BEST EVIDENCE VERSUS "BEST" AND VESTED INTEREST

Why do we get the mental health services we get?

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Empowerment Council

Scientific Progress

In Theory:

- Science proceeds toward the truth using the Scientific Method
- This method is a means to verify theories or find them false.
- Cause and effect is judged by controlling other causes of results
- Bad science is ideology vague enough to evade evaluation,
  and/or flawed methodology,
  followed by failure to properly interpret what results mean.

Examples of Bad Science

Freudian theory = Unfalsifiable Hypotheses

i.e. Unconscious wish fulfillment.

Epigenetics labeling of nongenetic systems as epigenetic

Benefits versus Risks of SSRIs

e.g. suppression of report of harms, and promoting unfounded benefits

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Scientific Sources

- A doctor writing about a patient = a case study
- A patient writing about themselves, not a study

- Room full people observed by scientists = research evidence
- Room full of people sharing common lived experience = not evidence

- Conclusions reached by scientists = science by consensus

  (Basis of DSM)
- Conclusions reached by pwle about common experience = radical ideology

“Best Interest” Individual Level

Informed Consent and Self Report

- ❑I.C. Criteria often unfulfilled (particularly risks and alternatives)
- ❑Assumption of superiority of medical “best interest” opinion
- ❑Evidence from self report often disregarded individually (treatment) and systemically (drug evaluation)

“Best Interest” Evidence – Appropriate?

Capacity legislation requires Substitute Decision Maker if assessed “incapable” .

All or nothing approach versus reality of range - Supported decision making

Lack of consent often conflates “poor insight” and incapacity *(See Starson – SCC)*

(In BC involuntary admission assumes incapacity.)

MacArthur Treatment Competence study found most people considered to have serious mental illness had abilities to make treatment decisions similar to persons who were not considered to have mental illness.

P. Applebaum and T. Grisso, "The MacArthur Treatment Competence Study: I. Mental illness and competence to consent to treatment", Law and Human Behaviour, (Executive Summary www.macarthur.virginia.edu)19, 105 - 126

Service User Use of Knowledge

Recovery as applied to “serious mental illness” described by people on the receiving end of this diagnosis for decades but dismissed.

Means of dismissal of evidence of pwle identified has had commonalities internationally:

“Antitreatment radicals” , “wrongly diagnosed” , “not representative”.

e.g. Andre Picard: (The Kirby Report) pays far too much attention to the views of "psychiatric survivors" who hide their vehemently anti-treatment views in the promotion of "peer support" and the language of "rights."

Service user application of science also dismissed through many years and many lives e.g.

- C. Harding et al, “The Vermont Longitudinal Study of Persons with Severe Mental Illness, I: Methodology, Study Sample, and Overall Status 32 Years Later”, American Journal of Psychiatry 1987, 144:6, 718 – 726
- R.Greenberg et al, “A Meta-Analysis of Antidepressant Outcome Under “Blinder” Conditions”. Journal of Consulting and Clinical Psychology 1992, Vol. 60, No.5, 664-669
- D. Antonuccio et al, “Raising Questions about Antidepressants”. Psychotherapy and Psychosomatics 1999, 68:3-14
- S.Chua, and P. McKenna "Schizophrenia-a Brain Disease? A critical review of structural and functional cerebral abnormality in the disorder" Brit. Jour. Psych., 1995, 166: 563-582.

Even experts presented by service user groups ignored e.g.

Schizophrenia: The Facts No One Wants to Know. Clarke Institute of Psychiatry, Toronto, June 16, 1999.

Sources of Knowledge: Dismissed and Preferred

Queen Street Patients Council 1992 – 2001

Annual list of Demands/Advocacy Issues at QSMHC included

“Overdrugging must stop”

Annual response from QSMHC: There is no overmedicating.

Validating report by head of pharmacy that standard doses at CAMH frequently exceed recommended dose had no effect.

Approximately 2002 CAMH CEO announces thanks to PET scan technology CAMH scientists have ascertained its patients are being routinely medicated at excessive dosages

Importance of Trauma

Identification by Service Users of Trauma as a Source of Mental Health and Addiction Issues dismissed for decades in favour of

brain based explanations and pharmaceutical solutions.

Analysis of research finding lack of evidence dismissed

e.g. biochemical foundation for depression.

Overwhelming evidence of trauma histories little reflection in care.

Trauma caused by practices in mental health system denied e.g. restraint, confinement, coercion.

Dismissive tendency to depict service user perspective as all or nothing

(e.g. equating questioning overapplication of medical model with 100% dismissal)

Treatment methods of “First World” Preferred

Several studies by WHO found higher recovery rates following diagnoses of schizophrenia in some countries (rating tested reliable):

- High rates of complete clinical remission were significantly more common in developing country areas (37%) than in developed countries (15.5%)

WHO International Studies of Schizophrenia, 1973...Geneva, Switzerland, World Health Organization

The result has not been to humbly follow the practices of developing countries.

Current Practices of Ignoring Best Evidence

Despite the demonstrated Effectiveness (and dollars saved) of Consumer/Survivor Initiatives

J. Trainor and J. Tremblay, "Consumer/Survivor Business in Ontario: Challenging the Rehabilitation Model", Canadian Journal of Community Mental Health, Vo. 11, No. 2, Fall 1992, p.p. 65 - 71

(Search Longitudinal Studies of Consumer Survivor Initiatives (CSI) in Ontario 1997-2004)

Many Independent CSI's in Ontario absorbed by Mental Health Services

Only 2 of 9 Independent Patient Councils Remain

Current Practices and Service User Voice

Patient Engagement

"The best practice that I saw at the UN was that internationally, people with mental disabilities are taking things into their own hands and having their own organizations and raising their own issues." *(Kleintjes et al, 2010. Mental health care user participation in mental health policy development and implementation in South Africa. International Review of Psychiatry, Dec, 2010;22(6): p. 572)*

White (1999) and Marmor and Marone (1980) argue in favour of representatives of organized consumer groups addressing the power imbalance between the public and health professionals. Marmor and Morone (1980) They observe that administrators have a preference for handpicking or co-opting non-aligned people because they do not have the knowledge or connection to broader interests of consumers or their resources. The researchers favour selection by the groups themselves, saying this method in community action programmes in the U.S. produced the most able, universally oriented and least co-optable representatives and most independent and competent boards. *(in Coney, Sandra , & the New Zealand Guidelines Group. 2004, Effective Consumer Voice and Participation for New Zealand, A Systematic Review of the Evidence p.41).*

Patient Engagement and The Service User Voice Cont'd

- There is evidence that consumer representatives provide more effective participation than using non-aligned consumers *(Coney ibid p. 54).* They have gained an understanding of patients as a population *(Duff et al. 1996).* Consumer groups were able to tap into individuals who would be too frightened to personally critique services *(King's Fund 2002)*

- *Duff, Lesley et al. 1996. Clinical guidelines: involving patients and users of services. Journal of clinical Effectiveness. 1(3): 104-112*

- "It's good for a patient to have some kind of a patient constituency so that they have a group to whom they are responsible, to whom they report or with whom they discuss." *(Jack Shapiro, Canadian Cancer Action Network Chair, in Knutilla)*

Patient Engagement in Ontario

Contrary to Best Practices Psychiatric Facilities across Ontario do not support or draw upon the voice of Service User organizations. Instead they select individuals to engage.

Following an inquest at St Joseph's hospital in Toronto a member of their patient advisory group reported they had not been told of the death, the inquest, or the inquest recommendations.

Why?

- Always ask who benefits from suppressing some evidence and privileging other (without consideration of good scientific method).

Thoughts?

What is to be done?

DO NOT STOP

Describing what is true and presenting good science.

Some progress has been made in recognising recovery and the effects of trauma.

See handout: Influencing Decision Makers

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