People diagnosed with 'mental illness' doing things for ourselves

OUR CONSUMER PLACE NEWSLETTER OCTOBER 2012

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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

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What's happening to our language? Some rather strange things ...

On October 8th, *The Age* newspaper included an article about the changes to laws regulating the use of involuntary ECT (see our discussion on page 3). BUT an interesting fact is that in the paper version of the article, they described us as "patients", but on the online version, they called us "consumers" – possibly the first time a headline in *The Age* has ever used this word to describe us (see the online article here: http://www.theage.com.au/national/health/reforms-to-give-consumers-a-say-20121007-277c2.html). As if this wasn't intriguing enough, the recently released discussion paper for the "Mental Health Practice Standards and Competencies" says that the word "consumer" might not be "suitable" anymore, and instead they recommend "person in recovery" or "person with lived experience" ... We don't want to argue about this word all the time (gosh, it takes attention away from other issues sometimes) but it is interesting to watch as others grapple with what to call us!

STOP PRESS! A new Mental Health Act is coming ...

On Monday October 8th, the Minister for Mental Health Mary Wooldridge released *A new Mental Health Act for Victoria: Summary of Proposed reforms* (www.health.vic.gov.au/mentalhealth/mhactreform).

> *There is an inherent tension in the mental health landscape – between a growing recovery-orientation (underpinned by consumer autonomy and self-determination) and involuntary treatment (underpinned by the loss of both autonomy and self-determination). This tension is approached in various ways in this new legislation, including ways that may actually change practice.*

The document begins with all the “right buzz words” – “partnership with consumers”, “a supported decision-making model of treatment and care” and “promote recovery-oriented practice.” The press release says it will “put patients in public mental health services at the centre* of decision-making on their treatment and recovery”. (*although see Merinda’s analysis of this idea of being “at the centre” on pages 6-9 of this newsletter.)*

Traditionally, mental health acts have been all about *substituted decision-making*, where we are deemed too unwell to make our own decisions, so a psychiatrist takes over and makes decisions for us. The Minister’s foreword refers to this new Act being based on a “supported decision-making model”. BUT the press release (rather ominously) refers to “a shared decision-making model.” These are very different ideas – supported decision-making is premised on the idea that *we have the right to make the decisions about our own lives* (including treatment), but we might require support to do this. This is in accordance with the UN Convention of the Rights of Persons with Disability. The new Act does introduce several measures to support us to make our own decisions:

- **Presumption of capacity:** We will be presumed to have “capacity” to make our own treatment decisions, but there will be a “capacity test”. If we are deemed “unable to consent”, we will be “supported to be involved in the decision-making process to the greatest extent possible”. It’s not clear how this will translate into practice. Overseas such “capacity tests” have been a backdoor way to revert to psychiatrist-knows-best (substituted decision-making) and involuntary treatment.
- **Advance statements:** (for an understanding of what these are, check out this lovely powerpoint by Neil Turton-Lane, from the VMIAC website, which introduces Advance statements really well: www.vmiac.org.au/pub/vmiac-cc/Turton,%20Lane-Advance%20Statements%20Powerpoint.pdf)
- **Nominated person:** we can nominate a person “to receive information and to support the patient [ie. us] for the duration of the compulsory treatment order.”
- **Advocate:** there is funding flagged for individual advocacy.

Other significant changes include (this list isn’t exhaustive):

- A compulsory review process before any use of ECT;
- Mental Health Tribunal to replace the Mental Health Review Board and Psychosurgery Review Board;
- A Mental Health Complaints Commissioner (separating this out from the Chief Psychiatrist);
- Access to a second psychiatric opinion (which, unfortunately can be ignored!);
- A fixed duration for involuntary treatment orders;
- Increased oversight of the use of restraint and seclusion.

We hope to have some more, deeper analysis in upcoming newsletters, so please send us your thoughts/deep analysis/opinionated soap-boxing to: service@ourconsumerplace.com.au.

News in the consumer world:

The Peer Conference: *A celebration of peer support in mental health*

The Centre of Excellence in Peer Support is delighted to invite you to the Peer Conference, a showcase and celebration of peer support in mental health. This exciting event will showcase a range of fantastic peer support initiatives from across Victoria and interstate. Make sure you come along to learn about what's happening in peer support, and what lived experience can achieve!

With support from the Mental Health Council of Australia, this **free event** is **open to all** consumer and carer peer workers, services, consumers and families/carers. Other mental health professionals are also warmly invited and encouraged to attend.

Date: Tuesday 30 October 2012, 9.30am – 4.30pm
Cost: FREE Morning tea, lunch and afternoon tea will be provided. Travel assistance and parking will be available to consumers and carers on request.
Who should attend? The peer workforce; Consumers and carers/families/friends; Other mental health professionals; Anyone interested in learning more about peer support.
Location: Amora Hotel Riverwalk Melbourne 649 Bridge Road, Richmond Victoria
RSVP: Wednesday 24 October **Places are limited!**

Details are available via the CEPS website: www.peersupportvic.org or call ARAFEMI Victoria on (03) 9810 9300. [Ed: actually, check out the CEPS website anyway – it's a great, expanding resource.]

Peer Zone

PeerZone is a new series of peer led workshops where people with mental distress explore recovery and whole of life wellbeing. See www.peerzone.info and watch our fun new video. We're rolling out PeerZone in Australia and New Zealand at the moment.

We are holding two free introductory days for peers who are interested in facilitating or participating in PeerZone workshops. We will tell you all about PeerZone, give you an opportunity to sample what's in the workshops, and talk about how you might want to get involved.

THE CANBERRA INTRODUCTORY DAY IS ON FRIDAY 26 OCTOBER from 9 to 4 pm at the Griffin Centre, 20 Genge St, ACT 2601. Please RSVP to info@peerzone.info by 19 October.

THE SYDNEY INTRODUCTORY DAY IS ON MONDAY 29 OCTOBER from 9.30 to 4 pm at Suite 35, 11-21 Underwood Rd, Homebush, NSW 2140. Please RSVP to info@peerzone.info by 22 October.

Remember, we are available to do PeerZone introductory days in other centres or to talk to you about delivering PeerZone facilitator training and support services to peers in your area.

PeerZone wishes to thank Richmond Fellowship ACT and Mental Health Community Coalition ACT for sponsoring the Canberra event, RichmondPRA for sponsoring the Sydney event.

\- Mary O'Hagan and Sara McCook Weir

Workshop: Managing Meetings: for Consumer & Carer Consultants

DATE: Thursday 22nd November 2012
TIME: 9:30am to 3:30pm
LOCATION: Northcote Town Hall, 189 High Street NORTHCOTE, Vic., 3070.

Registration may be done online: www.nevil.org.au. Enquiries to Lina Wilson (03) 9288 2194.

Exciting press coverage of consumer leaders

An excellent article by freelance journalist Joel Magarey was published in The Age on October 8th, 2012, based on interviews with many consumer leaders (including many whose material didn't make it into the final cut, due to space restrictions). There is a big picture of consumer academic Cath Roper, looking fabulous with her conspicuous pink hair, as well as some lovely articulation of what it is that we do. Check it out here: http://www.theage.com.au/national/health/in-their-shoes-new-approach-to-improving-care-20121007-277bz.html

Indigo Daya launches her new website

Many of our readers will be familiar with the passion and eloquence of Indigo Daya – Indi is project manager at Voices Vic, but is also a freelance recovery trainer and speaker. She has just launched her new "consumer-informed mental health website": www.indigodaya.com. The site includes new recovery-informed mental health training, upcoming talks, new ideas about mental health reform and recovery, consulting opportunities, and lots more. Check it out!

Southern Health's Mental Health Week exhibition

(From Vrinda Edan, Director of Consumer and Carer Relations, Southern Health)

Once again I am extremely proud to present the Annual Mental Health week Art Competition. This is now the 4th year we have conducted the competition and have purchased over 50 pieces in this time. The work is displayed throughout the Mental Health Programs facilities.

I would like to invite you to browse the work and make your votes on line at: http://www.southernhealth.org.au/page/About_Us/Mental_Health_Week_Art_Competition_-_Vote_For_Your_Favourite

The work will be displayed thorough out Southern Health sites during Mental Health Week with the majority of works on display at Dandenong Hospital.

inside out & associates

If inside out & associates are not on your radar yet, they should be! They are a group, based in NSW, that brings a range of perspectives to the table to discuss cutting edge issues around mental distress and mental health. They create spaces for "critical conversations". Upcoming events include:

- **Care without Coercion: Critical Conversations about Power, Self Determination & Recovery in Mental Health** - Wednesday 14th November 2012 at University of NSW.
- **Youth Hearing Voices: understanding and supporting young people who hear voices –** Monday 3rd December at Macquarie University, NSW. Speakers include Dr Marius Romme,* Sandra Escher* and Kellie Comans.
- **Life History and Voices:** an Introduction to the Maastricht Approach to be held on Wednesday 5th December 2012 (also with Marius Romme and Sandra Escher)

*Founders of the Maastricht Approach to Voice Hearing, Marius and Sandra are known for their extensive research into the voice-hearing experience and an approach based on acceptance and understanding the meaning behind these experiences. This is Dr Marius Romme and Sandra Escher's first visit to Australia!

For more information, go to: http://www.insideoutconversations.com.au/

Why I don't want to be 'piggy in the middle' – by Merinda Epstein

Does the idea of "consumer-centred" really stack up to examination?

Introduction

The contemporarily fashionable representation of 'consumer centred care' is that of a circle of caring 'others' and us standing in the middle. We are being 'done to'. At first I was genuinely impressed to see what we all considered was a new and more respectful way to understand consumers – as the centre of things. Up until that time I think the predominant metaphor didn't have consumers in it at all. What it had was the most expert (powerful) out the front and the other clinicians, workers, community, carers - all submissive, facing the expert with a stuttering conversation but more likely a lecture about 'the invisible us'. We were right to want this changed.

My new position firmed up as I sat on the Federal Government Expert Committee on the Education and Training of the Mental Health Workforce in about 1995. We were working with the consultancy firm KPMG and emphasis was for some time on creating a logo to depict the ideas we were working towards. There were images of clasped hands (clinician male and consumer female) and there were images of shadow bridges made by joining shadow hands, there were various depictions of people around in a circle and the consumer in the middle. I didn't like any of them.

The image of the 'consumer in the middle'

By this stage the language around consumer-centred services was starting to enter the rhetoric and this circular depiction seemed to describe a new and potentially powerful notion that services should primarily be there for consumers rather than be arranged around the convenience and needs of staff. This was a potent idea for many consumers too. It felt like there was something to be gained from clinicians and services placing themselves around the perimeter looking at the central proposition, "what can I do for you?" – and it was a new place for the consumer in all manner of ways. This suited the prevalent idea that clinicians and policy makers should be looking to the centre towards 'their' patients/ 'their' clients and 'empowering us. All these idea were looking rhetorically useful in this new world of mental health service provision.

> *They had all assumed we would like us to be central, 'the most important person', with kind people around the circumferences looking in to see what they could do for us, helpers. Slowly I developed my critique.*

What I didn't like about this circle idea

People I met politically in mental health circles were shocked when I said I didn't like the depiction of the consumer marooned in the middle being starred down by everyone else. They had all assumed we would like us to be central, 'the most important person', with kind people around the circumferences looking in to see what they could do for us, helpers. Slowly I developed my critique. Several aspects of the 'enlightened' model made me feel uneasy:

1. This was an ideological position which limited the possibilities of the consumer-as-actor[1] . The position in the middle was passive or so it seemed to me.
2. The idea of being 'empowered' by another was errant nonsense. In order to 'empower another' we must first of all assume that 'the helper' has rightful power over us. The depiction was a misrepresentation of how power works in society and in mental health.

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[1] *A term conceived by famous sociologist, Max Weber and refers to aspects of 'Role Theory' – that we play out multiple roles in* our lives, for example 'patient', 'mother' 'teacher', 'clown in company' and this is based on the important idea that we are active decision makers in our own lives (have 'agency')

3. Where is the consumer community in this depiction? Where is peer support? There is no action or even potential for action in the centre of the circle.
4. The circumference of the circle inaccurately suggested that all the players on the edge were held in equal esteem and had equal amounts of power. This was wrong. At least the previous representation didn't pretend there was no power and authority plays going on. As I became more involved in the political life of the mental health sector I watched (and participated in) the political manoeuvrings as different interests in the sector gained and lost power and influence.

Where is the consumer community in this depiction? Where is peer support?

It was politically expedient to spend a lot of time speaking rhetoric about a consumer centric model. It was not how the system was ever going to work and I felt less and less disposed to support this circle thing which I now believed to be, at its best, a mirage. We were told we were central. We weren't. We were considered fair game by other powerful 'stakeholder' groups – and I use this word with considerable clenching of teeth. I don't like it. Many of us don't. It assumes that everyone, including the consumer, has equal interest and investment in the life of the consumer concerned. How can this be? It can't. A consumer is not a stakeholder in his or her own life. The language used by Wadsworth [2] which describes consumers as the Critical Reference Group is much more useful. Herein, however, lies a challenge to critiquing consumer-centric circles. How can we be out of the middle without just being yet another 'stakeholder'?

CONSUMER CENTRIC POLITICS

The idea of consumer-centric services arose out of the shemozzle above and that is one of the main reasons I dislike it – it's lazy. Sticking the consumer in the middle, metaphorically, and then metaphorically poking them (just to make sure they are still alive) seems daft to me.

I have known the Mental Health Council of Australia (MHCA) since its inception and I vividly remember the final meeting of the National Community Advisory Group (NCAG). Minister Michael Wooldridge told us that the consumer voice would not be depleted with the arrival of the MHCA. Basically we voiced our concerns loudly. We were spot on. In the consumer-in-the-middle paradigm there is no capacity to multiply, to grow bigger. As we predicted, the number of 'stakeholders' can grow exponentially and it's now history in regard to the MHCA. Every organisation and their dog have joined the circumference around us. It is now a jowl by jowl bunfight of institutions starring down on us. Unfortunately the middle is portrayed as a finite place – a 'thing' or an 'it' that lives there is also finite. In relation to the MHCA we are constrained by the fact that consumer politics is often played at the grass roots level with small, localised organisations and to become a member of the MHCA the organisation has to be national. There are only three consumer organisation members of MHCA. For every new organisation that joins hands encircling us, our power is diluted.

CONSUMER CENTRIC SERVICES

Ironically, this whole idea of so-called 'consumer centric decision making' in mental health was taking place in a covertly hostile service environment. The rhetoric of consumer-centric remained but consumers started using the word tokenism to describe the very real ways the system worked against us gaining any real power. People did not feel central to anything.

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[2] Wadsworth, Y., Do It Yourself Social Research, Allen & Unwin, Sydney 1997

There are many ways in which services ‘do to’ or ‘do for’[3] (outer circle directed) instead of ‘doing with’ us: from writing histories, to appointment systems, to language which damages us, to forced treatment, to benevolent paternalism, to tick box consumer participation, to defensive medicine, to pretend decision making in support services. Within a service context, whether it be a clinical service or a Psychiatric Disability Recovery and Support Service, there is a projection of a false image of consumer centricity. If we were truly central we would be writing or co-writing our own notes, we would really be making own decisions about what we need and who we need to do it with. We would be in charge of our own lives and futures rather than being managed by ‘Case Managers’. We would more overtly honour the importance of peer support.

Not only are consumer-centric services not what they say they are but I now argue that the concept itself is problematic. The only places where equality of power is demonstrated is in good examples of peer support where everyone is there together. This is as far away as you can get from consumer being ‘done to’ by the system’s representatives circling around her.

CONSUMER CENTRIC MEETINGS

1. Chairing often defaults to privileging those with institutional authority in the system (which is definitely not us).
2. We are outnumbered and disempowered despite much rhetoric around ‘inclusion’.
3. We are subject to institutional paternalism often invisible to those with institutional power.
4. We experience institutional silencing, often in silence.
5. Conversations canvassing the most important ideas are often drawn to a premature close by chair-people
6. Despite being rhetorically cast as the central player we are treated as ‘other’, different to and therefore less than, other committee members.
7. We receive unfair and impossible demands to be ‘real’ consumers and accusations of elitism.
8. The strange and impossible call for us to be ‘consumers like ***our*** consumers’. Apparently if we are ‘well and able’ enough to demand concessions then we are not ‘real’ consumers.
9. The cry for ‘representation’ rather than expertise.
10. Consumer committee members often get brownie points for all the wrong things:
    - staying quiet,
    - being ‘reasonable’,
    - playing the power game without question, subjugating ourselves to people of higher rank (most clinicians, managers etc.),
    - doing bureaucratic things masterfully and in a timely fashion (and not complaining that you’re the only one on the committee who doesn’t have a PA.).

None of this is reflective of consumer-in-the-middle ideology. It’s pretence. Consumers are simply being invited in to what for many of us experience as a hostile environment with good afternoon teas but not a lot else.

Decision making committees are often not very useful places for many of us. None of this is reflective of consumer-in-the-middle ideology. It’s pretence. Consumers are simply being invited in to what for many of us experience as a hostile environment with good afternoon teas but not a lot else.

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[3] Wadsworth, Y., Do It Yourself Social Research, Allen & Unwin, Sydney 1997

THE METAPHORS THAT WORK FOR ME

As a lover of children's literature and games it is possibly not surprising that this is where I often turn for inspiration. In this case there are a plethora of story books and participatory games that have helped me capture the ideas that were developing for me.

Three games are perhaps the most relevant. They are Piggy-in-the-Middle, Poison Ball and Keepings off. All of these popular games involve an outer circle and the use of the ball to biff the child in the middle. Interestingly the child is called 'piggy' or 'it' which make the analogy even stronger. That place of 'in the middle' is not such a safe place to be. For example:

- **Keepings Off**: The consumer is in the middle and all the 'benign and helpful' stakeholders start throwing the ball over our heads, just to the left, just to the right – dummy then throw in a different direction. When we fail to catch it after ten minutes of pointless jumping and lurching and two scraped knees, someone feels sorry for us and gives us the ball – system benevolence.

A NEW MODEL

I haven't developed an alternative way of depicting our place in all this confusion and yet I am convinced that Piggy-in-the-Middle is not a good place for us to be.

As a lover of children's literature and games it is possibly not surprising that this is where I often turn for inspiration. In this case there are a plethora of story books and participatory games that have helped me capture the ideas that were developing for me.

My thinking to this point has been to keep the circle idea as there does seem to be the potential for democracy here. There would be **NO** consumer in the middle. There might be a symbol for the middle which is defined outside the central picture as a key defining something we think is CENTRAL; for example, peer support.

TWO RINGS.

Around the circle there might be two rings. The inner ring would depict consumer leaders in a variety of areas: committee sitters, artists, response-able project managers, Voices Vic, VMIAC, storytellers, public speakers, academics, learned experts, writers, singers and people working in 'The Systems'; consumer consultants, consumer academics, personal helpers and mentors (PHAMs), etc.

The second ring might have **other players** of whatever description. This would include the clinical groups and all the organisations that play the field in mental health provision. These would include the sorts of organisations that are most of the members of the Mental Health Council of Australia[4].

This model would have equal numbers in each circle making the outside circle sparser. The inner circle depicts a true appreciation of the differences in institutional power between consumers and other players and captures the idea that there is an increase in authority represented by the inner ring.

CONCLUSION

These are just my preliminary thoughts. I think this is something worth debating. Although the 'consumer-centred' idea was a substantial step forward from the clinician-centred ideas of the past it has now mostly rhetoric riddled with problems which we must seek to address.

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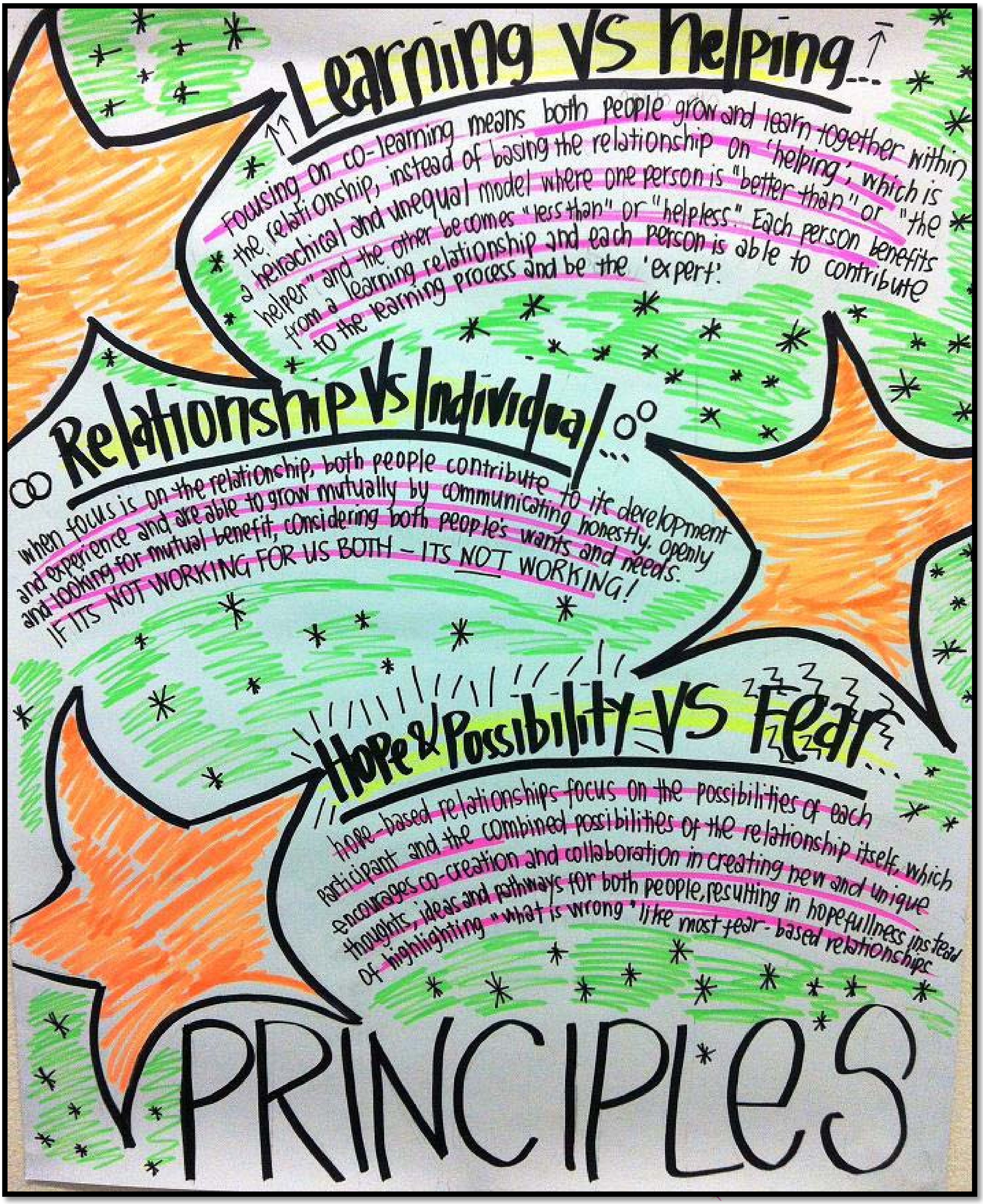
[4] http://www.mhca.org.au/index.php/about-us/mhca-membership/77-site-pages/102

Intentional Peer Support creations:

Two posters –by Mahlia Jewell (Mahlia.jewell@hotmail.com). Mahlia lives and works in NSW and has a background in graphic design. She created these two posters – one on the 4 tasks of IPS and one on the 3 principles of IPS – as she recognised that posters can be an effective way to share important ideas with colleagues and to generate conversations. Enjoy!



Learning VS Helping

Focusing on co-learning means both people grow and learn together within the relationship, instead of basing the relationship on 'helping', which is a heirachical and unequal model where one person is "better than" or "the helper" and the other becomes "less than" or "helpless". Each person benefits from a learning relationship and each person is able to contribute to the learning process and be the 'expert'.

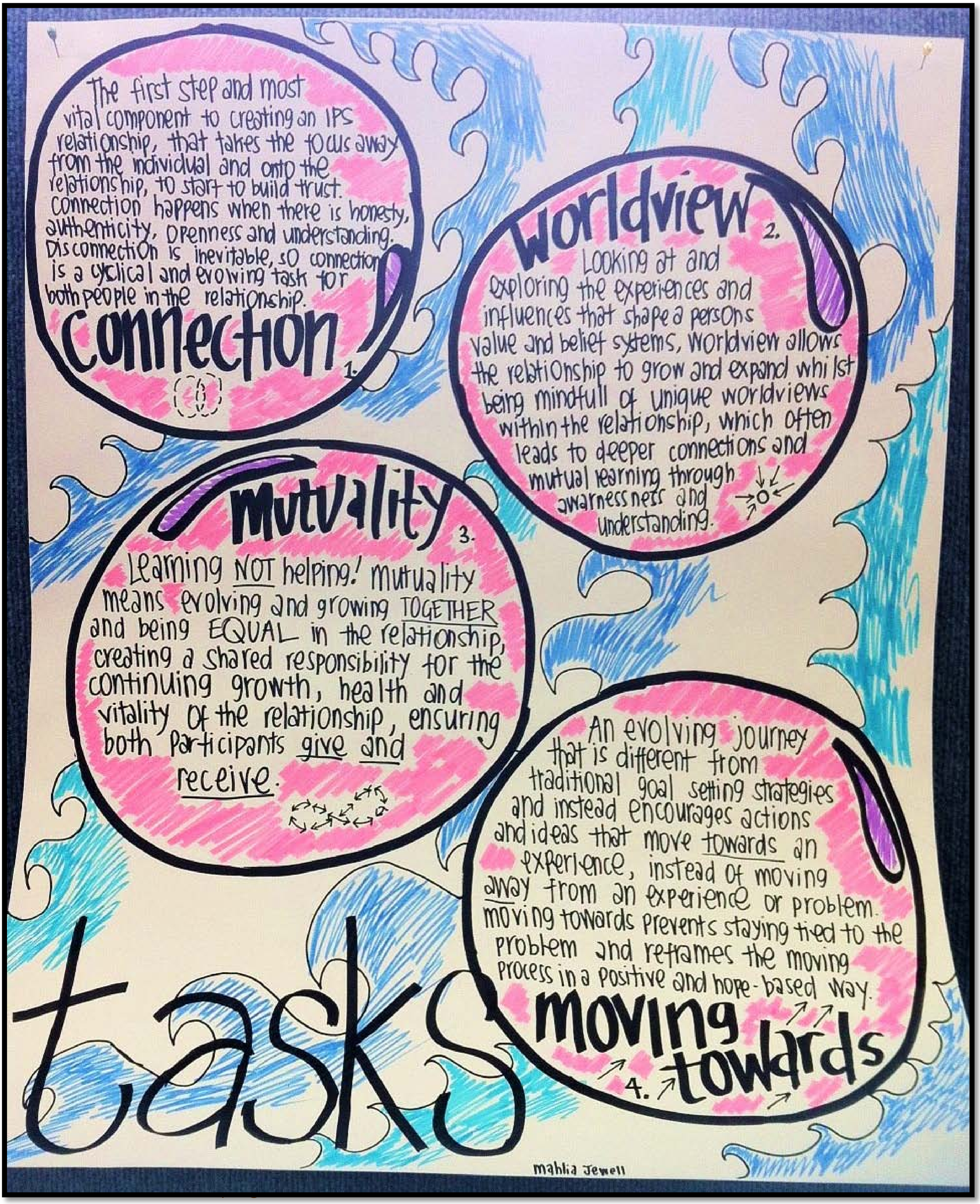
Relationship VS Individual

when focus is on the relationship, both people contribute to its development and experience and are able to grow mutually by communicating honestly, openly and looking for mutual benefit, considering both people's wants and needs.
IF ITS NOT WORKING FOR US BOTH – ITS NOT WORKING!

Hope & Possibility VS Fear

hope-based relationships focus on the possibilities of each participant and the combined possibilities of the relationship itself, which encourages co-creation and collaboration in creating new and unique thoughts, ideas and pathways for both people, resulting in hopefullness instead of highlighting "what is wrong" like most fear-based relationships

PRINCIPLES



tasks

Connection

1.

The first step and most vital component to creating an IPS relationship, that takes the focus away from the individual and onto the relationship, to start to build trust. connection happens when there is honesty, authenticity, openness and understanding. Disconnection is inevitable, so connection is a cyclical and evolving task for both people in the relationship.

Worldview

2.

Looking at and exploring the experiences and influences that shape a persons value and belief systems, worldview allows the relationship to grow and expand whilst being mindfull of unique worldviews within the relationship, which often leads to deeper connections and mutual learning through awarnessness and understanding.

Mutuality

3.

Learning NOT helping! mutuality means evolving and growing TOGETHER and being EQUAL in the relationship, creating a shared responsibility for the continuing growth, health and vitality of the relationship, ensuring both participants give and receive.

moving towards

4.

An evolving journey that is different from traditional goal setting strategies and instead encourages actions and ideas that move towards an experience, instead of moving away from an experience or problem. moving towards prevents staying tied to the problem and reframes the moving process in a positive and hope-based way.

Mahlia Jewell

INTRODUCING ... the Bipolar Babes

In this edition, Sally Fisher introduces the Bipolar Babes of Melbourne's inner north – a friendship group taking a light-hearted approach to a serious condition. Sally is a reporter/editor currently working part time at Mind Australia and attempting to trade her word-smithing skills for photography. She dreams of being an economic geologist in her next life and owning a dog that likes to run.

It was three years ago when I spotted a tiny advertisement for the Northcote Leader community newspaper asking interested women to join a group called the Bipolar Babes. It leapt right out at me. I wasn't looking for a support group and the ad was only four lines long, it seemed the Bipolar Babes had found me; they were calling.

I'd been diagnosed with bipolar disorder 1 about 10 years before this and despite always taking the medications and spending many long, hard sessions over many years on my psychoanalyst's couch, I was stupendously secretive about my condition. I never told my bosses at the various jobs I'd held. I was determined I wouldn't miss out on promotions or assignments overseas as I believed the stigma was just too great to gamble with at work. It was better, I thought, if I looked and was assumed to be the same as everyone else.

I was stupendously secretive about my condition. I never told my bosses at the various jobs I'd held. I was determined I wouldn't miss out on promotions or assignments overseas as I believed the stigma was just too great to gamble with at work. It was better, I thought, if I looked and was assumed to be the same as everyone else.

This determination to hide something so significant in my life was like a valve under surging, spurting pressure. I couldn't talk to my parents or siblings about my bipolar, friends were told a few scraps more and my husband was carrying the load when it came to how I was coping or, often, not. Because I wouldn't let others in, he was alone in caring for me when I plunged into episodes of mania or the long, grey, featureless months of untreated depression.

Whenever I did try to talk about it, say after a friend pointedly asked how I was, I'd usually choke with the beginning of tears, you know the deep pain that grips your throat before the real crying starts. It was as if my body was stopping me when it came to the matter of my brain. And until I could talk of my bipolar with honesty and clarity, and maybe even crack a gag about it, I was never going to accept it and let it be part of my life. And this had serious repercussions for my treatment as it stopped me from managing my condition effectively.

I couldn't talk to my parents or siblings about my bipolar, friends were told a few scraps more and my husband was carrying the load when it came to how I was coping or, often, not.

So I took a deep breath and called the number in the advertisement. A calm, professional voice answered and after a brief conversation with the founder of the group, Susan, I was given an address and time for the next meeting. I turned up, palms sweating buckets with nerves, on the designated night.

It was winter and the address was a little council house in Northcote, strangely surrounded by a tall, barbed-wire topped fence. It was so dark I couldn't see the way to the gate, I fumbled with the latch, then the door to the house was stuck fast and I couldn't get in. I heard laughter as someone struggled with the door. This gave me the chance to dither. I panicked. Should I bolt back to the car and race off into the night? Quick, Sally, run my conscious-self screamed. Running away from pain, you see, is in my head, in my blood...I did it so often.

I thought perhaps here was a place I could safely rest the burden I'd been lugging so long.

But the door was suddenly thrown wide open. There was nowhere to run. Light hit me. And there stood the founder, Susan. She welcomed me with a big warm hug as did Natalie, another stalwart member of the group, and Dee who now provides the lovely new space where we meet, surrounded by brilliant artworks by people with mental illness.

And at that moment, when I was welcomed with hugs from strangers on a bleak Melbourne night, I thought perhaps here was a place I could safely rest the burden I'd been lugging so long.

What struck me most that night was that these women did not look like they had a serious mental illness. I know that sounds bad to the recovery movement and shows how alien I was to it then. They did not speak like victims, their passion for life was, and is, thoroughly infectious. They talked of bipolar in an articulate way, they even made jokes about it and their bouts of craziness.

I found in that dark little council house that I did not need to be so secretive. And when I went to drive home from that first meeting I was in floods of tears and sobs from my gut. It wasn't just relief at starting to learn a vocabulary (outside of the analyst's warm office crowded with divertingly good art). For here I was, finally talking about my bipolar with its psychoses, depression, mixed episodes, weight gain from drugs and heart-breaking self-confidence snaps that always came hard on the heels of the florid, exciting manias to women who understood, and better yet shared their experiences and helped me learn to cope, even thrive.

This meeting was the start of the slow cracking and shedding of the secrecy I'd built around my bipolar self for the previous ten years.

The Bipolar Babes, started by Susan, is a group of about 10 women who have bipolar 1 and 2. We are a friendship group, we don't have a clinician chairing our meetings. We all either work, have worked or are studying, are committed to the clinical support that helps us and have in common a desire to make the most of our lives in the face of the challenges of our diagnoses.

We are not a large group but we are committed to each other, helping when one plumbs the depths or heads for the heights.

We are not a large group but we are committed to each other, helping when one plumbs the depths or heads for the heights. Some of us have become close friends outside the group and this means we call and visit each other when we're anxious or struggling with insomnia or worse. Sometimes we just go for a walk and talk.

Says Susan, the founder: ``When I finally had a formal diagnosis of bipolar disorder after another debilitating episode I felt so lonely trying to recover and rebuild my self-esteem. I knew there must be others out there like me who felt this isolation … women who lived with bipolar disorder but were not defined by their illness … women who wanted to share the language and experience of mental illness with friends who would be there for them through the ups and downs. How lucky am I!!!’’

> *Trying to articulate this complex condition to others is very hard. Bipolar Babes has been a lifesaver.*

Says Nat: ``I first met the Bipolar Babes nearly four years ago. When I met Susan and the other members, I was overcome with a sense of relief. These women knew exactly what it was like to experience the highs and lows of bipolar episodes. They could identify with this completely. Trying to articulate this complex condition to others is very hard. Bipolar Babes has been a lifesaver. I’ve formed very close friendships with the group members - their support, kindness and compassion has made a world of difference. I honestly don’t know where I’d be without them.’’

Says Dee: ``Hope is very important and you can have a family, a partner, a career. I’m living proof to others and myself that it can be done. I’ve been hospitalized … I’ve confronted every fear from losing my kids and husband to losing my friends, money and my mind.

> *… we’re slowly realising we could be a formidable group.*

``I’ve confronted all these things head on,’’ Dee says. ``Do I fight or flight? How do I undo the damage? I want people to know even when they are in the depths of depression they can be saved and you can come back even stronger. Facing it makes you more resilient for the future. And we are also carers.’’

We Bipolar Babes don’t sit around and moan. We often go out for dinner and chat, and mental illness sometimes won’t even come up. We’ve had picnics and gone to the movies and we’ve discussed writing a pamphlet to go into GPs’ surgeries as a guide to help people diagnosed with bipolar, because we all remember when we were given our diagnoses and turned out onto the street, knowing little about bipolar and less about to start searching for help. We share information and experiences with medications, aromatherapy, diet, spirituality, relationships and more.

Recently we started work on a strategy to lift our profile and help other women by using the professional and personal skills we have. And we’re slowly realising we could be a formidable group.

At first I felt I was becoming part of a secret society. But thanks to my heavenly husband, highly gifted talking-therapy doctor, Luis Riebl, and beautiful and supportive Bipolar Babes, it’s a secret I’ve just spilled. I’m lugging the load no more.

★★★★★★★★★★

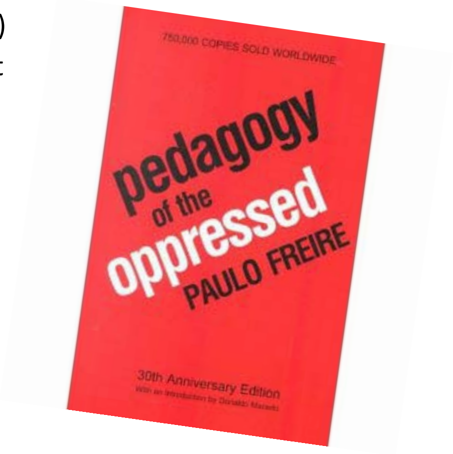
For further information about the Bipolar Babes, call Susan: 0409 552 691.

★★★★★★★★★★

FEATURED ARTICLE

The consumer/survivor movement and Paulo Freire's *Pedagogy of the Oppressed*

By Flick Grey, based on a her talk at the Consumer Day, TheMHS Cairns, 2012



Paulo Freire's book *Pedagogy of the Oppressed* (1968) is a classic text in radical education. At first glance, it isn't directly relevant to mental health – Freire was writing in Portugese about the education of illiterate peasants in Latin America in the 1960s! This topic wasn't my idea, it was suggested (somewhat enthusiastically) by Ross O'Donovan, one of the organisers of The Mental Health Services (TheMHS) consumer day in Cairns (which was held in August 2012). I'm often wilfully non-compliant if someone gives me directions on what I should talk about, but I trusted Ross's thinking – whacky as it often appears at first glance – and once I re-read Freire's work, with a specific focus on how it might be relevant to the consumer/survivor movement, I found myself utterly compelled, and grateful for Ross's enthusiasm and non-conventional thinking.

There's so much in Freire's writing that is relevant to mental health, if we think about mental health in the context of social justice, rather than the narrow scope of health. While there are several concepts that are generative, the central theme I take out of the book is Freire's articulation of the kinds of *relationships* that ought to underpin mental health systems. As I read, I was thinking about the little pockets in which such relationships are currently being built – I was thinking specifically about Intentional Peer Support, Voice Dialoguing and (possibly) Recovery Colleges (so long as they are not education in the "banking" sense – see below. For more information about Recovery Colleges, see Repper et al's 2012 briefing paper *Implementing Recovery through Organisational Change* – available at www.centreformentalhealth.org.uk).

I will outline a few generative concepts from Freire: Subjects, education, words, dialogue and finally *Conscientizacao* (and no, I don't know how to say that one out aloud!). These are relevant to therapeutic relationships, but also more broadly.

> *... people desire to be Subjects – those who know and act – rather than objects, that are known and acted upon.*

Subjects

Freire writes that people desire to be *Subjects* – those who know and act – rather than *objects*, that are known and acted upon. He describes this as "man's ontological vocation," what we are born to do – to act upon and transform the world. In so doing, we move towards ever richer and fuller lives individually and collectively. He notes that subjects are able to participate in dialogue, whereas *objects* have which interventions or treatments are performed upon them. He specifically notes that it is dehumanising and oppressive to be the objects of humanitarian action. Too often in mental health, consumers are treated as objects (or "treated" as objects), albeit objects of benevolent action.

Education

Freire's discussion of education is of course central to this book – the word "pedagogy" in the title invokes educational theory. In the context of mental health, this discussion of education is relevant both to how worker-client relationships can be analogous to teacher-student relationships, but also more broadly in the way in which recovery can be reconceptualised as "learning." For example, in Intentional Peer Support, the first principle is "Learning vs Helping" – shifting mental health relationships from "helping" towards co-learning. Likewise, voice dialoguing involves learning more about one's voices, and Recovery Colleges are of course about framing recovery as an educative endeavour.

Freire is critical of much of the way education is approached in practice. In Freire's analysis, the dominant, oppressive notion of education is a "banking" concept, whereby teachers deposit information into students: students receive, file and store these deposits. Under this model, "the teacher thinks and the students are thought about" and "the teacher chooses and enforces his choice, and the students comply." (p.54)

He says this "banking" concept of education, combines with "a paternalistic social action apparatus," with the result that some people are constructed as recipients of welfare, as individuals who have deviated and need to be taught how to get back on track. "Banking education" is about "filling" empty minds. A consequence of this approach is that it mystifies both knowledge and the process of learning, and teaches us that "someone else" knows more than we do. It treats students as objects of assistance, and in so doing, it inhibits creativity and domesticates.

"The teacher is no longer merely the-one-who-teaches, but one who is himself taught in dialogue with the students, who in turn while being taught also teach. They become jointly responsible for a process in which all grow." (Freire, p.61)

He contrasts this "banking model" with "problem-posing," dialogical education, in which teachers and students collaboratively approach issues that are of relevance to the students' lives and together they engage in critical dialogue. In such an approach, participants specifically endeavour to explore the world. It encourages critical thinking and meaning-making. It is grounded in creativity and stimulates true reflection and *action* upon reality. It acknowledges people as having a history (what we would call "lived experience") and is very consciously grounded in that.

People are – and these are my words, not Freire's – meaning makers. We don't need deposits made into our heads – like education about how to give up smoking, medications given to us against our will or mystifying diagnoses that "explain" our experiences. These are all "banking approaches" and they treat us like objects.

"They do not come to teach or transmit or to give anything, but rather to learn, with the people, about the people's world." (Freire, p.161)

Instead, Freire calls for education to be based on a relationship of mutuality, where the educator and the student are together on a mutual journey of discovery. For anyone familiar with Intentional Peer Support, this might be ringing bells loudly (including, the tasks of exploring "worldview" and "mutuality", and the principles of "learning instead of helping" and "relationship rather than the individual"). These are the kinds of therapeutic relationships I pursue.

Words

Freire speaks of the importance of being able to speak our own words, and of oppression as being robbed of our words. He writes of Subjects speaking our world, in dialogue, naming the world and hence transforming it (he notes that this naming of the world must be an act of humility). In my understanding, this is about being able to name our experiences, to express them in terms of our own worldview, rather than having our experiences “explained” in other people’s words – like a diagnosis. Freire says “it must not be a situation where some name on behalf of others.” (p.70). For me, this resonates loudly – the main diagnosis I was given has a really silly name, and isn’t how I would describe my own experiences. This process of giving words to one’s experience is complicated – I am still learning to speak of my experiences *in my own words*, not the words that were given to me by others.

Parts of Freire’s analysis could almost have been written specifically about (some) psychiatrists, for example this paragraph:

> treat[ing] the oppressed as objects to be analysed, and (based on that analysis) presented with prescriptions for behaviour. … someone who decrees the ignorance of someone else. The one who is doing the decreeing defines himself and the class to which he belongs as those who know or were born to know … The words of his own class come to be the “true” words, which he imposes or attempts to impose on the others … whose words have been stolen from them. Those who steal the words of others develop a deep doubt in the abilities of the others and consider them incompetent. Each time they say their word without hearing the word of those whom they have forbidden to speak, they grow more accustomed to power and acquire a taste for guiding, ordering and commanding. (p.115)

Dialogue

For Freire, the act of dialogue is liberatory. In looking critically at the world, in a dialogical encounter with others, we come to recognise the contradictions in our lives (ie. the dialectical relationship). This process overcomes the paternalistic teacher-student relationship (in Freire’s context), or the worker-consumer relationship (in the mental health context).

Freire also refers to the work of Martin Buber, who makes a powerful distinction between *I-thou* relationships (which are Subject – Subject); and *I-it* relationships (which are Subject – object). Real dialogue necessitates and *I-thou* relationship, where both participants are Subjects. Freire stresses that dialogue is not about one-way communiqués from the elites to the masses! I’d argue that Beyond Blue posters, or the patronising posters that you see plastering so many waiting rooms, telling you that cannabis can cause psychosis (tut, tut!), that smoking harms your health (who knew?) or to eat a healthy diet (no more comfort food!) are the kinds of non-dialogical communiqués that Freire is denouncing. These are, I would argue, objectifying us, rather than engaging in dialogue with us.

To really engage in dialogue, you must have faith, trust in people. Freire warns that “without this faith in people, dialogue is a farce which inevitably degenerates into paternalistic manipulation.” (Freire, p.72)

To really engage in dialogue, you must have faith, trust in people. Freire warns that “without this faith in people, dialogue is a farce which inevitably degenerates into paternalistic manipulation.” (p.72) He also writes of having a “profound trust in people and their creative power” (p.56). Again, this reminds me of the Intentional Peer Support principle of engaging from a place of hope, rather than fear and contrasts with anti-smoking policies and campaigns – do they really have faith and trust in us, or are there elements of “paternalistic manipulation”?

Conscientizacao

Conscientizacao is really the culmination of the previous concepts and is Freire's ideal education environment. It refers to "looking critically at the world in a dialogical encounter", or "learning to perceive social, political, and economic contradictions and to take action against the oppressive elements of reality." It's a combination of reflection and action. He writes that a peer can facilitate the process of *conscientizacao* better than a "teacher" brought in from the outside – a clarion call for peer support! He writes that "At the point of encounter there are neither utter ignoramuses nor perfect sages; there are only people who are attempting together, to learn more than they now know." (p.71)

> *"Even if people's thinking is superstitious or naïve [or psychotic or anxious] it is only as they rethink their assumptions in action that they can change. Producing and acting upon their own ideas – not consuming those of others – must constitute that process." (Freire, p.89)*

How is this all relevant to mental health?

This intersection between learning and "recovery" is becoming clearer for me.

I have already mentioned Intentional Peer Support, but this also reminds me of voice dialoguing, of making sense of voices, exploring them, learning about them, rather than controlling them, or having medication or another person control them.

And then there are Recovery Colleges, where consumers can go and enrol in courses, to learn things that we want to learn, like techniques for dealing with traumatic responses, or budgeting, or how our medication works on our brain chemistry. These are based on the idea that there are things we want to know more about, and that an educational environment, rather than a "treatment" environment, can be transformative. It needs to be stressed, though, that Freire's observations about "banking" vs "problem-posing, dialogical" educational models are relevant here – a Recovery College would not be worthy of its name if it used a "banking" model.

> *"The important thing, from the point of view of libertarian education [or mental health recovery], is for the people to come to feel like masters of their thinking." (Freire, p.105)*

Finally, I wanted to include a provocation: ***Is the concept of oppression a good "fit" for mental health?***

On the one hand, there are clear cut oppressions. For example, the European Network of Users and Survivors in Psychiatry are calling for a Truth and Reconciliation process in mental health – a process like they had in South Africa post-apartheid, where the community would publicly bear witness to the harms people have experienced in psychiatry. And it's not just critics of psychiatry who are calling for this – a similar argument has been made by Mike Slade, who many of you may have heard of – he's a prominent UK psychologist and was the keynote speaker at the Inaugural Recovery Forum in Melbourne in June this year, which was hosted by our own Chief Psychiatrist, Ruth Vine. Slade has argued that the first step towards genuine partnership with people with lived experience should be a public apology for the wrongs done in the name of psychiatric treatment. Slade writes that 'real reconciliation and partnership may only be possible once a line has been drawn, through the symbolism of an apology, which explicitly recognises the need for a new trajectory in the future' (Slade,M. (2009) *Personal Recovery and Mental Illness*, Cambridge, Cambridge University Press). He argues that public apologies are justified when the dominant group has inflicted harm on the subordinate group over a sustained period. While a few very specific apologies in psychiatry have been made – for harms inflicted upon individuals – there hasn't been general acknowledgement of wrongful treatment. And we have a profound, deafening silence around continuing wrongful treatments.

On the other hand, I don't think it's that simple. Many people come to the mental health seeking – and finding – support and healing. I see a professional therapist myself, and while there is still a lot of learning she can do through working with me, I voluntarily seek out this time and pay for it because her services are useful to me. Perhaps a significant part of this usefulness is that she grounds her work in her own experiences of "having suffered." The question is, do we use our experiences and relationships to engage in a dialogic, meaning-making encounter – possibly even *conscientizacao* – with another Subject who is free to name their own world, or do we "teach" or "treat" someone, as an object. These questions are as relevant to peer relationships as professional ones. Freire gives us some tools to articulate what socially just relationships in mental health contexts might look like.

* * *

References in this article are to the 1996 Penguin edition of *Pedagogy of the Oppressed*. The book is also available online for free at:
http://69.195.71.185/_media/resource/freire_pedagogy_of_the_oppresed.pdf

* * *

THUMBS UP/THUMBS DOWN

1. **THUMBS UP:** to mental health workers who work alongside us, recognising that they have much to learn from us.
2. **THUMBS UP:** to all consumers who stick at very difficult jobs in the mental health sector trying to make things better for others.
3. **THUMBS DOWN:** to consumers on the Speaking Circuit who have turned themselves into a commodity, or who tell their stories in educational contexts for their own therapy.
4. **THUMBS UP:** to consumers who use story in thoughtful, powerful ways.
5. **THUMBS DOWN:** to consumers who use story which degenerates into anecdote and then degenerates again into gossip, or who tell their stories completely oblivious to how other people are affected by it.
6. **THUMBS UP:** to increased checks and balances for any use of Electroconvulsive Therapy (ECT), as proposed by changes to the Mental Health Act.
7. **THUMBS UP:** to freelance reporter Joel Magarey who wrote the best article on mental health we have seen this year. Monday October 8th 2012 in *The Age*.
8. **THUMBS DOWN:** to consumers sitting on committees who forget they are consumers!
9. **THUMBS UP:** to Sue Kidd from Bendigo Campus of LaTrobe University who is completing a PhD on consumers as culture changers in mental health services.
10. **THUMBS DOWN:** to the feeling that there is never enough time to get *everything* done ...

CAMPFIRE

4 mental health week

@

CERES

Environment Park, Brunswick

Sat 13th Oct ~ 6pm – 10pm

All consumers – labelled & no-name, families, friends, mh workers & everyone invited to get together under the stars *

acoustic musicians – home cooking maestro’s
also needed to help create this fabulous night really pop
The Campfire is an all ages & creeds event to celebrate Life
(family friendly drink only please)
Bring your torch, yummies, warm clothes

CERES
African Village Fireplace
Parking at main carpark - corner Stewart & Roberts Sts.
Brunswick
(follow the lights, laughter..)
Deets? skybeanz@gmail.com