A consumer’s guide to mental illness interventions: a historical overview
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1. **INTRODUCTION**

WE ARE **PART OF AN HISTORICAL MOMENT**

At any moment in time, we respond to the political, social and economic imperatives of that moment but we need to bear in mind how present understandings and approaches are informed by the past even as we deal with the now and acknowledge that further change is inevitable.
SNAPSHOT

What follows is not a thorough nor thoroughly researched history of psychiatry.

Nor is it a comprehensive study of the history of the consumer/survivor movement.

It is a snapshot for consumers to better understand the context in which we work today.

The particular issues and periods have been chosen by Our Consumer Place and reflect our interests and the limitation of our knowledge.

It is not strictly chronological.

ourconsumerplace.com.au
HISTORY: A DEBATE ABOUT IDEAS, A DISCOVERY OF FACTS, A CREATING OF DRAMA


HIGHLY RECOMMENDED


Aboriginal groups ARE NOT all the same.

They are discreet nations with their own language and culture.

They do not share the same history.

Nonetheless there are familiar historical themes.
Prior to 1788, Indigenous people were able to define their own sense of being through control over all aspects of their lives, including ceremonies, spiritual practices, medicine, social relationships, management of land, law, and economic activities. This was their school, spiritual and emotional wellbeing.
There was no separate term in Indigenous languages for health as it is understood in western society.

The traditional Indigenous perspective of health encompasses everything important in a person’s life, including land, environment, physical body, community, relationships, and law.

Ref: The Context of Aboriginal Health: Overview of Australia
The Nyoongar (also spelt Noongar) are an Indigenous Australian people who live in the south-west corner of Western Australia, from Geraldton on the west coast to Esperance on the south coast.

Understanding a Nyoongar worldview requires us to revisit our own histories, for, in so doing, we can better understand the structures by which we live.

Nyoongar ontological worldview (Nyoongar ways of being) and Nyoongar epistemological worldview (Nyoongar ways of knowing) have been de-legitimised by the dominant (epistemological) world-view of those who colonised Australia.

NYOONGAR PEOPLE: AN HISTORICAL TRIUMPH OF CULTURE

Nyoongar peoples have a distinct way of seeing the world and since colonisation in 1829, they have gone through constant adaptation and cultural exchange (Host and Owen 2009).

The impact of colonisation in the south-west of Western Australia has had a powerful influence on Nyoongar health.


There is a resilience and strength within Nyoongar community and, as a consequence, Nyoongar culture and law still remain vibrant and dynamic.

If we are to begin the decolonising process, we must challenge the reluctance of the broader society to recognise the existence of Nyoongar law and culture in contemporary society.

Atrocity, display, legacy of abuse.
GEORGIAN PERIOD
1714 - 1830

Most Georgian Britons regarded lunatics not as suffering fellow human beings but as demons, monsters, wild beasts – ‘mad dogs, or ravenous wolves’ as one London mad-doctor branded them. “Insanity was sub-human, and those afflicted with it had no place in the chain of being.”

in Taylor 2014
MAD PLACES

17th Century: Not uncommon for gentry to release mad people out of cages for entertainment after grand dinners.

CRUEL, UNUTTERABLY CRUEL

"In the gloomy mansions in which hands and feet were daily bound with straps or chains... all was consistently bad. The patients were a defenceless flock, at the mercy of men and women who were habitually severe, often cruel, and sometimes brutal ... cold apartments, beds of straw, meagre diet, scanty clothing, darkness, sickness and suffering, and medical neglect..." John Connolly Reformer 1830.

in Taylor 2014

ENTERTAINMENT

For most of the 18th Century, Bethlan hospital was a popular tourist destination where, for a few coppers, visitors could stroll about gawking at gibbering figures chained to walls or locked up, naked, in filthy cells'.

Taylor, p. 107

This ‘grotesque of sports’ generated income.
18TH CENTURY – MEDICAL TREATMENTS AND MAD DOCTORS

MEDICAL TREATMENTS PREDOMINATED

1. Shackling
2. Bed-strapping
3. Straight-waistcoats
4. Blood-letting
5. Induced vomiting
6. Frigidity
7. Oral and anal suppositories

... were near universal mad doctor practices.

ROTATIONAL THERAPY CIRCA 1750

Rotating Therapy!! Melbourne doctors won The New Inventors (invention program on the ABC) a few years ago with a very similar concept!
MORAL TREATMENT: END 18TH CENTURY

Emancipation, influential reformers.
“By the mid 18th Century there were signs of change. Enlightened physicians argued that mental disorders were brain diseases, not signs of diabolic influence of bestial states.” (Taylor 2014: 107)

Lunatics were not brutes, it was said, but souls deserving succour.

Philippe Pinel at the Salpêtrière, 1795 by Tony Robert-Fleury. Pinel ordering the removal of chains from patients at the Paris Asylum for insane women.
REFORMERS: 
CREATIVE OPTIMISTS

In 1770 Bedlam was closed to tourists and the following decade King George III’s episodes of derangement earned him much sympathy. But the most change came with the development of a new therapeutics known as ‘Moral Treatment’, which by the end of the eighteenth century was exerting a strong influence on institutional psychiatry.

Phillipe Pinel (France) ‘judicial kindness’ (listening, probing, personal conversations, note taking).

William Tuke 1810 – 1840 Quaker principles, especially of group work and friendships (peer support?) York Retreat.

John Connolly: campaigner and leader in treating people with the dignity of conversation and purposeful activity (occupational therapy?)
MORAL TREATMENT... NOT PERFECT BUT A BIG CHANGE IN ATTITUDES

PHILLIPE PINEL 1745 - 1826

“I cannot here avoid giving my most decided suffrage in favour of the moral qualities of maniacs. I have no where met, excepting in romances, with fonder husbands, more affectionate parents, more impassioned... than in the lunatic asylum, during their intervals of calmness and reason.”
Established in 1796 by the tea merchant William Tuke and fellow Quakers.

Moral treatment: humanity, reason and kindness.

Decidedly non-medical model: No physicians, minimal use of medications and restraints.

High staff: resident ration (10:30)

Tuke on resocialisation "All who attend dress in their best clothes, and vie with each other in politeness and propriety."

Metaphor of family.
Moral Treatment in its stronger versions meant the abandonment of often brutal ‘medical’ remedies popular among mad-doctors, in favour of a psychotherapeutic approach that utilised the asylum environment and staff – patient relationships as healing agents… By the end of the 18th Century it was gaining a strong influence…
Asylum as attempt to place moral treatment within a healing setting: Beautiful and bountiful: Early 19th Century till the end - END OF 20TH CENTURY (ALMOST).
SAFE ON THE HILL...

"A well conducted asylum would be a sanctum were chaotic minds would be soothed into sanity..."

(Taylor 2014)
Largest asylum in Britain.

Produced all its own food, wine and beer.

Drama troupe and musical players.

Everyone had useful work when they could do it.

Moral therapy in Tuck/ Pinnel’s image.

Healing potential of other patients (although in some asylums much effort was still made to separate ‘friends’ who could be a bad influence).

Segregated sections: men and women; chronic and other; pauper and not.

Physical health (regarded as important for the first time).
BACKWARDS: DEMENTIA AND CHRONICITY

This is the stereotype of asylums.

Cruelty and force.

People languished for decades.

Medical experimentation was common and secret.

Clothing bought in bulk.

Later 19th Century Pauper lunatics – (first evidence of targeting need?... Or maybe something else!)
17TH & 18TH CENTURIES: LOCKING UP YOUR KIN

Misuse of asylums especially by wealthy families.

Bribery.

Committing people for religious, artistic, moral or other questionable reasons.

Contemporary Mental Health Acts now specifically stop such behaviour.

Suitcases brought to an asylum by people who were never to leave:


American asylums were much bigger than their European counterparts.

Thelma's Suitcase. Only one suitcase not going home. From a USA museum collection of asylum suitcases.
CAMILLES CLAUDEL
1864 -1943

Notable sculptor, ex-lover of Auguste Rodin.

Her father, her protector, died on 2 March 1913, Claudel was committed by her practise and devout Catholic brother 12 days later.

"Voluntarily" committed, although her admission was signed off by a doctor and her brother.

Family refused to release her up until her death in the asylum 30 years later.
CAMILLE AND AUGUSTE

After 1905 Claudel destroyed many of her statues and disappeared for long periods of time.

Rodin of stealing her ideas and of leading a conspiracy to kill her.

She was diagnosed with Schizophrenia, a diagnosis that has been challenged by history.
Community in asylums.

Most asylums had recreation facilities (tea rooms, sports clubs, workshops, festivals, radio stations).

Many asylums were not closed but open communities.

There were many private asylums.

After-care in the community.  
(Start of community services)

1st and 2nd World Wars impacted most positively on conditions in asylums: Tavistock – psychotherapists recruited by Churchill, to treat shell shock – letter called Post Traumatic Stress Disorder.
"Of all the indignities suffered by asylum patients, the ward round was one of the worst. I still have nightmares about it, this ‘ceremonial of control’ as R.D. Laing once described it. I have done a lot of public speaking and it is nowhere near as difficult as the command performance needed for these (a)ward performances."

Taylor p. 16
"Friern’s (Colney Hatch) history exemplifies [western asylums] that began on a high tide of reformist optimism and descended into troubled waters before finally floundering in a flood of anti-institutional, anti-welfarist sentiment. ..it is possible that [history] will be more favourable for asylums… than psychiatric modernists would have us believe."

Taylor p. 104


This is available on line and is a much more thorough analysis of the asylum era.

Doug and Berta Lockhart (2013) Souls of the Asylum, Balboa Press USA

This tells individual stories of real people in the 19th and 20th Centuries' asylums in the United States. (with illustrations)


Exhibiting Madness in Museums: remembering Psychiatry

‘Phrenology - the study of the mind’, phrenos - Greek word for mind.
During the late eighteenth century, Viennese physician Franz-Joseph Gall (1758-1828) claimed that there were twenty-six specific organs on the surface of the brain, and that they could be determined due to their effect on the physical shape of the skull.
By the middle of the 19th century Phrenology was largely discredited but was popular in parlor games into 20th century.

Phrenology was significant in that it provided a physiological explanation of the workings of the brain for the first time.

Part of a story of historical swings between physiological explanations and psychological ones.
First half of the 20th Century but influence far beyond.
What progress we are making. In the Middle Ages they would have burned me. Now they are content with burning my books.

--SIGMUND FREUD
THE END OF FREUD AND THE PSYCHOANALYTICAL MOVEMENT

First half of the 20th Century;

European tradition.

Peaks in mid 20th Century.

Brain chemistry inadequate.

Training long and complex.

Has its true believers and equally true detractors but holds a definitive place in what makes us who we are today.
PSYCHOANALYSIS ‘GONE’ BUT NOT OUT!

FREUD MUSEUM: LONDON

Slammed by number crunches;

Charged as elitist.

Accused of being old fashioned by ‘modern’ behaviouralists.

Hard to get an evidence base – doesn’t mean it doesn’t work, however.

Freaky: issues around personal autonomy and western ideas of independence.
Tarnished greatly by US experience where the therapy fed into a non-European culture and an economy ripe for the abuse of wealthy people in search of themselves;

Fed into the political discourse at the end of the 20th Century about the ‘genuinely ill’ and the ‘just’ worried well.

This is both an exercise in economic rationing as well as a debate about ‘method’ of intervention.
MENTAL ILLNESS AND 20TH CENTURY ATROCITY

On all continents and in many countries atrocities have occurred in the name of psychiatry. Although Nazi Germany and the post war soviet block stand out they are not alone.
POLITICAL ABUSE OF PSYCHIATRY – AN HISTORICAL OVERVIEW
ROBERT VAN VOREN


http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2800147/

http://ukrainianweek.com/Society/72920
HITLER: EUGENICS, ATROCITY AND MENTAL ILLNESS

Buses used to transport patients to Hadamar euthanasia centre. The windows were painted to prevent people from seeing those inside.

The so-called "Euthanasia" program was National Socialist Germany's first program of mass murder. It predated the Holocaust, by approximately two years.

The effort represented one of many radical eugenic measures which aimed to restore the racial "integrity" of the German nation. ..to eliminate what eugenicists and their supporters considered "life unworthy of life".

United States Holocaust Museum
Forced sterilizations began in January 1934, and altogether an estimated 300,000 to 400,000 people were sterilized under the law. A diagnosis of "feeblemindedness" provided the grounds in the majority of cases, followed by schizophrenia and epilepsy.

Most of the persons targeted by the law were patients in mental hospitals and other institutions. The "Sterilization Law" did not target so-called racial groups, such as Jews and Gypsies...

United States Holocaust Museum
Anti-Soviet political behaviour, in particular, being outspoken in opposition to the authorities, demonstrating for reform and writing critically were seen as both criminal and a symptom (e.g., "delusion of reformism"), and a diagnosis ‘sluggish Schizophrenia’.

Within the boundaries of the diagnostic category, the symptoms of pessimism, poor social adaptation and conflict with authorities were themselves sufficient for a formal diagnosis of "sluggish schizophrenia."
Sluggish schizophrenia was a root of self-deception among psychiatrists to placate their consciences when the doctors acted as a tool of oppression in the name of a political system.

Marat Vartanyan (1932–1993), a key apologist of Soviet psychiatric abuse.
INDIA, CHINA, AFRICA, ASIA, TIMOR, FIJI, PAPUA... HOME


Choudhary L. N. Political Abuse of Psychiatry in Indian Journal of Psychiatry, 2013 Jan-Mar; 55(1)96

World wide movement to 'control' psychiatry.
'A radical age brought bold innovations, which occasionally extended to a rejection of the asylum system tout court in favour of a ‘democratic communality psychiatry’ run by patients for patients… But this radical time was brief.

Taylor p. 146
ANTI-PSYCHIATRY:

For some it was seen as divisive and doctor-bashing but for others it is about ‘hope’, eschewing anger about malpractice, force and medical imperialism.

Like all things that set themselves up as anti something there is always the risk that the idea will fall flat in the absence of an alternative;

Radical times (anti Vietnam war, Gough Whitlam, student protests...)

Laing & Szasz: ‘Fathers of anti-psychiatry’.

Sociological critique of social control: Marx, Engels, Goffman & Foucault, Cooper.

The Frankfurt School: the social as important as the organic.

Labelling Theory.

Mad Pride put a toe in the water in Australia.
FOR THOSE WHO WANT TO KNOW MORE

Bracken P. and Thomas P. (2010)  
From Szasz to Foucault:  
on the role of critical psychiatry  
in Philosophy, psychiatry and  
psychology. Volume 17,  
Number 3 pp 219 -228

Radical psychology:  
A journal of psychology,  
politics and radicalism  
http://radicalpsychology.org/

The Frankfurt School and  
Critical Theory in Internet  
Encyclopedia of Philosophy  
http://www.iep.utm.edu/frankfur/

Asylum Magazine for  
Democratic Psychiatry  
http://www.asylumonline.net/
Homosexuality and psychiatry.
By the end of the 19th century, medicine and psychiatry were effectively competing with religion and the law for jurisdiction over sexuality. As a consequence, discourse about homosexuality expanded from the realms of sin and crime to include that of pathology. This historical shift was generally considered progressive because a sick person was less blameful than a sinner or criminal (e.g., Chauncey, 1982/1983; D’Emilio & Freedman, 1988; Duberman, Vicinus, & Chauncey, 1989).
WHEN BEING QUEER WAS A DISEASE

THE HISTORY OF PSYCHIATRY AND HOMOSEXUALITY READINGS

Sodomy and Other "Crimes Against Nature"

Medicalizing Sexual Inversion

Psychoanalysis and Homosexuality

Declassification of Homosexuality by the American Psychoanalytic Association

History of the Association of Gay and Lesbian Psychiatrists
1973 – **DSM**

DE-PATHOLOGISES

HOMOSEXUALITY

Weight of empirical evidence.

Politically active GLBTI community.

Change in directors of the American Psychiatric Association *(APA)*.

Fierce opposition of some psychiatrists who demanded a plebiscite of all members of the APA.

Vote held in 1974: Board’s decision ratified.

Great optimism, excitement hope... And then social control (rescripted).
FROM 1950S... PSYCH. DRUGS CHANGED EVERYTHING?

Breakthroughs heralded with enormous hope.

DSM Classification of ‘diseases’ -American Psychiatric Association (Northern America, Male, Conservative, Psychiatrists with a lot of power).

John Cade – Lithium.


Medicine, left untethered, forgot why it existed. Patients, still hidden away, became potential experiments, ripe for double blind trials that looked entirely scientific but which were sometimes more about the careers of the researchers than the needs of patients.

A Brief History of Psychedelic Psychiatry [http://www.theguardian.com/science/neurophilosophy/2014/s]

Selling Sickness: the pharmaceutical industry and disease mongering: in British Medical Journal 2002 [http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1122833/]
Deep Sleep Therapy – Chelmsford Hospital

Deep sleep therapy (DST) was also called prolonged sleep therapy or continuous narcosis.

Patients were administered drugs which kept them unconscious for a period of days or weeks.

Victims of excessive psychiatric treatment at Chelmsford Private Hospital, 1988
Twenty-six patients died at Chelmsford Private Hospital during the 1960s and 1970s.

Government was forced to appoint a Royal Commission.

The Citizens Commission on Human Rights, a psychiatric reform group established by the Church of Scientology advocated for victims.

See Daniel A., Scandals and Crises in Psychiatry in Scapegoats for a profession Chapter 3: pp. 45-46

COMMUNITY CARE

Necessity, politics, economics and real concern and care.
JOLLY HOCKEY STICKS: COMMUNITY CARE CIRCA 1990s – BEYOND DEPENDENCY

Decision-makers genuinely full of hope and an expectation that without big institutions people’s lives must improve.

Hospital stays: short and crisis only;

Asylum unmitigated evil.


Services minimised to prevent dependency.
Like the asylums in their heroic foundation phase, community care arrived in a tide of optimism. Replacing mental hospitals with community-based services was not just going to improve life of the ‘mental patient’, it was going to eliminate the unhappy, stigmatised figure completely’… assisted by new drugs, people with mental disorders would shake off their outcast status and become normal, or near-normal, family members, workers and citizens.

Taylor 247
WHAT WE [SORT OF] KNOW

The time was right: medicalisation & public and political sentiment against asylums.

Community largely unprepared for influx of people with ‘mental illness’.

Policy inadequate, untargeted.

Many people from ‘the back wards’ ended up homeless, chronically symptomatic, in prisons.

Done too fast in order to achieve political and economic objectives.

Supports appallingly inadequate.
THE PHOENIX RISING:

Friern closed and is replaced by Princess Park Manor (a posh housing development): 1998 film

“With its manned security gate, high-tech locking systems omnipresent surveillance cameras, Princess Park Manor aims to keep out what ‘Friern’ was meant to keep in.”

Taylor p.246
WHERE DID OUR BUILDINGS GO?...
OUR LAND... OUR PLACE...

THE ASYLUM IS NOW KNOWN FOR ITS REAL ESTATE VALUE

PRINCESS PARK MANOR, FRIERN BARNET, N11

3 BED APARTMENT FOR SALE £1,200,000K MA

Flooded with natural light from large south-facing windows, this outstanding three bedroom duplex flat features a wonderful reception room with a double-height ceiling and a mezzanine-level reception room.
Psychotherapy was mainstream in both public and private services.

Public services were not so strongly gate-kept;

People were prioritised according to economic need, experiences of trauma- rather than diagnosis;

Not regulated nor consistent.

Much of this was criticised in a movement towards re-medicalising services around the world.
‘COMMUNITY CARE’
WARNING SIGNS

Consumer/survivor language was appropriated to save money: ‘recovery’, independence, self-reliance, independent decision making;

Mainstreaming was not actually something demanded by consumers.

Development of consumer organisations around the world moved forward at this time.

The birth of an effective ‘carer’ lobby, built out of need and desperation: the difference between what was and what ought to have been.

TRIESTE: A CASE STUDY OF HOPE
TRIESTE: A MUST KNOW ABOUT

We can’t help people to make purposeful decisions about their lives if they don’t know and we don’t know what is possible?
FRANCO BASAGLIA: DEMOCRATIC PSYCHIATRY

Franco Basaglia March 1924 – 29 August 1980) was an Italian psychiatrist and neurologist who proposed the dismantling of psychiatric hospitals, pioneer of the modern concept of mental health.

Charismatic leader, reformer and principal proponent of the law which abolished mental hospitals in Italy.

The most influential Italian psychiatrist of the 20th century.
GETTING TO KNOW
WHAT’S GOING ON
IN TRIESTE

Trieste: History of a transformation http://www.triestesalutementale.it/english/mhd_history.htm


Psychiatric Reform in Italy by Dr. Giovanna Del Giudice, Mental Health Department, Trieste http://www.triestesalutementale.it/english/doc/delgiudice_1998_psychiatric-reform-italy.pdf

FOR THOSE WHO WOULD LIKE TO KNOW MORE

Psychiatric Cultures Compared: Psychiatry and mental health care in the 20th Century (2005), Amsterdam University

Geography: Netherlands, Gheel USA, Britain, Germany, Japan…

Atrocity: Communist State, Nazi Germany. French State, Fascism in Italy

Issues: The family, welfare, psychiatric nursing, psychotropic drugs…

This overview can be downloaded: http://dare.uva.nl/cgi/arno/show.cgi?fid=133259
Burdekin and beyond.

Consumer business.

Not everyone has a serious experience of mental illness: a case study in language.

Mental illness and the family: an historical case study.

The future?
An expose of what had got lost in the haste to move people into the community.
AUSTRALIA: BURDEKIN REPORT (1991)

Human Rights Commissioner 1986 -1994


THE LOGIC OF A ‘NEW BEGINNING POST BURDEKIN’

‘Carer/psychosis lobby’ deserving & clamouring.

Those who fell between the cracks from deinstitutionalisation.

‘Mental illness’ services. Medical remedy driven.

Justified by appeals to ‘the most needy’, ‘most vulnerable’ ‘most deserving’.
First incursion of Federal Government into State health policies and programs.

First senior appointments of consumers and carers (National Community Advisory Group – NCAG).

Service model radically changed and gradually all psych. nurses and allied health positions became case managers – to the chagrin of many.

Cocoa-pops public anti stigma campaigns - "Just like any other illness only crunchy."

One in Five campaign now denigrated by so many consumers.
SOME CHARACTERISTICS (IN IDEOLOGY AT LEAST): **FIRST NATIONAL STRATEGY**

- Evidence-based medicine.
- Case Management.
- Decentralisation.
- Mainstreaming.
- Risk Management.
- Community Treatment Orders.
- Community Services.
- Large new players such as beyondblue.
SERVICE ORDER AND EFFICIENCY

Most of these tenets, developed with good intentions survive in rhetoric and tokenism.

Big business (pharmaceutical companies) or scientific/medical elites have captured the research agenda and budget;

Mainstreaming has lost us our gardens and our beloved trees and private places.

Community Treatment Orders, at first a shining light in the Victorian mental health scene (getting people out of hospitals) has decayed into a risk prevention industry that harms people imprisoned on the streets.

Case management may have delivered illusionary relationships, cursory interactions, people as ‘cases’ and disillusioned clinicians.
Mental Health Research Institute now exclusively brain research.

Marginalise all experiences that are not clearly brain diseases.

DSM hugely influential but with critics (Survivors, Asylum Magazine, radical psychology,

Brain disease brilliant for some consumers to fight prejudice.

Brain disease delays plans of recovery for others.
Australia’s structure as a Federation of States with State and Territory governments historically having responsibility for health provision posed many problems and change progressed slowly.

New Zealand, without this impediment, achieved more including the appointment of Mary O’Hagan as the first consumer Mental Health Commissioner (out of a commission of three) 2000 -2007.

However demarcation disputes continue, the failure to develop consistent Mental Health Acts around Australia.

From 1993 – 2012 progressive Federal governments enacted policy for the Council of Australian Governments in an attempt to bring all the States and Territories along with substantial changes to service provision.

Australian Health Ministers Advisory Council (AHMAC)
POWER, CAPITALISM
AND THE 21ST CENTURY

Rise of powerful players such as beyondblue, Mad Dog Institute, Butterfly Foundation in the 1990s.

Powerful ‘carers’, often ex-politicians or from the business sector have.

Individual psychiatrists like Ian Hickey and Patrick McGorry are, depending on your view, personal empire builders or visionaries of the 21st Century;

Federal and State and Territory governments continue to engage in cost shifting and dilly-dally as they jostle to make the other tier of government pay. The Australian Health Ministers Advisory Council (AHMAC) was instrumental in trying to minimise this.

2015 Turnbull Government makes sweeping changes bypassing State and Territory Governments to fund local organisations.
Australian Bureau of Statistics.

Every 7 years.

Wars between funding high prevalence disorders (anxiety and depression) which are more people but less cost per person or low prevalence disorders (the schizophrenias) at more cost but less people.

Survey in two parts that are totally different.

High prevalence (nationwide tick the box survey, fill in at home job).

Low Prevalence (psychosis predominantly with totally different methodology).

What experiences and questions are asked is decided by a committee of the Australian Health Ministers Advisory Council (AHMAC).

The wider ranging high prevalence survey can’t include everyone (ABS advises that if it is too long people won’t complete it.)

In 2007 Borderline Personality Disorder was completely taken out at the death knell because there were not enough people in the room barracking for it.

From these surveys the next 7 year National priority areas are determined.
Emphasis attempted to focus on psychosocial services for the ‘seriously mentally ill’.

Community lobby organisations (Richmond Fellowship, Mind & NEAMI) started to receive money for providing services.

Strings progressively became attached. Difficult to campaign against important priorities of the funding master.

Services included residential, programs, day services etc.

Organisations once soul mates in defiance became competitors for funding;

Organisations grew exponentially and inevitably developed big bureaucracies reaching interstate.
The arrival of new Diagnostic & Statistical Manual reminds us that the DSM is not a scientific endeavour.

The status as an illness is a democratic process (perhaps). New illnesses are decided by vote (agreement) by the American Psychiatric Association (male psychiatrists in main part).

New diagnoses met with mixed response because the document has multiple meanings:

1. Code and communication for clinicians;
2. The only way to get any resources or services for some consumers and families;
3. Pathologising normal experiences for others;
4. Nothing but medical imperialism for some.
NDIS

National Disability Insurance Scheme (NDIS)
Poorly drafted Bill at the fall of the Gillard government.
Promised a lot but can deliver to so few;
Badly suited to psychiatric disability;
Some people using existing services have lost them.
Have to prove permanent impairment! What happened to recovery?
Individualises after a decade of talking about community
Listen to consumers, Indigo Daya & Nathan Gritxi; Raising Community Voices and the Barwon NDIS Experience [source]

ATAPS

Access to Allied Psychological Services (ATAPS)
Medicare funded response to the paucity of services for poor people who do not fit the criteria for Serious Mental Illness
Result of sustained lobbying by Australian Psychological Society (APS)
Restricted to brief counselling and limited therapy
People with major childhood trauma (seriously affecting life and safety including death by suicide) do not meet existing eligibility criteria because their needs are often chronic. [source]
16. CONSUMER BUSINESS
CONSUMER ACTIVISM

World Network of Users and Survivors of Psychiatry.

CONSUMER WORKFORCE

**TIMELINE**

Consumer peak body - Victorian Mental Illness Awareness Council formed 1981 – International Year of the Disabled. Ongoing systemic and individual advocacy; research; representation…

1989 – 1996 Understanding & Involvement Project created and road tested the idea of staff-consumer consultants to be employed systemically particularly in acute settings.

Consumer Consultants introduced across Victorian clinical services

Consumer consultants introduced into the community sector

Personal Helpers and Mentors PHaMHs introduced


Through time workers in the consumer sector have become more organised and fought for better conditions. Some consumers (albeit including carer workers) have over ten EFT (effective full time) staff.

2015: Consumers also employed as educators, academics, freelance writers, speakers and researchers.
THINGS ARE SOO... MUCH BETTER NOW...

‘Working for Wellness’. … The PR language is upbeat, the message relentlessly cheery. ‘Mental health care [has been] transformed’.

‘Mental Health Choices’. ‘Living Independently. ‘Mental health care [has been] transformed’.

Making Recovery a Reality. Taylor p. 350
Throughout the last 25 years the rhetoric has offered consumers a lot however there is a pattern of corruption to the spirit of change. Ideals have been found wanting:

**Independence** has led to homelessness, statelessness and prison for some.

**Choice** has been ephemeral when forced treatment is evoked and benevolent prejudice has led to people’s choice to live rough, for example, not being honoured

**Recovery** as consumers first envisaged it has been coopted by powerful others and too often become hollow rhetoric. We have collectively sometimes silenced people who don’t actively aspire to recover as it is presented to them.

Consumers spend endless hours sitting on reactive, pointless committees.

Local Consumer Advisory Groups exist and are sometimes taken seriously – not always

Consumers in the public, private and community sectors sometimes have no idea at all about what each other is doing and talk at tangents.

Consumer organisations continue to implode and too many people get hurt by the very people who should be their greatest allies. This is a pattern that goes over 30 years of active consumer participation.
NOT EVERYONE HAS A SERIOUS EXPERIENCE MENTAL ILLNESS!

Serious Mental Illness (SMI) A case study in 21st century language manipulation.
SERIOUS MENTAL ILLNESS: LANGUAGE IN POLICY FOR A QUARTER OF A CENTURY

Reification refers to making an idea into something concrete - a deception. Serious Mental Illness is an ethereal idea.

The idea of serious mental illness arrived undefined in the Burdekin Report and has been claimed and reclaimed for 25 years.

Re-badged: severe, severe & enduring, low prevalence...

It came to mean psychosis not by science but by politics.

Creating an acronym (SMI) further cements the perception of a ‘science’ that doesn’t really exist.
IT DOESN’T NEED TO HAVE ANYTHING TO DO WITH EXPERIENCED SERIOUSNESS: GATE-KEEPING

Consecutive national MH strategies needed gate-keeping language otherwise the risk of spiralling expenditure and political censure.

Being honest about tools for gate-keeping was (and is) politically unpalatable.

Language of dire prognosis used in tandem with terms like ‘the most vulnerable’, ‘greatest needs’ etc. works much better with the public (community) than ‘we haven’t got enough money’ or ‘we don’t want to prioritise this’ or ‘its politically expedient not to fund this’.
No one wants to be told that they have a diagnosis that is so serious that recovery is unlikely...ever.

No one wants to be told that they have a diagnosis this is, by diagnostic definition, never serious.

No consumer wants to ‘know’ that his/her best friend is dead from an illness that is by diagnostic definition non serious.

Sometimes we do want to know it is all about gate-keeping.
‘Just behavioural’.
‘Not a real mental illness’.
‘High functioning’ and ‘low functioning’.
‘Only a pd’ (personality disorder’).
Only neurotic.
Met un-need.
‘Worried well’.

All mental illness is serious! (implying the exact opposite).

Psychosis is mental illness (implying impairment so great that recovery is impossible).

Treatable conditions.

Public services as ‘serious’ and private services as not.

• Some of these are sexist.
• The stigma attached to each of them is very different and sometimes competing.
• They all stop people being seen as fully human.
Juxtaposition of interpretation: a case study in history
Sometimes history lives within our veins and repeats through time leaving us with visceral reactions that we struggle to understand in the present context.

The history of the relationship between people society deems to be mad and the families and carers of mad people is full of oscillating authority, power and hurt.

These relations are, in part, determined by dominant cultural attitudes of their day, gender politics, power relationships and the history and philosophy of science.
FAMILY IS DIFFERENT IN ABORIGINAL COMMUNITIES

Kin relationships traditionally vital;

Colonisation and dispossession weaken ties;

Institutional sexual assault in missionary run places;

Stolen generation further assault;

No real articulation of the individual with ‘mental illness’ as separate from the family in Aboriginal cultures;

Increasingly the legacy of colonisation challenges family emotional ties and wellbeing.

Aboriginal women, in particular, are demanding this is addressed amongst increasing suicide rates, fear and dislocation;

Elders and extended families (Aunties and Uncles) remain strong, healing and vital.

Everyone is family.


14TH-19TH CENTURY: FAMILY AND MADNESS

FROM 14TH CENTURY

Geel, Belgium.

“For more than 700 years its inhabitants have taken the mentally ill and disabled into their homes as guests or ‘boarders’. At times, these guests have numbered in the thousands, and arrived from all over Europe.”


19TH CENTURY

“Home-based nursing could never match skilled asylum therapeutics... because it is there [in the home]... where circumstances that excite the manacle paroxysms frequently exist” in the Last Asylum Barbara Taylor.

“Families reluctant to lock their loved ones away were assured that it was only in a well-regulated, salubrious environment, under the care of medical specialists, that offered any hope of recovery. in the Last Asylum Barbara Taylor.
THE ASYLUM ERA

18TH AND 19TH CENTURY

Camille Claudel was not alone;

Many family members who were seen to have shamed the family for political, religious or ‘society’ reason were locked up by their families.

Sometimes the more articulately the imprisoned person argued their case for release the more obstinate and brutal the family and authorities became.

20TH CENTURY

In the later years of the asylum era families continued to have a major influence in negotiations with authorities. See: http://www.sciencedirect.com/science/article/pii/S0160932713000410

In the 1990s Royal Park Reception Hospital (asylum) in Melbourne was closed. To recognise its 90 year history an exhibition of historical artefacts was displayed. In the original admission records from the 1950s a major (perhaps main) reason for locking women up was battery by family members.
Throughout history theory and understandings of mental illness swing between biological explanations and familial/experiential ones.

Families and the family lobby do not want to be blamed at an already stressful time. Adults surviving trauma are often re-traumatised by the family lobby misrepresenting them.
During the second half of the 20th Century psychotherapeutic understandings of mental illness had ascendancy.

1. Object relations (determining role of the ‘significant other’).

2. Schizophrenogenic mothers.

Gender: In both cases ‘mothers’ were more often targeted as instrumental in the development of mental illness in children and adults.

Object relations theory in psychoanalytic psychology is the process of understanding the development of a psyche in relation to others in the environment during childhood. In the theory, objects are usually internalized images of one's mother or father or primary caregiver.

Kleinian school of post Freudian psychoanalysis https://en.wikipedia.org/wiki/Melanie_Klein
History pivoted once again.
The theory was proven wrong.

Carers, relieved and now more organised
The National Alliance of the Mentally Ill (NAMI),
a conservative lobby group in the USA generalised no wrong doing to all experiences of mental distress.

Consumers with backgrounds of trauma were silenced.
The gender implications were too often neglected.

The Ghost of the Schizophrenogenic Mother in AMA Journal of Ethics September 2013, Volume 15, Number 9: 801-805
1990-2000: **CARERS AND FAMILIES**

Burdekin and beyond carers, incensed by the Schizophrenigenic debate, helpless and hapless in the face of:

1. their children’s experience of brain disease;
2. with extraordinary stigma and isolation;
3. Few resources and no one to talk to who might understand;

hit back.

Carers/families sought and attained an unprecedented amount of power in mental health policy debates;

Lobbying capacity through well connected carers, businessmen and ex-politicians particularly, increased exponentially.

Organisations with huge amounts of political clout arose around the western world.
Family carer lobby grew out of more open governance of sector.

Consumers and carers were put together as a single lobby group which disadvantaged consumers but less often family carers.

Issues of trauma and trauma informed care were relegated to ‘not’ or ‘less’ important;

A time of emphasis on the brain rather than the ‘mind’ suited the carer lobby.

Family carers learnt how to discipline their passion for political gains.

Some families started to talk about their family and the person with mental illness; preserving the idea that the rest of the family must be "normal".
Consumer politics was fractured largely because power and influence was new.

Consumers were sometimes coopted by carer organisations.

Consumer workforce took up a lot of energy.

Coverage of different experiences and diagnoses fairly and with natural justice made simplistic political doctrine almost impossible.

Consumers knew about and could not neglect, the traumatic family backgrounds of many.
What have we learnt from the past.
A NEW ERA COMING, REPEATED?

Royal Commission into Institutional Child Abuse;

Royal Commission into domestic violence;

Children in detention centres.

National Disability Insurance Scheme.

New Victorian Mental Health Act.