Becoming more peer-focussed (?)

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Overview

- Why become more peer-focused?
- Where am I coming from?
  - Consumer perspective
  - Consumer leadership
- What does it look like to do this work REALLY well?
- What's happening elsewhere?
- What's your future vision? Different modes of consumer participation.

Why become more peer-focussed?

a. “Consumers have a right to participate in the services they use.”
b. “It’s therapeutic for our consumers, to get more involved.”
c. “It’s cheaper to employ consumers to do some of the support work.”
d. “Because “consumer participation” is the “in” thing at the moment. It ticks boxes for our funders, or is being pushed by Management.”
e. “Now that you ask, I can’t exactly explain it, but it definitely seems like the right thing to do.”
f. “Because consumers have incredibly valuable insights, and we’d be crazy not to embed these insights into our practices as much as possible.”
g. “Because the mental health system exists entirely for consumers, so ultimately they are the best placed to run the system”
h. “Because other NGOs are more sophisticated than us in this area and we’ll be less competitive if we don’t.”

Where am I coming from?

- Consumer Academic, working at Our Consumer Place (www.ourconsumerplace.com.au)
- Two main concepts underpin our work, pushing beyond the idea of “consumer participation”:
  1. Consumer *perspective*
  2. Consumer *leadership*

(1) Consumer perspective

- Historically emerged from international, grass-roots consumer/survivor/ex-user (c/s/x) political activism.
- Is "a way of looking at mental health that values the lived experience of those having been diagnosed with 'mental illness' as a crucially important source of insight."
  -Epstein and Grey (2010) *So, You have a 'Mental Illness'? ... What now?* p.3
  ➔ lived experience + *valuing* that lived experience and the perspective it gives

NOT benevolent "inclusion," it's about recognising value and *desiring* what we bring. (Cath Roper: "What is it that only consumers can do?")

- Has tended to be devalued, under-recognised or discounted by mental health professionals
  - Mental illness as the absence of insight?

(1) Consumer perspective (cont.)

- Consumer Perspective informs:
  - *individual expertise* in our own lives
    → supported decision-making paradigm instead of substituted decision-making
    (e.g. UN Convention on the Rights of Persons with Disability)
  - *expertise in service design, delivery and evaluation*
    → consumer leadership at every level in mental health services
  - *collective expertise*
    → consumer leadership in the community's mental health discussions, conceptualisation, policy, etc
- Is NOT about consumers becoming mini-experts in "medical model" (e.g. Cert-IV in mental health)
  - Is no longer consumer perspective
- Is NOT dependent on notions of being "representative" or a "real consumer"

(2) Consumer leadership

- Happell and Roper, (2006) ‘The myth of representation: the case for consumer leadership’ *Australian e-journal for the Advancement of Mental Health,* 5(3)
- *Consumer Leadership: a literature review* (2007) Victorian Govt Dept of Human Services.
- Leaders vs “real” consumers or “our” consumers?
- Peers vs consumers (Mind)?

"... but are they REAL consumers?"

- This spectre haunts potential for consumer leadership to flourish

"Real" (or "our") consumers	Those "Other" consumers
"Legitimate"	Not like "our consumers"
Legibly mentally ill	Not "representative"
Associated with overt poverty ("social inclusion")	Professional / not "grassroots"
"serious" mental illness	"Recovered"
"dumb" (both meanings)	"Too political / intellectual"
"Low functioning"	"High functioning"

- Unhelpful confusion of issues and assumptions to do with: class, diagnostic hierarchies, "capacity", visibility, access to educational opportunities, intelligence, suffering

How does it look to do this work REALLY well?

- Good intentions are never enough.
- Amazing (consumer-perspective) research has gone before but is under-utilised. Including:
  - Lemon Tree Project,
  - Deep Dialogue,
  - Understanding and Involvement

  (see www.ourconsumerplace.com.au for more information about these resources)

Roots / trunk / branches / leaf work

From: Epstein, M and Shaw J. (1997) *Developing effective consumer participation in mental health services: the report of the Lemon Tree Learning Project.* Victorian Mental Illness Awareness Council, Brunswick, Vic.

- **Roots:**

Take time, energy, resources. Deep, slow, deliberate work that is about developing infrastructure for institutional change.

Is the hardest work and the most important.

- **Trunk:**

See U&I (12 “musts”)

- **Branches:**

Building on and supplementing existing skills

- **Leaves:**

Unfortunately, the most popular, easiest and least effective. Once-off talks, tokenistic gestures, (my talk today??)

‘Three sites for good practice in consumer/staff dialogue for change’

1. **Other People’s Committees**

   Decision-making sites that look like familiar meetings. Often have consumer reps on them.

2. **Consumer-only sites**

   Opportunities to unite, plan, strategise, organise, gain critical mass, nourish ourselves for those times when we are relatively powerless.

3. **Deep dialogues**

   Non-decision making site, where ‘real’ discourse can occur. Not about ticking off decisions, but about engaging in the hard issues (NB: see the “musts” in the 2 Deep Dialogue Projects).

What's happening elsewhere?

- Neami: embedding consumers into all levels, offering real support, autonomy, supervision, conducting REAL research, led by consumer priorities.
- Doutta Galla: Consumer participation development project, led by a highly experienced consumer leader (Lana Woolf)
- Brook RED: entirely consumer-run service in QLD, utilising Intentional Peer Support (entirely consumer-developed approach).
- Are you an "expanding" and "innovative" organisation? What does that actually mean? Where does consumer leadership fit into your strategic vision? (Priorities).

Arnstein's Ladder of Citizen Participation[6, 46]

Degrees	Rung	Explanation	Example
Degrees of Citizen Power	Citizen Control	Citizen control over funds and budgets. Citizens have majority of seats on decision-making board or full managerial power.	Consumers manage a project or program.
	Delegated Power	Citizens have dominant decision-making authority or veto. Officials are accountable to them.	Funding for consumer-driven programs/groups. Citizens appoint staff or have staff reporting to them.
	Partnership	Power is redistributed through negotiation between citizens and power-holders. Works best when citizens have an organised power-base in the community.	Negotiated memorandum of understanding or agreement between government agencies and consumer groups to work on a joint project. Joint governance. Joint research projects.
Degrees of Tokenism	Placation	Placing handpicked people on boards or public bodies. Also citizens' advisory committees, taskforces etcetera that have no policy-making function and limited authority.	Consumer reference groups, citizens' juries and advisory committees with no power to effect decisions; solitary consumers on boards. Joint research projects.
	Consultation	Attitude surveys, neighbourhood meetings and public hearings with no commitment that citizen concerns will be taken into account.	Satisfaction surveys, focus groups, submission processes, open forums, public meetings, annual plan consultations.
	Informing	A one-way flow of information.	Newsletters, presentations at meetings.
Non-participation	Therapy	Groups are formed but are diverted from the real task by meaningless activity.	
	Manipulation	People are placed on advisory bodies but officials make the decisions.	Customer relations, token consumer representatives on committees, emphasising patient satisfaction within existing resource allocation structure, formal advisory groups and appointed representatives.[47]

What’s the future vision? What’s the limit?

- “I look forward to you taking my job some time” – (paraphrasing Kim Koop, head of VicServ to me, private conversation)
- If you don’t envisage consumers taking over your job as the ultimate aim, then what is the limit of consumer leadership/participation and why?

Consumer Participation is for all to participate, at whichever level people self-select to, utilising whichever mechanisms people feel most comfortable with. There should be no 'exclusion criteria' set that actively inhibits anyone from participating. … Consumer participation is all 'developmental.' None of it is 'implementation'

Consumer Participation is about changes within services. Not only changes being made in response to consumers feedback, in a quality improvement context, but also about changes to systemic practices, from ones that do not actively support consumer involvement to ones that enable and support consumers to participate, without the need for prior training. When consumers are given the opportunity, they will develop innovations that the services do not think of.

Also, Consumer Participation is about changes to service systems' 'usual practices,' from ones that inhibit Consumers from participating to ones that support it.

-Gordon S. (2005) The role of the consumer in the leadership and management of mental health services *Australasian Psychiatry,* 13(4): 362-5.