Reclaiming Our Power - Consumer Leadership in New Zealand

Background

In the New Zealand consumer movement we are attempting to move from consumer involvement and participation to consumer leadership. For some years the terms 'consumer leadership' and 'consumer led services' have been used without it being particularly clear as to what they mean or what, if any the difference is between leadership and involvement or participation.

Purpose

Kites is trying to determine if there is or can be a commonly held view of consumer leadership within New Zealand and what services would be like if they were consumer led.

The Project

The project consists of several aspects:

- Kites Trust as a case study
- Review of the publications on consumer leadership
- Interviews with consumers

The intention is to build on what has been learnt from this stage of the project and continue to work on meeting our stated purpose.

Defining Consumer Leadership

In order to be transparent and avoid potential bias for the project, we considered our own definitions of consumer leadership.

Suzy Stevens – *Consumer leadership is when a consumer or group of consumers have the power to make decisions which when acted on, bring about the outcome/s they want.*

Eileen McAtee - At *the start of this project my vision of consumer leadership was about individual consumers in roles with a lot of influence. After being involved with the interviews and research I now see leadership as something much broader- someone behind the scenes plugging away is a leader too.*

Case Study - Kites

Part of the project's purpose is to determine what services would be like if they were consumer led so we thought we would start by looking at our own organisation.

Aspects of Kites:

- Public perception sometimes that we are a consumer run organisation but actually we are not
- We do not provide 1:1 services to consumers, rather we work at a systemic level
- Majority of our funding is from the government via the local District Health Board
- We have a reasonably flexible contract for research and development

Governance

Kites is a charitable trust. It has a Trust deed and is governed by a Trust Board.

Trust Board

- 2/5 Trust board members identify as consumers
- Did have a consumer chairperson at one point
- 2nd consumer board member has only recently been co-opted onto the board
- Neither are currently office holders
- Nothing in the Trust Deed specifically requiring any consumer member /s (although the purpose of the Board is " To allow non-governmental organisation, mental health service providers and consumer representative organisations in the Wellington region to combine strengths and work collaboratively in a structured and formal way to meet the aims of the board")
- If there was a requirement to have consumer members, the board may have problems finding enough board members with the time and skills?

Operational

Kites is a small NGO.

Management

- Kites has a Manager, responsible to the board.
- Our manager is sympathetic and supportive of consumer issues but does not identify as a consumer
- Consumers are listened to – issues raised are acted on currently, BUT
- If our current manager left we would be in a vulnerable position.

Staff

- Currently 4 consumers in a staff of 7
- Some of the consumer roles are part-time
- There has been an ongoing practice of employing consumers at Kites

Policies

- Recruitment practice is to state in job advertisements that people with personal experience of mental illness are encouraged to apply
- Consumer participation - best practice & guidelines

Our findings

We looked at our own organisation in regard to Arnstein's ladder of citizen participation.[1] At the governance level Kites is at 'consultation' only (*where consumers may hear and be heard but lack the power to ensure our views will be heeded by the powerful - "lack of muscle."*)

At an operational level we could be seen as functioning at a level between 'consultation' and 'partnership'. (*Advise or negotiate with traditional power holders*.)

In light of this consumer leadership project we have to be honest and say that our own organisation although supporting the concept of consumer leadership, Kites is not obviously role modelling consumer leadership within its own structures.

Review of Publications[2]

"We want services led by us that enhance our autonomy, recognise us as whole human beings, expect our recovery and offer us a broad range of solutions and resources."[3]

There is not a great deal of literature available about consumer leadership but if consumer leadership is defined as participation that is aimed at the systemic level, then most of the literature about participation is also helpful in describing consumer leadership. There is some useful Australian work on this topic; the Victorian Quality Council (VQC) released a comprehensive report about consumer leadership in health last year[4] . Although written about the health sector in general most of the findings of that report apply to consumer leadership in mental health and reflect many of the themes that we identified when we spoke to consumer leaders in the Wellington area.

The VQC report describes the nature of consumer leadership as organic- that is it arises from and is embedded within a community of interest, which it remains accountable and responsible to[5] .Because of this it is essential that the role the consumer movement plays in setting the agenda and supporting consumer leaders is acknowledged by organisations in the mental health sector[6]

The VQC report found that traditional leadership qualities were required by consumer leaders in health with an extra emphasis on communication and negotiation skills. An overall sense of vision is also essential [7]

[1] Originally published as Arnstein, Sherry R. " A ladder of Citizen Participation," JAIP, vol. 35, No. 4, July 1969, pp 216-224

[2] See list of references in Appendix

[3] Mental Health Commission, 2004 Our Lives in 2014 p. 7.

[4] The Victorian Quality Council Consumer Leadership; report of the findings of a literature review and consultation process into consumer leadership February 2007

[5] Ibid,p. 2

[6] Ibid, p.31

[7] Ibid, p.22

Different viewpoints

Rob Warriner, who works in supported employment in New Zealand, wrote a provocative opinion piece for the Platform website last year[8]. He suggests that the time of a consumer movement in mental health is over and that the dividing line between mentally ill and sane is no longer a helpful one.

Brenda Happell and Cath Roper, in an article they wrote for the Australian e-journal for the Advancement of Mental Health in 2006[9], suggest that we should not get hung up on whether individual consumers are representative of the broader population of mental health consumers as research indicates that they prioritise the same issues. They argue it is also discriminatory because representative clinicians on committees or advisory groups are not required to prove that they are representative

Consumer Positions

Legislation and sector wide standards in Australia and New Zealand require health services to seek the advice; participation or involvement from consumers in all aspects of mental health services. Mary O'Hagan and Sarah Gordon have advocated for the benefits of consumers being placed into positions of influence as a way to ensure the consumer voice is heard[10].

The VQC report found that for consumer leaders to succeed we need a commitment at management levels to working in partnership with consumers[11]. Once that commitment exists the practical factors required like the necessary resourcing, scope and autonomy should follow.

Training

The VQC report on consumer leadership contains suggestions on the key areas for training and concludes that any training must include the whole sector.

"Programmes need to include health service providers and administrators, as well as consumers, because these groups strongly influence how effectively consumers can participate."[12]

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[8] Rob Warriner, The Consumer Movement and A Post-Institutional Mental Health Environment – Is There A Tension Emerging?, 2007 retrieved from http://www.platform.org.nz/page/157-Discussion-Starters+Consumer-Tension

[9] [9] Happell, B. & Roper, C,.(2006). The myth of representation: The case for consumer leadership. *Australian e-Journal for the Advancement of Mental Health,* 5(3), retrieved from www.auseinet.com/journal/vol5iss3/happell.pdf

[10] Mary O'Hagan, from participation to leadership opinion piece for Likeminds Newsletter , October, 2005. [10] Sarah Gordon The role of the consumer in the leadership and management of mental health services, 2005. Australian Psychiatry vol 13, No 4

[11] The Victorian Quality Council Consumer Leadership; report of the findings of a literature review and consultation process into consumer leadership February 2007p.31

[12] The Victorian Quality Council Consumer Leadership; report of the findings of a literature review and consultation process into consumer leadership February 2007 p.27

Peer Support Services

The recent growth in peer services is an opportunity to demonstrate consumer leadership. What can become problematic however is where these services interact with the health system as a whole, or if they are run as part of a larger organisation that is not consumer run. This is recognized in the VQC literature review:

". Consumers may be co-opted to the organisational and funding pressures rather than user demands. Funding agencies may not respond well to a consumer-run approach." [13]

The QVC literature review identifies the fact that evaluation of peer support services, which is still a developing area, may be problematic for some of peer run services:

"Despite growing empirical support, they have in many cases had difficulty convincing critics of their documented effectiveness, a phenomenon that may be amplified within an evidence based practice paradigm."[14]

Interviews

We had approximately a month in which to identify and interview people for the project. We approached people we knew and 'twisted a few arms' to eventually obtain interviews from 11 people who identify as consumers/service users from the Wellington area.

We selected participants[15] using the following criteria. They:

- Were known to us and living in or near Wellington
- Were available to be interviewed within our timeframe
- Were working in a position of responsibility in a mental health service, and some
- Had participated in:
    - the International Mental Health Leaders forums, and/or
    - the writing of 'Our Lives 2014'.

It is important to note that those interviewed did not self-identify as consumer leaders for the interviews. Some stated strongly that they did not see themselves as leaders and several found it difficult to agree with our suggestion that they might be considered as leaders. Exclusions made were consumers in the addiction (alcohol and drug) services and age-specific such as youth, older people. This was a matter of pragmatism and not desire. Future work on consumer leadership must address any differences between mental health and addiction consumers and determine how age may affect any definitions.

The interviews were face to face and took approximately 1 hour. There were 8 questions[16] asked of each participant.

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[13] P.61 Victorian Quality Council QC Consumer leadership: A Literature Review, 2007

[14] Hardiman ER, Theriot MT, Hodges JQ. 2005, Evidence-based practice in mental health: implications and challenges for consumer-run programs. Lyceum Books, Inc., *Best Practices in Mental Health*, Vol. 1, No. 1, Winter.

[15] Details of participants is provided in the Appendix

When asked how to define **consumer leadership** responses varied but some themes emerged.

- Leadership is hard to define – it is organic and relies on context
- Leadership can be within mental health services or the consumer movement which is not necessarily the same thing.
- Leaders need support from the wider consumer movement or a network of peers
- Leaders are respected, gain trust of others.

Leadership in the Consumer Movement

"For social change you need a very strong consumer movement."

We asked participants what they felt has been achieved by consumer leadership in New Zealand. Most felt that there had been achievements but that they were difficult to quantify.

[16] A list of the questions is in the Appendix

All felt that there have been at least some significant changes since deinstitutionalisation.

- The consumer voice is a lot louder. Items in the papers, on radio and TV.
- A lot of mental illness issues are out of the closet and in the public domain.
- Peer run services
- Consumer run agencies where there are people who have 'been there' offering information from their own perspectives.

There were those who described how as a movement we have to take responsibility for what is or isn't being achieved.

"The sector isn't listening to consumers. But we have to look at what we are saying….But that's another story."

I can be a leader in the movement without the mental health services. It is a question of mandate. People often claim to speak from the consumer movement without mandate. There is tension between the movement and the sector.

Some made comments about how fractured the consumer movement can seem to be and that we don't always support each other to be leaders.

"There's no virtue in being oppressed in, fact it shows you how to do it really well."

Consumer Leadership in Organisations

"Major mental health providers need a consumer presence in them. Counterbalanced by achieving organisational change slowly."

We asked participants to describe from their experience how organisations can support consumer leadership.

"Pretty simple really – encourage and enable the voice and put your money where your mouth is. Put your heart where your mouth is."

"If an organisation is totally consumer run it is more straight forward but if it is not consumer run then if it's not supported at the top level, forget it."

Common themes included:

- Having good networks/ sharing information
- Being properly funded / having enough resources
- Being paid at least at the same level as non-consumers - pay parity
- Offering consumers opportunities- there is no consumer career path
- Employment accommodations
- Opportunities to improve skills
- Training – academic level, business/accounting
- Having peer support and opportunities to meet with peers/likeminded people.

Designated consumer positions
There were opposing views regarding the creation of consumer positions in non-consumer organisations. For some, it was seen as a way to get consumers recognised in services.

"Even if a position is tokenistic, it has been a foot in the door"

Others felt consumer positions can be barriers in themselves.

"[Consumer positions] become opportunities to push or palm things off to consumers. It is similar to Mâori or Pacific positions in New Zealand. [We] become marginalised."

"If 'Consumer', 'Mâori' and 'Pacific' are the titles, then that is all they will ever be. They can be disregarded especially in a clinical versus consumer area. HoNOS is a good example of this. It's all about clinical stuff and the consumer side is ignored".

Barriers

We asked what were barriers to consumer leadership in organisations. Many spoke of the **discrimination** they had experienced.

"There can be the perception that consumer leaders are there to make lives difficult. It's attitudinal – 'Oh my god, here they go again, raking it up!'"

The **lack of buy-in** from clinical leaders especially psychiatrists was described as a barrier.

"…perception that consumer leadership is a threat to some of the current mental health professional in our management team."

For others a barrier they had observed was **self stigma** [in others].

"Consumers in positions not willing to disclose - don't want to be seen as one of them."

Some of those working in non consumer run organisations described the importance of integrity and **ongoing tensions** between staying loyal to personal beliefs and having to publicly stay loyal to their employing organisation.

"Who do you work for? That organisation? Or are you responsible to consumer networks? Both?"

"There is conflict between oneself and the organisation's beliefs."

"Politics are important. Unless you have a revolution (usually a violent one) nothing changes over night."

Cultural context

Consumer leadership in New Zealand must be considered in a cultural context. The terms 'tangata whaiora' and 'tangata motuhake' have been adopted by some.

"In Maori we have a saying – You must understand the beginning if you wish to see the end."

Ngâ hiahia ai ki te timata â ka kite ai tatou te mutunga.

For Mâori, leadership is not necessarily something that one person decides to take on.

"The Koroua or Kaumatua tell you to go up. We don't put ourselves up.""

To be a person from one of the Pacific Island cultures and a mental health consumer can be a 'double whammie'. Double the reason to feel marginalised and discriminated against in a predominantly while English-speaking country.

"The consumer aspect mirrors the Pacific stuff."

Pacific consumers have, at times found themselves in a difficult situation where others in power positions have assumed that they are representatives or spokespeople for the whole of the Pacific consumer community.

Advice for leaders

Even though many participants did not themselves identify as consumer leaders they were prepared to give some words of advice for current or prospective leaders.

- Get educated. Know the sector, learn the rules, the sector personalities.
- Debate at the same level as managers and know as much about what works as they do.
- Somebody who is going to be a useful and effective leader needs to acquire skills.
- Be prepared to go public.
- Prepared to be honest – with yourself and others

"Don't play the mental illness card all the time. It can backfire. Saying 'I've got a mental illness, you can't talk to me like that' etc. This plays into stereotypes [like] we can't work, speak etc…Go home and enjoy your mental illness after work instead."

Summary

At this time we are not in a position to be able to make any concrete conclusions about consumer leadership in New Zealand. As a project, there is a lot more work to be done before it can meet it's purpose:

> **To determine if there is or can be a commonly held view of consumer leadership within New Zealand and what services would be like if they were consumer led.**

However, we have made a significant start by looking at our own organisation, briefly reviewing some of the publications available and interviewing a group of people who identify as mental health consumers/service users who, in our minds at least, demonstrate leadership qualities.

In summarising our work so far, the closest we can get to a definition of consumer leadership is:

> **It's the next step up from participation and it's not always a choice we make.**

We have learnt that consumer leadership can be defined in the context of the consumer movement and within mental health services. There are different considerations for different cultures.

We contend that **consumer leadership is about power** and enacting it can/will be political.

Whether we are part of the consumer movement, employed in a mental health service or getting on with life in whatever way we want;

Leadership is about reclaiming our personal power.

Appendix

Interview Participants

We would like to sincerely thank:

Colin Slade
Gary Platz
Leo McIntyre
Lynda Thoumine
Mary O'Hagan
Mike Sukolski
Monica Cartner
Renee Torrington
Sarah Gordon
Te Wera Kotou
Vito Nonumalo

Interview Questions

1. What makes you want to get involved/work in the mental health sector?
2. How would you define a consumer leader? Give 3 attributes.
3. What are the qualities of a leader?(in this context)
4. What have organisations done that has helped or supported consumer leadership? (in your experience)
5. What have organisations done that has hindered or supported consumer leadership? (in your experience) / What are the barriers to consumer leadership?
6. Can you talk about some of the achievements of consumer leaders in NZ?
7. What advice would you give to consumer leaders / what can we do to nurture consumer leadership?
8. Can you identify 5 other consumer leaders in NZ?

PUBLICATIONS - REFERENCES

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