Recovery, Empowerment and Consumer Visions for Change

Kelly Pope
CYT Consulting
*Pour* *Sip* yum

Input Output Outcome
Was this a positive experience or a negative one?
UNEMPLOYED
Consumer satisfaction measures

Very satisfied
Somewhat satisfied
Neutral
Somewhat dissatisfied
Very dissatisfied
“Patients want more information and involvement in decision-making, good relationships with providers, clear management plans, good coordination among services, the opportunity to record their wishes in advance directives, and contact with fellow patients who can provide peer support. Clinical outcomes are predicted by patients' perceptions that services have met their needs.”

What users and relatives want from mental health services

Noble, Lorraine Marya; Douglas, Brian Christopher 2004
RECOVERY

Expectations

Reality
Do clinical outcome measures assess consumer-defined recovery?

Retta Andresen\textsuperscript{a,*}, Peter Caputi \textsuperscript{b}, Lindsay G. Oades \textsuperscript{a}

\textsuperscript{a} Illawarra Institute for Mental Health, University of Wollongong, NSW, Australia
\textsuperscript{b} School of Psychology, University of Wollongong, NSW, Australia

\section*{Article Info}
Article history:
Received 22 May 2009
Received in revised form 15 December 2009
Accepted 14 February 2010

\section*{Abstract}
There is an international call for mental health services to become recovery-oriented, and also to use evidence-based practices. Addressing this call requires recovery-oriented measurement of outcomes and service evaluation. Mental health consumers view recovery as leading as meaningful life, and have criticised traditional clinical measures for being too disability-oriented. This study compares three measures of consumer-defined recovery from enduring mental illness: the Recovery Assessment Scale, the Mental Health Recovery Measure and the Self-Identified Stage of Recovery, with four conventional clinical measures. Correlational analyses supported the convergent validity of the recovery measures, although certain subscales were unrelated to each other. More
“... little relationship was found between consumer-defined recovery and the clinical measures. Analyses of variance revealed that scores on the recovery measures increased across self-identified stage of recovery, but scores on most clinical measures did not improve consistently across stage of recovery. The findings demonstrate the qualitative difference between the two types of measures, supporting the claim by consumers that clinical measures do not assess important aspects of recovery.”

Retta Andresen, Peter Caputi, Lindsay G Oades
Recovery Star
Un-recovery Star

- poverty
- trauma/iatrogenic trauma
- discrimination
- racism
- homosexuality/transphobia
- unstable housing
- sexism
- loss of welfare state
- loss of rights
- economic inequality
**KEY PCOM POINTS**

1. Measuring a client’s progress to determine whether the intervention is helping them.
2. Privileging the client’s voice as the most critical in any counselling intervention.
3. Holding paramount that change is achieved and maintained by the client him or herself and not by the professional.
4. Recognising that not all health/social service workers are accurate in ascertaining the success of interventions.
5. Recognising that clients are 100% accurate in ascertaining the success of interventions.
6. Using the client’s own [cultural, social] conceptualisation of wellness as an essential paradigm by which to determine their progress.
Paperwork and people work often seen at odds...

Of COURSE we’re patient focussed and I’ve got the paperwork to PROVE it!
“One of the most serious problems faced by a country like El Salvador is the lack of a “social mirror” for looking at themselves: something to help recognise themselves in the reality they know, and to become aware of their own identity as they work at constructing their own world”
Mystery
I’m going to be HONOSSt here...
The Democratisation of DATA
Version 1.3

Data Commons Blueprint

A high-trust, lower-cost alternative to enabling data integration and reuse
**Why do you need this information?**

Who does the information belong to?
What is going to happen with it?
What will I get out of all this?

Are there adverse consequences of greater information sharing?
Will this have a systemic impact, will it change my ability to access services or support?
Will information be shared with agencies or people I don’t want it to be shared with?

Doesn’t this all feel a bit too “Big Brother”

Outcomes is about doing and attaining rather than being, why can’t I just be?
“Not everything that can be counted counts, and not everything that counts can be counted.”

Albert Einstein
“Think really carefully about which measure gets used nationally and include service users as partners in deciding outcomes – this is about us. What you set up as outcome measures are what services will focus on – we need to be involved”
Life expectancy reduced by up to 25 years. The most common causes of death being cancer and cardiovascular diseases.
Seclusion events at mental health and addiction services in New Zealand
By age group and sex, year ended June 2012, number of people

Source: Ministry of Health
PEOPLE'S MENTAL HEALTH REPORT
Consumer views on what to measure

• Costs or detriments people incur through accessing services
• How many people who have gone through the mental health system, go on to never need support from the system again?
• Successfully coming off medication
• How can we prioritise people receiving both timely and quality support?
• What things really matter and make a difference for people? What contributes to recovery for people in New Zealand?
• What are peoples’ experiences of treatments like medication?
• Specific populations experiences
• What other supports do people use, beyond the mental health service they are access, what helps with their wellbeing and recovery?
How can you contribute to the collection of data that is valuable to consumers in your community, using your services, residing in your region?

How could you find out what information is important to collect?

How can data best be made accessible to communities, like people with lived experience, to enable us to make change?
Get in touch :) 

Kelly Pope  
Crazy Young Things Consulting  
kelly@cytconsulting.com