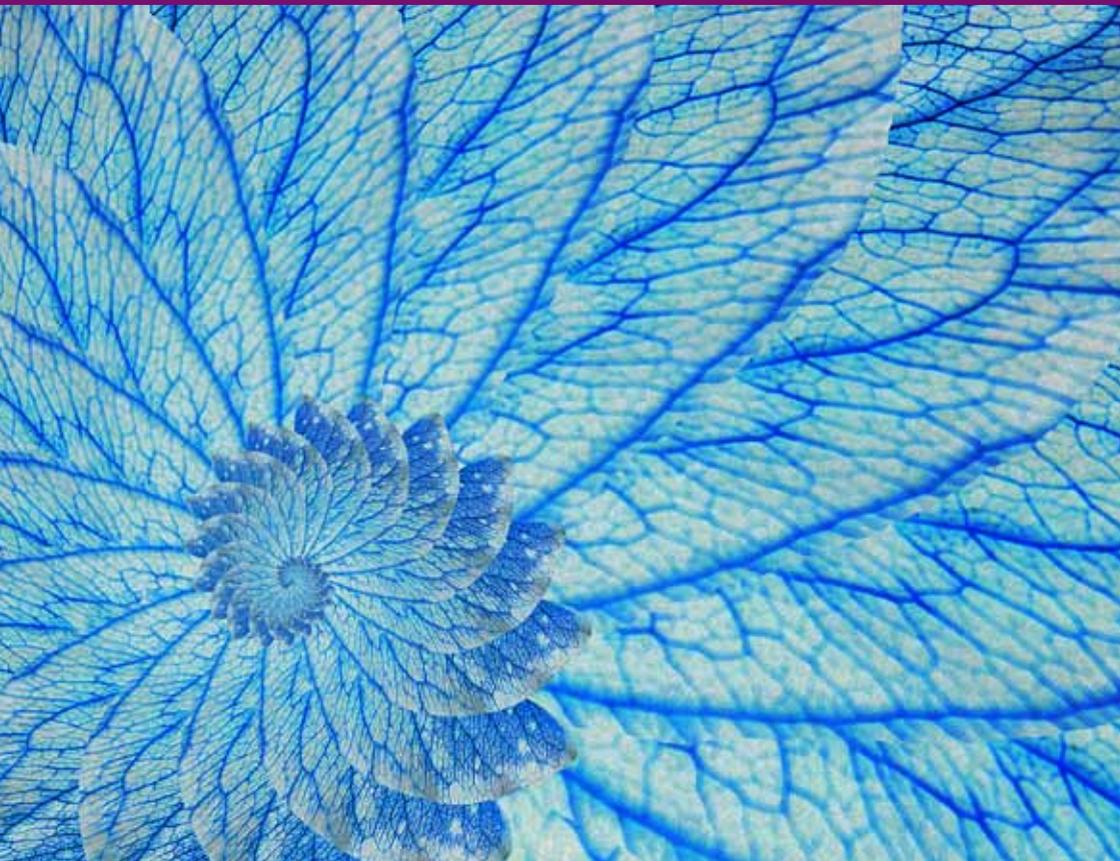


FLIP SIDE

The Association of Participating Service Users



Consumer Participation

No. 33 Summer 2013

INSIDE

Articles and Stories:

Editorial

Learning Curve

Why? Why Not?

What I've Gained

Being Involved

Hopeful

Our Silence Lets Others Define Us

Poetry:

Fifteen

Australia, God's Sunburnt Masterpiece

Art:

Luna Park by John La Mude

Front and back cover:

Ben J

Photos:

Mat

EDITORIAL

After a history soaked in blood and injustice, and two world wars, the nations of the world have united and in December 1948 put together 30 Articles of what they called The Universal Declaration of Human Rights. This document gave a foundation to the multitude of social movements that shaped the second half of the 20th century. The world in the '50s was a very different one from the world in the '90s (at least in the 'developed' part of the world).

The human rights movement included the international health policy. The 1978 International Conference in Alma-Ata set up the goal "Health for all" and this goal is still the driver of the World Health Organisation's (WHO) work. The Declaration of Alma-Ata is considered a milestone in international health policy. The declaration consists in 10 points, and community and individual participation is a major component throughout the document.

continued on next page

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Participation is also the main ingredient in the process of WHO's Human Rights Based Approach to Health. WHO views participation as a democratic right as well as an accountability method:

“Participation and inclusion means that people are entitled to active, free and meaningful participation in decisions that directly affect them, such as the design, implementation and monitoring of health interventions. Participation increases ownership and helps ensure that policies and programmes are responsive to the needs of the people they are intended to benefit.”

In 2006 the Victorian Government issued the policy “Doing it with us not for us”. This document set out a strategic direction for consumer participation in the Victorian health service system. It put forward three main reasons for participation: service improvement, democratic right and accountability mechanism.

Consumer participation has found its place in the Victorian health system, particularly in disability and mental health. However consumer participation in Victorian alcohol and drug service system is still developing and encountering many barriers, lack of specific funding being probably the major one.

However consumer participation in Australian alcohol and drugs service system claims a major victory. When HIV AIDS hit in 1980's Australia has developed a uniquely efficient response. Health professionals and members of community sat around the table and came up with a set of strate-

gies to prevent this deadly virus. In alcohol and drug services it resulted in development of the needle and syringe program. Thirty years later Australia can claim an international gold medal in the battle against AIDS. This victory would have not been possible without the involvement from Australian consumers.

In this issue you will read the stories from people who got involved and shared their life experience to improve services for their peers. Their stories are patchworks of empowerments and disappointments, satisfactions and frustrations, uncertainties and pride – this is the story of consumer participation in Victorian alcohol and drug sector. There is certainly much left to do, but it is happening.

Thanks to all those who have contributed their stories and to all those who have ever participated.

Bibliography

‘Declaration of Alma-Ata’ available at http://www.who.int/publications/alma-ata_declaration_en.pdf

‘Doing it with us not for us’ available at <http://health.vic.gov.au/consumer/pubs/doing.htm>

‘Human Rights-Based Approach to Health’ available at http://www.who.int/hhr/news/hrba_to_health2.pdf

‘Rampant’ a documentary about Australian response to the AIDS epidemic is available on YouTube.

‘The Universal Declaration of Human Rights’ available at <http://www.un.org/en/documents/udhr/index.shtml>

LEARNING CURVE

A couple of years ago I spent a number of months in a rehabilitation program. The program was fantastic and the workers there were the first people to introduce me to the idea of consumer participation/activism. The rehabilitation program was one of many services offered by a particular drug and alcohol organisation. One day, there was a flyer from the organisation on the program fridge stating that, for the first time, a consumer advisory committee was to be established and positions were open. I was really excited. A few of us in rehab were interested and, after speaking with the rehab workers and filling out a brief form, we became some of the committee's first members.

Our consumer advisory committee was very informal. It was not a paid position and after a while there was no process for joining, membership was granted on the spot. In some senses I liked the informality of it; we consumers were quite close to the Drug and Alcohol workers who made up half the group. The atmosphere was welcoming and, at the start, relaxed. At the same time I would become quite frustrated because a lot of time (meetings only ran once a month for an hour) was spent chatting and not much would be accomplished. Another annoying aspect present from the beginning was the tendency for a couple of loud males to dominate the group, making jokes and constantly interrupting. I felt that it was an oversight on the part of the group facilitator not to address these issues. At the start, another woman and I suggested we develop a set of rules/guidelines for group members – but this was never followed up on.

Our committee worked on a number of interesting projects. The organisation we worked for was looking to overhaul their services at one point; how they were run and also the presentation of promotional material. This was probably the biggest project we worked on. Our committee met with board members so that they could hear our ideas for change. This was the only time I really felt that our contribution was tokenistic. Some really important, pressing issues that were raised were ignored, and only the least radical ideas acknowledged and noted down. We also examined the issue of the (then) recent reforms regarding the banning of smoking in detox and rehab facilities. We put together an art and poetry exhibition for Drug Action Week, which was great.

Unfortunately, the group became more and more casual and disorganised – turning into more of a monthly social gathering. A lot of the D&A workers began to miss meetings so it was almost entirely consumers and the facilitator attending. The same loud people dominated and I would have to shout to be heard. Also, the

meetings started to revolve around a lot of drug banter – who had done what, how much, who had been the most ‘hard-core’ drug user. This frustrated me immensely and I think the oversight regarding group rules was a big one. I also should have said something at the time, but I was too shy. I would not be now after that experience.

The group had a lot of potential. There definitely needs to be a social component to any advisory committee, but when this becomes the driving force there is a problem. Perhaps if it had been a paid position and membership entry was more involved people might have taken the role more seriously. I am no longer an active member, but stay in touch and can return at any time. Perhaps it is run differently now. Overall I have to say that I think it is fantastic that this organisation does have a consumer advisory committee – I think it is the obligation of any organisation like that to have one. The consumer participation movement fills me with excitement and I am very proud to be a part of it.

Anonymous



WHY? WHY NOT?

As a long term service user I can honestly say that consumer participation is one of the most valuable tools any drug and alcohol service can have. Not only is it empowering to the service user, it is also one of the most important ways drug and alcohol workers can connect with their clients and make them a real part of their own recovery.

By engaging service users in real and meaningful consumer participation such as board positions, having service users as part of the staff recruitment panels or even engaging service users in peer positions you are giving them a voice and some ownership in their recovery and life direction. Taking ownership of our addiction is a major part of our recovery and as we are the ones who have lived with the scourge of addiction it makes perfect sense that we might have some good ideas regarding what is helpful in our recovery and what is not.

We don't want to take over services and we are not suggesting we know more than the qualified workers but we do have insight we could share regarding what works and what doesn't. If we could come together surely we could all benefit from the experience. The nature of addiction is reoccurring and chronic. This suggests to me that clients of drug and alcohol services are often involved for long periods of time. If this is the case then it would make sense if the worker and the client could build a relationship based on respect and understanding rather than power that this would be far more beneficial to both and more indicative to recovery.

The mental health sector long ago realised the power of consumer participation in regards to their clients' recovery and ongoing well being. One only has to look to this sector to see consumer participation in action. There is no reason why the drug and alcohol sector can't follow suit and build an army of talented and experienced consumers who are ready to participate.

So it seems to me the question is not, Consumer participation, why? But, Consumer participation, why not?

Anonymous



WHAT I'VE GAINED

I have been a committee member of a Consumers and Carers Advisory Council for two years. In that time I have been impressed at times by AOD and mental health professionals. They have been involved with our council and willing to work with consumers at all levels to create better results for all people using AOD and mental health services. Everybody now understands that to get the best outcome for consumers and carers we must work hand in hand.

I have gained so much information to help myself and other consumers. So please if you can spend the time, become a member of consumer groups. You will find that you become a well informed consumer and this will help you understand what workers do for all of us, as it did for me. You will be impressed with how much workers do for us and are willing to work with us, which was not happening in the past. Like most consumers, in the past I had found workers not interested in us, but in the last three years things have changed. Workers now understand that they need consumers and carers involved in the detoxes and rehabs and that when consumers are involved outcomes get better.

Being part of advisory committees and organizations helps you grow and understand that you do have a say in how you get treated. So don't be scared to join any consumer committee and get involved. In the early days APSU saved my life for being there for me with training and advice on any level. So if you want to be part of a group, APSU will help you with information on where the groups operate from and times they meet.

FIFTEEN

Custody is just a bed for the evening,
Time to sober up, it's been a long day deceiving,
Got his apprenticeship hanging
around under the clocks,
Learnt to be cold as stone, and quick as a fox.

Time doesn't matter, and what are dreams?
When life is over at fifteen.

Home is not an option and people don't understand,
Inside that little, little body is a weary old man.

Time doesn't matter, and what are dreams?
When life is over at fifteen.

Anonymous



BEING INVOLVED

A year ago I felt I needed to do more than simply not use if I wanted to stay abstinent and enjoy my life. One of the things I did was to become involved with the Southern Region Community Advisory Council (SRCAC). All the members of the Council have experience using AOD services, either personally or as family members, and have a desire to make use of this experience so that those who come after us can have an easier journey toward the life they want for themselves. There is self-interest too; even though I am travelling pretty well these days, I don't have any guarantee that I won't need to use these services again in the future, so I may reap the benefits of change myself.

I have some responsibilities in the group, being careful not to take on more than I can handle (I can't afford too much stress) but enough to feel useful and that I am making a contribution, however small. I am remembering old skills I had forgotten about, and developing new ones through training and opportunities that being on the Council provides. The best bit for me, though, is getting to sit around a table with people whose lives have taken wild turns they would never have chosen for themselves; who have survived, and who want to help others. I find this inspiring, and it helps me when I really don't want to be bothered with what I know I have to do to stay well.

Through my involvement with SRCAC I was invited to take part in another group formed by the Health Department to advise on the process of change in the AOD Service Sector. In this I have the opportunity to share my experience of what it is like to be in 'the system', and how it is when one's partner is struggling with their drug and alcohol use. As someone in recovery, I also know a thing or two about change! I firmly believe that these professionals are well-intentioned and want the best for me and my family, and I believe that my experience can help them to help others. This is great! My suffering, and the suffering I caused others, can have some value, some purpose.

Consumer Participation isn't the only thing I do for my recovery, but it is an important part. While I get paid to attend these meetings and I keep an ear out for opportunities of further work, the money is only one of many benefits I get from being involved. I have learned that there is no one 'right' way to recover: that everyone is different and gets to choose their own goals. This, then, turns my thinking to what I want from my life now, what has helped me in the past, what

continues to work for me, and what I need to do for the new goals I set myself. I guess I am reminded that I get to choose my own path, and I find this liberating.

I notice some growth in myself also. I'm not as exhausted after a meeting. I can listen more closely and understand more. It feels normal now to be sitting with people who are very different to me, who have important things to share, and I can respect them for who they are. I can see the progress I am making towards being the person I want to be, and this makes me glad and grateful for the opportunity to be involved.

Richard



Luna Park
by John La Mude

HOPEFUL

I am the carer representative on the Residential Rehabilitation Advisory Group Panel for the Victorian Alcohol and Drug Strategy.

We have only met on one occasion and the time just flew. There were so many items to discuss.

There was a very interesting discussion regarding what works and what is not effective for clients in remote areas and this took up a large amount of time. These issues needed to be aired but it might have been more productive to have had a time limit on items for discussion.

I had endeavored to have my say on a couple of topics, but I had little impact as there were others who wanted to make sure they were heard and virtually spoke over me. However at the end of the session the facilitator, who obviously noticed my reticence when others spoke over me, said she would make sure I had more opportunities to put my views forward at the next session.

Now that I am aware of the procedure at the Panel discussions I shall be better prepared and have notes to refer to, so if I am cut off, I shall be able to resume where I left off without difficulty.

Although I felt a little frustrated with the process on this first occasion I am hopeful of greater involvement in future sessions.

Anonymous

OUR SILENCE LETS OTHERS DEFINE US

I have been reflecting a lot on this question in the last few weeks since I attended the APSAD conference last November in Melbourne. A fairly prominent research academic during her keynote address made the comment that “recovery is a solution in search of a problem”.

This rather clever put down plays on the fact that recovery as a solution is largely defined by the person in question. If the solution is self-defined then surely so is the problem.

As a person in recovery I was irritated and I'm a bit sick of all the recovery bashing of late so I decided I was going to speak up. With heart in mouth I went up to the speaker afterwards and suggested that if she wanted to know what “problem” recovery is a solution to, then perhaps she should ask the people in question.

I was firmly reassured that “Consumers find recovery meaningless” as if it were a well-known, well-accepted fact!

I was stunned.

As a treatment service user (I hate the word consumer as it implies a commercial transaction) and a person in recovery, I felt I had been told that my experience was meaningless.

My experience is not meaningless. I fully accept that not all treatment users would use the word ‘recovery’ or even accept the concept. But I am a treatment service user (aka “consumer”) and recovery for me is not meaningless. Nor is it some solution looking for some unknown, undefined, unmeasurable, non-existent problem. My problem was rampant uncontrolled addiction and recovery was my solution.

I didn't tell her that I was either a treatment service user or in recovery - I felt exposed enough as it was.

But I did ask her if she had seen the recent survey by ReGen of their ‘consumers’. She said she hadn't so I described how ReGen asked the question, “What does ‘Recovery’ mean to you?” offering three options.

Eighty-eight percent ticked “Yes, it's a good way of describing what I'm trying to

achieve” and twelve percent ticked “No, it’s not relevant to my situation”. Even more tellingly none of them - zero percent - stated “Don’t know. I’m not really sure what it means.” Though a small percentage of ReGen’s consumers did not find recovery relevant NONE of them found recovery meaningless.

ReGen concluded that “the findings do provide a clear indication that the concept of recovery is an important one for many.”¹

So in response to this evidence, I asked her on what basis she made her claim. Irritated, she cut me off, tersely thanked me for my ‘comment’ and walked off.

Had I got the chance I would have asked ‘When you say “consumers” find recovery meaningless, consumers of what? Consumers of drugs or treatment services?’

The word consumer is used in this sector with incredible ambiguity. Drug consumers who have no need or interest in recovery are probably quite likely to not have much idea of what it means. Some drug consumer representative organisations have made quite clear, they have no interest in representing people in recovery or those seeking recovery, indeed they reject the concept as “artificial, unhelpful and stigmatising”.

It would be really interesting to know if the people they claim to represent feel the same way. As an ex-user they claim to represent me - as a person in recovery, they say go somewhere else. It’s all very confusing.

Yet at the same time they claim exclusive leadership in consumer representation in the demand reduction space including recovery oriented services such as rehabs and therapeutic communities. The logic is that only people with connections to the community can represent the community. That sounds all very wholesome until you unpack what does “community” and “connections” mean.

- Are people from the drug using community really the best representatives for those people who are trying to escape from that community?
- Are people who reject the notion of recovery the best representatives for those people who are seeking it?
- What do the 88% of ReGen’s clients who say they are seeking recovery want?

- Would they prefer consumer representatives who find their goals “meaningless”?
- Would they prefer consumer representatives who find the language they choose to use to describe their aspirations repugnant - “artificial, unhelpful and stigmatising”?
- Or perhaps they would prefer representatives who have succeeded in achieving the same goals they aspire to?

It is really important that us treatment service users speak out and challenge those who claim to speak out in our name without a genuine mandate. Because there are plenty of people in this sector who will try and do so to further their aims.

Remember “By our silence we let others define us” and we can’t let that keep happening.

1. ReGen’s Recovery Survey - <http://www.regen.org.au/news/287-recovery-survey>

Anonymous



AUSTRALIA, GOD'S SUNBURNT MASTERPIECE

A woman stands at Earth's front door,
Protective of her child.
She feeds it from her ample store
With Nature reconciled.

God fashioned her from Nature's best
In style and temperament,
From cavern's depth to mountain's crest,
His island continent.

She blooms as does a flower fair
Where oceans lap her feet,
In drifts of snow her mountains wear,
In burning desert heat.

Her patience fashioned tenderly
From blend of creed and race,
Of wild-life, rare, her beauty be,
Of Rock and Reef, her grace.

She suffers drought's hostility
And, steadfast, bears the pain,
Resilient in adversity
'Til falls the blessed rain.

When first her sons marched off to war,
A foreign land their stage,
Her infancy closed firm its door
And, strong, she came of age.

She lives while full, her rivers flow,
Gives generously her soil,
When tapped, her depths, for wealth below,
Gushed forth the precious oil.

She is our home, our nation,
May bonds with her ne'er cease.
The pride of God's creation
Is His sunburnt masterpiece.

George Hall



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Self Help Addiction Resource Centre

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