ingenuity, complexities and structures, with great governance processes to enable the new organisation to get off to a substantial and robust start.

The 3 dimensional work would have started with the launch of the new independent organisation in September 2014 (signalling the completion of the Project); at this stage the CRG and Mental Health Australia would have completed their work and handed over to the new Board. To our deepest disappointment, the National Mental Health Commission's *Review of Mental Health Services and Programmes and Services* last year meant that funding for this transition would not be confirmed

until the recommendations of the Review were considered by Government. This meant that important (3D) activities such as recruiting the Board and CEO (which were originally part of the Project) had to be put on hold until funding was confirmed.

The Project is funded until the end of May 2015, this will enable the CRG and Mental Health Australia to complete their work. We are well on track for that, and still working feverishly. Along with the necessary work, we have also had significant discussions about viability and sustainability for the new organisation, with full realisation the government may decide not to fund the new mental health consumer organisation.

With funding uncertainty the CRG has continued to put our energy into producing a pack of key documents (the constitution, the policies and procedures, the establishment of a Board selection process, governance manual, and a naming and branding exercise- all of the 2D papers) to be handed over to the future organisation if it is funded. This will be an invaluable resource for our future peak!

In the budget forward estimates, money was set aside to fund the transition of the Project to an independent and sustainable national mental health consumer organisation. As you may know, a figure in Forward Estimates does not guarantee funding, and at the time I writing this we still do not know what this means for the actual transition phase. In a recent public statement, the new Minister for Health (the Honourable Sussan Ley MP) stated *"I can confirm the Government is committed to working with mental health experts and other levels of government over the next 12 months to deliver better outcomes for the sector and Australians long-term"*. We hope this is as promising as it sounds.

I reflected on the Penrose triangle as a concept to understand the 3 dimensional outcome of making the new national mental health consumer organisation a reality based on the work the CRG has done on paper (2 dimensionally). Each of us may have a different perspective on what the new organisation may mean. Each of us may believe in something different. Each of us may see something different. Each of us may have different experiences. All of us, I believe, strongly desire the 2 dimensional (or foundation) work of the CRG, to transition to the 3 dimensional, existing in 'real time', sustainable and dynamic national mental health consumer organisation.

This is a call to action for you all!

We indeed are the very experts Minister Ley needs to be speaking to, and the consumer peak needs to be funded to do that. We must get our 2 dimensional work off paper and make it a 3D reality- let's use our voice to have the Minister release the funding to establish the new consumer organisation!

I encourage you to follow this [link](#) and sign a petition asking for the funding to be released so all of the incredible hard work, hopes and expectations of each and every one of you can become a reality.

Let's turn this:



Into this:



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