

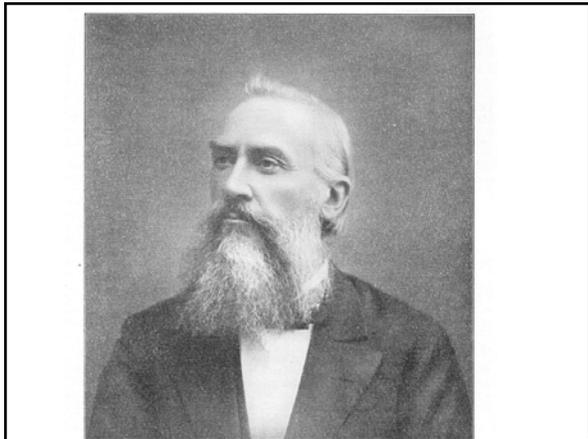
*A Volunteer Research Register, as
Essential Infrastructure for Research
on Schizophrenia and Related
Disorders*

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*Community & Voluntary Sector
Research Forum,
Rutherford House, 23rd June, 2013.*

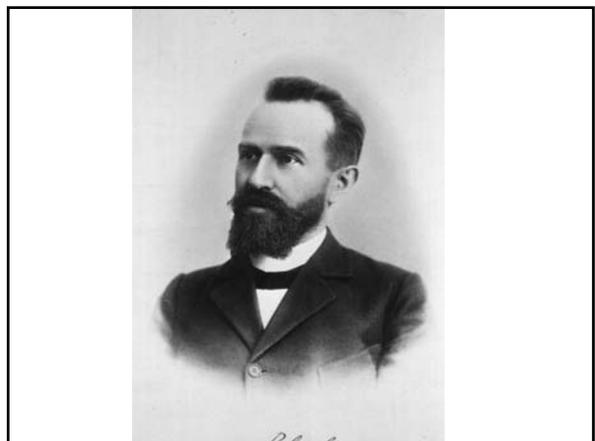
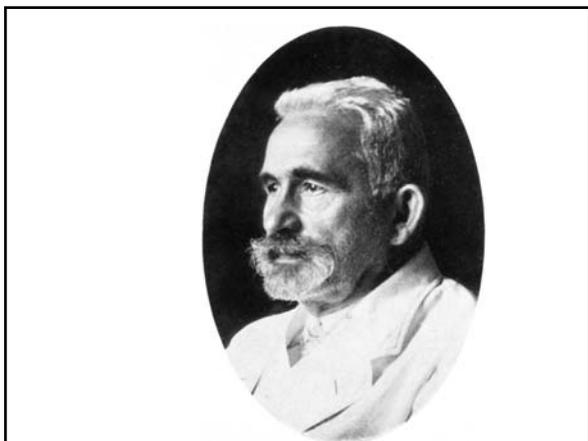
My own story

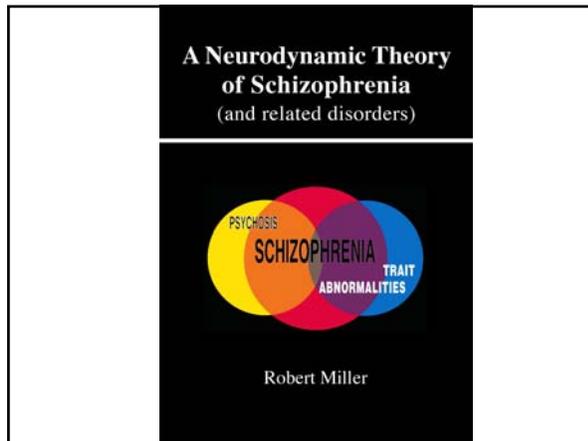
- Comments:
 - (i) Doctor's anxiety about giving me the 'schizophrenia' diagnosis
 - (ii) My reaction to this news
 - (iii) The diversity of conditions the diagnosis includes
 - (iv) Not a robust scientific concept
 - (v) . . .but an important area for serious research
 - (vi) My maxim: 'The *only* way in which scientific concepts can be securely validated is when they are defined in ways which support strong explanatory arguments.'



History of 'Schizophrenia' concept

- (i) Karl Ludwig Kahlbaum (1828-1899)
- (ii) Emil Kraepelin (1856-1926): '*Dementia praecox*; separation from manic-depressive illness.
- (iii) Eugen Bleuler (1857-1939) 'Schizophrenia' (confusion in relation to 'split personality')
- (iv) Continuing controversy
- (v) 1970, John Pringle, UK, founder of National Schizophrenia Fellowship'
- (vi) 1977, New Zealand 'Schizophrenia Fellowship' founded, now 'Supporting Families in Mental Illness'
- (vii) Henry Nasrallah, ~1989.





Lecture, Montreux, 5.02.2008

- 'Overall it is my view that science, in the areas I know, is now way off course, the primary motivations being personal ambition, institutional prestige, and, in the end national prestige. A large part of the industry of schizophrenia research is pursued to provide jobs for the boys, rather than fundamental understanding, and least of all, alleviation of the disablement and suffering of those with the disorder. Now, let's pause for a few moments, take our breath, and then we'll get on to the real science.'

In this area, New Zealand is not so far behind . . .

Service-user activism:-

- (i) Royal commission; Mason report.
- (ii) Service-user activism: Has been very strong, but has been somewhat undermined
- (iii) Service users often reject the term 'schizophrenia',
- (iv) . . . or they reject the term 'mental *illness*'
- (v) . . . or prefer the term 'mental *distress*'

Reasons why I continue to use the term 'schizophrenia'.

Areas where research is needed:-

- (i) Basic neuroscience, with correct balance btw experiment & theory
- (ii) Research to understand *symptoms* more than any 'diagnosis'
- (iii) Research on basic phenomenology; first person accounts important
- (iv) Research on social impact of the disorder
- (v) Research of treatment strategies – pharmacological, psychotherapeutic, social etc
- (vi) Research on improvements in service delivery

Much of this could be driven by, or done in collaboration with service users, many of whom now are strong enough to be essential partners in the research process.

Infrastructure for Research on Schizophrenia

- (i) I know of good doctoral students in this area, who did not continue, because of difficulty recruiting enough participants.
- (ii) What is needed a 'Volunteer Research Register'
- (iii) This should enlist the participation of those with a diagnosis, their family members, and others to form comparison groups.
- (iv) This means bringing together groups (researchers, service users etc), who have strongly held views, but which differ greatly
- (v) To achieve this, many other issues have to be addressed
 - (a) Misunderstanding, stigma and fear both by the general public and often at government levels, and by public media
 - (b) Administrative concepts which are unhelpful
 - (c) Tricky ethical issues
 - (d) Funding

New Zealand Schizophrenia Research Group

- (i) Our history
- (ii) Our style in recent meetings
- (iii) Grant from Rotary, Auckland
- (iv) Forthcoming negotiations with HRC, over possible partnership linked to VRR concept
- (v) Plans for focus groups in main centres
- (vi) Publicity: Discrete, but well aimed at key stakeholder groups
- (vii) 'Build ship while we sail it' to retain flexibility
- (viii) Fund-raising
- (ix) Envisage that the VRR would be separate from, but affiliated with NZSRG, run 50/50 by researchers and volunteers.

Approximate sequence/time-line

- (i) Preparatory work to 'spread the word' to potential volunteers, and potential researchers.
- (ii) Seminars/talks by NZSRG board members, such as today
- (iii) Compile lists of 'Prospective Volunteers', and 'Potential Researchers, without having any specific proposal in mind.
- (iv) Continuing discussions with the above two groups, to refine the processes to be adopted. Focus groups.
- (v) Approach to the Health and Disabilities Ethics Committee at national level, for advice, support, and authorization of the VRR.
- (vi) System for 'support persons'/'mediators' for 'hard to access groups.'

Approximate sequence/time-line

- (vii) *When the register of prospective volunteers is of sufficient size:-*
 - [a] A call to researchers for projects the VRR might be able to support
 - [b] A system for alerting volunteers to forthcoming projects, with a call for volunteers in the specific projects
 - [c] NZSRG/VRR would then act as a 'go-between', to put researchers and volunteers in touch with each other.
- (ix) Separate website for the VRR, including a forum for publication of results.
- (x) Set up measures for independent scrutiny of VRR operation, especially on ethical aspects, beyond any ethical approval for individual research projects, to preserve the reputation of the VRR.