A FREE Hearing Voices Network event

time for (real) change?

Is it time for a revolution in mental health & society?

Event Report

9.30am - 4.45pm, 20 April 2015
@ Amnesty International Human Rights Action Centre
New Inn Yard, London, EC2A 3EA

An increasing number of people, groups and organisations are becoming concerned with the current paradigm of pathologising and labelling human experiences and understandable reactions to trauma and adversity.

In this one day event, the Hearing Voices Network brought together people and organisations who seek change to explore a) what needs to change and b) what we can do differently to make it happen.

Organisations represented, include: Asylum - BPS DCP - Council for Evidence Based Psychiatry - Critical Psychiatry Network - Friends of East London Loonies - ISPS UK - National Hearing Voices Network - New Paradigm Alliance - 'Only Us' Campaign - Peer Supported Open Dialogue - Positive Outcomes for Dissociative Survivors - Recovery out of The Bin - Speak Out Against Psychiatry - Spiritual Crisis Network - Social Work Action Network - Soteria - Southwark Assoc. for Mental Health

Time for (real) change? Event Report

1) Jacqui Dillon - Introduction

Jacqui opened the day by describing the Hearing Voices approach and giving a brief history of the movement. She highlighted that this is a different approach to expertise that emphasises mutual respect. The core message is that voice hearing is a meaningful experience with diverse explanations. We heard about the 180 groups in the UK and the many countries with groups that are part of Intervoice. She then asked participants to consider joining HVN and introduced the day.

2) Rachel Waddingham - Introduction

Rachel called for sharing ideas around mental distress and social exclusion. She said that today was about asking questions and discovering what we can do together. She also admitted that the name of the conference may have been 'borrowed'!

Opening Presentation by Joanna Moncrieff

"Where are we now and what needs to change"

Joanna opened with a quote by Moore and questioned the notion of 'objective' statements which in fact uphold the status quo. She described the increases in prescription medications and diagnoses, including for children, and showed that there was no parallel increase in outcomes. In fact there are now more admissions and CTOs and an increase in benefit claims for mental health.

She stressed the rate of tardive dyskinesia (4-5%) and that the associated cognitive deterioration is not widely known. Whilst there is increased awareness of the harm of drugs, the effects are suppressed by psychiatry as they try to link these with diagnoses. She said there is in fact an 'epidemic of drug treatment' due to the diseased centre model which assumes that drugs correct abnormal brain states.

Joanna called for a drug-centred model which puts the focus on the drugs creating an abnormal brain state which may or may not be useful to people. She called attention to the fact that there is no evidence now or in the past for how drugs work (including 'anti-depressants', 'anti-psychotics', mood stabilisers etc) and that this is due to the agenda of powerful groups. She also pointed out that placebo controlled trials are also more problematic as a way of collecting evidence. She highlighted that compulsory medication legal controls as it is in fact a form of social control.

Marketplace #1

The first 'marketplace' for sharing information from allies and organisations with similar aims and objectives:

Social Work Action Network (SWAN): Talked about their mental health charter and related campaign in the Guardian against compulsory IAPT.

PODS (Positive Outcomes for Dissociative Survivors): Described their service including support and information.

Spiritual Crisis Network (SPN): Katie Mottram explained that SPN support understanding experiences through spirituality and highlighted that in Brazil, where there is a more holistic understanding of distress, there is a 90% success rate. 'Psychiatry should not be the reality police'

"Only Us" Campaign: Mirabai Swingler talked about her 'Only Us' campaign which encourages professionals to acknowledge their lived experience. 'Remember you are a human'

Peer Supported Open Dialogue: Dr Lauren Gavaghan described the RCT across four trusts which is aiming for organisational change and having a new 'way of treatment'.

FEEL (Friends of East End Loonies): Briefly introduced themselves, described some of their recent activities and invited people to their monthly meetings in Tower Hamlets.

Soundbite #1: Liam T Kirk, Speak Out Against Psychiatry

"Mental health 'treatment' as a human rights issue"

Liam talked about his involvement with SOAP (Speak out Against Psychiatry) and his expertise by experience. Described his childhood experiences and then introduced the Human Rights Act – article 8 'right to respect for private and family life'.

Coffee Break

A space for networking, meeting new allies and grabbing some caffeine or fruit tea

As is often the case at these events, we took full advantage of the coffee break to talk with one another, check out the stalls and share our perspective on the morning's proceedings.

Soundbite #2: Rachel Waddingham, HVN & ISPS UK

"The Human Rights Act: What does it mean for us?"

Rachel pointed out the irony of being in Amnesty International, without any representatives being there (despite being invited). This is a sign of how mental health is overlooked in mainstream considerations of Human Rights. She then highlighted the relevant sections of the ECHR and pointed out which aspects of the mental health system infringe these rights. She concluded that this was able to happen because of the medicalisation of distress.

Presentation by Molly Carroll

"Man's Handmade Scalpels"

Molly began by explaining that she wanted to join up individual healing with the collective and she was going to talk about three instruments that are used to oppress and traumatise.

The first was the removal of agency and self-determination. She pointed out the similarities between diagnoses, treatment and medication with racism and how the civil rights movement fought against this. The second tool was disbelief, denial and decontextualisation. She highlighted Atos and benefit sanctions and the systemic denial of sexual violence. Finally she talked about victim blaming and focussed on the idea of 'benefit scroungers' and how that fits in with the neoliberal agenda. The second part was about resistance and the feedback session included ideas around returning meds, using humour and ridicule, living 'as if' and protest.
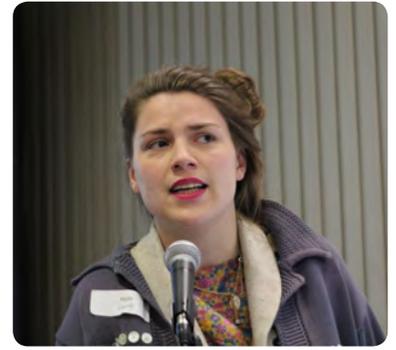
Marketplace #2

The second 'marketplace' for sharing information from allies and organisations with similar aims and objectives:

ISPS UK (International Society for Psychological and Social Approaches): Jen Kilyon described the work of ISPS UK which aims to create dialogue about different perspectives on psychosis.

Council Evidenced Based Psychiatry (CEP): James Davies from CEP talked about their work collecting evidence that the domination of medical model is bad for mental health.

Speak out Against Psychiatry (SOAP): Cheryl Prax talked about the next international protest for the abolition of ECT.

Recovery in the Bin: Robert Dellar spoke about opposing neoliberal recovery model of mental health. 'Tough on psychiatry. Tough on the causes of psychiatry.'

New Paradigm Alliance: Isabel Clarke introduced the New Paradigm Alliance and their manifesto and invited attendees to join them.

British Psychological Society: Che Rosebert spoke about the work of the BPS's Psychosis & Complex Mental Health Faculty, including their latest publication 'Understanding Psychosis & Schizophrenia' which is intended to open up a more helpful dialogue around these experiences.

Presentation: Dolly Sen

"It's not institutional racism. It just happens every day"

Dolly opened with Suman Fernando's report on racism in the mental health system and described how nothing has changed with some horrifying statistics. She said that bringing up institutional racism never leads to open discussions. She went on to share her experiences of racism from childhood and how she was not able to talk about this in the psychiatric system, and encountered subtle racism in hospital.

Whilst psychology and psychiatry seem to have mixed feelings about whether racism is trauma, Dolly underlines that it 'breaks your heart' and causes extreme mental distress. She has observed the pathologisation of black people's experiences of pain in the system. She said that there needs to be space to explore distress, gain a sense of worth and to build community justice and participation.

Presentation by Dave Harper, UEL & Asylum Editorial Collective

"Campaigning for change: Ideas from the work of Gene Sharp"

Dave discussed ideas from Gene Sharp for revolution. Started by pointing out how much has not changed in the mental health system, for example sectioning is twice as high than in the 80s. Models of change have focussed either on understanding to change law or policy. However Sharp's ideas were around having different tactics for each pillar of dictatorships (in this case Psychiatry). He talked about how much resistance is just reactive and how debates around the DSM could have been broadened out. He suggested that a start could be made with low risk methods focussing on widely recognised issues, such as employment discrimination.

Workshops

Our workshops were intended as discussion based spaces to begin the process of agreeing what needs to change and how we can go about achieving this. Also see the typed up flipcharts and powerpoint presentations to get a feel for these sessions.

Double Agents: Creating change from inside the system.

This workshop explored some of the tensions, challenges and opportunities facing those who work within the mental health system to create change. Facilitated by Steven Coles.

Many ideas were contributed during these workshops, including: kidnapping psychiatrists and other mental health professionals so that they can experience coercion first hand; networking with different organisations; the use of humour.

Changing The World: What can we learn from effective Human Rights Campaigns?

This workshop looked outside the mental health field to explore a range of ways Human Rights activists and campaigners have been able to make a difference to the world we live in. Facilitated by Rachel Waddingham (round one) and Jacqui Dillon (round two).

During these workshops we explored the potential for non-violent action including consciousness-raising; louder and more active action; making statements; finding allies in non-mental health agencies. Attendees pointed out that people are often oblivious because they're not personal engaged so we need to think about how to reach out to these people. We could use the media and powerful visual imagery to engage people's emotions/minds and bring them in to our movement.

Errrr ... But

A supportive and non-judgemental space to explore the tensions and concerns people had about the themes raised during the day. Facilitated by Jacqui Dillon (round one) and Rachel Waddingham (round two).

Attendees at this workshop sessions shared a range of concerns and worries, including: the danger of peer workers being assimilated into the system; the radicalness of lived experience being undermined when people just become agents and cheap labour; the challenges of being able to share positive experiences of the mental health system without silencing others' negative experiences.

Can We Work Together?

How we can work together to acheive change? This workshop explored the potential scope for collaboration. Facilitated by Stuart Bakewell & Giles Tinsley

We say 'we', but who do we mean? Further questions asked included different ways of treating people? What is 'treatment'? Who are leaders (i.e. service-users or professionals)? Our final consensus was that we want a coherent campaign, a social movement with representation.

What Next?

Final thoughts, words and ideas from participants

In the final half hour of the conference we gathered back together to share our experiences of the day and see whether we could agree on some ways forward.

Some quotes from the final session:

> 'I appreciated being here and meeting everyone. I feel like I have a voice. Thank you very much!'

> 'I appreciate the way HVN takes leadership and call for HVN to take leadership of the campaign'

> 'This is fucking cool. We need to make effort to translate stuff and share knowledge.'

> 'I have a bigger perspective on what is known and how I am going to work in services and how to make society a place we can live in'

> 'Being here has confirmed everything I have done on my own in mental health research. Because I am a patient I have lost trust in psychiatry. My health is due to my own research'.

Participants present seemed keen for HVN to take a lead in developing this initiative. However, HVN trustees felt that it needed to be a collaboration where ownership is shared amongst a wider group of stakeholders. They agreed, instead, to host the first working group as a way of following up on the enthusiasm and passion shared during the conference and get things started. They made it clear that they'd hope other participants / organisations would help chair future meetings.

Jacqui Dillon - Conclusion

Today has spoken to our shared frustration. This is not the end!

Campaign Working Group: Saturday 26 September, 1.00 - 4.30pm @ Freedom From Torture (Holloway, London). See: www.**realchange2015.eventbrite.co.uk**
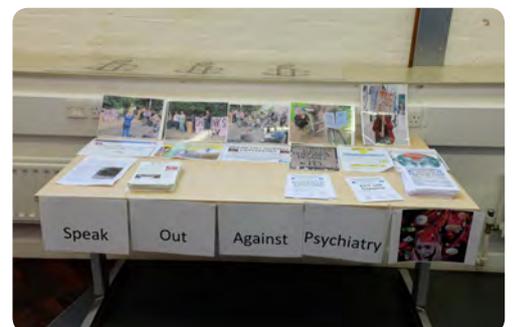
Jacqui Dillon

Welcome & Introductions

Slide 1

Hearing Voices Network
for people who hear voices, see visions or have other unusual perceptions

A FREE Hearing Voices Network event

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Is it time for a revolution in mental health & society?

Jacqui Dillon
Hearing Voices Network
National Chair, England

Slide 2

The Hearing Voices Approach

- In 2012 we celebrated the 25th anniversary of the Global Hearing Voices Movement
- Inspired by the pioneering work of Professor Marius Romme & Dr Sandra Escher and Patsy Hage
- Voices make sense when looking at the traumatic circumstances in life that provoked them
- Contests the traditional psychiatric relationship of dominant-expert clinician and passive-recipient patient
- Based on mutually respectful relationships – authentic partnerships between experts by experience and experts by profession, working together to bring about the emancipation of voice hearers
- Views voice-hearing as a significant and meaningful human experience
- Acceptance of Diverse Explanations
- Normalising & Hopeful Approaches
- Value and Importance of Peer Support

Slide 3

Hearing Voices Network
for people who hear voices, see visions or have other unusual perceptions

- Information
- Self- help groups
- Publications
- Newsletter
- Training
- Conferences & Events
- Individual & Group Membership
- Website
- Research
- Media
- Intervoice

Slide 4

International Developments

- Australia,
- Austria,
- Belgium,
- Brazil,
- Bosnia,
- Canada,
- Denmark,
- England,
- Finland,
- France
- Germany,
- Greece,
- Holland,
- Ireland
- Italy,
- Japan,
- Kenya,
- Malaysia.
- New Zealand,
- Norway,
- Palestine,
- Scotland,
- South Africa,
- Spain,
- Sweden,
- Switzerland,
- Tanzania,
- Uganda,
- USA,
- Wales….

Slide 5

Join Us – Become a Member

Membership of the Hearing Voices Network means that you will receive a newsletter four times a year, you will be notified of events, conferences, meetings etc. We will also support and help anyone wishing to start a new group.

Membership Prices (for 1 calendar year)

Individual	Fee	Organisation	Fee
Waged	£15	Organisation	£40
Unwaged	£10	Funded Group	£40
People in Secure Settings	£5	Self-Funded Group	£20

Sign up Today!

Slide 6

Extra Information

Refreshments:
- We are providing tea, coffee and biscuits at break times and welcome any donation you can make towards the costs. As this is a free event and we an unfunded charity, we are unable to provide lunch. However, there are many cafes in the area. Ask a volunteer if you are not sure where to go.

Marketplace:
- If you have some flyers or information you would like to share with attendees, you are welcome to display these downstairs in our 'marketplace'. Just ask a volunteer to help you find a space for them.

Post-conference report:
- We will send a report to all attendees that we encourage you to share far and wide to bring more people in to these conversations. As well as providing an overview of discussions and workshops, as well as any agreed actions, we would like this report to be a collaboration with those who took part. If you would like to contribute some brief reflections about your experience of the day, please email it to info@hearing-voices.org

Need any help:
- If you want to speak to someone from HVN, ask any questions or want to check something out - please seek out a volunteer (you will find them around the venue helping show people the way, or on the HVN Information Desk during breaks).

Safe Space:
- If you need somewhere quiet to relax during the day one of the 'Action Rooms' will be set aside for this purpose. We ask that all attendees are mindful of the diversity of views people bring to the day and treat one another with kindness and respect.

Joanna Moncrieff

"Where are we now and what needs to change"

## Time for (real) change
HVN conference April 2015

Where we are now and what needs
to change

- In any society, the dominant groups are the ones with the most to hide about the way society works. Very often therefore truthful analyses are bound to have a critical ring, to seem like exposes rather than objective statements, as the term is conventionally used (to denote mild-mannered statements in favour of the status quo)
- Barrington Moore, *The Social Origins of Dictatorship and Democracy*, 1966

Age-standardised disability-adjusted life year (DALY) rates of unipolar depressive disorders by country (per 100,000 inhabitants) in 2004.[1]
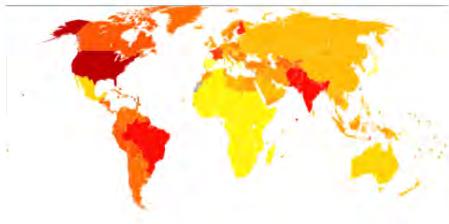


Trends in prescriptions in England 1998-2010

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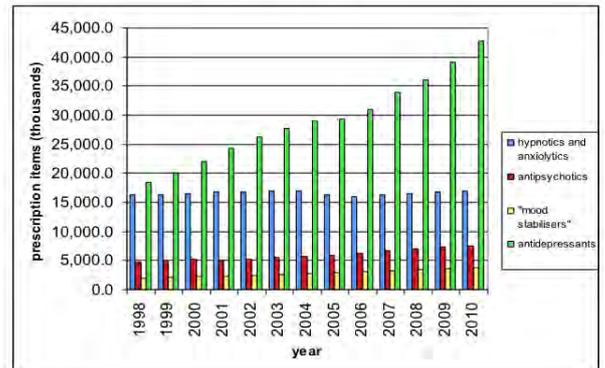
Trends in antidepressant prescribing 1992-2010
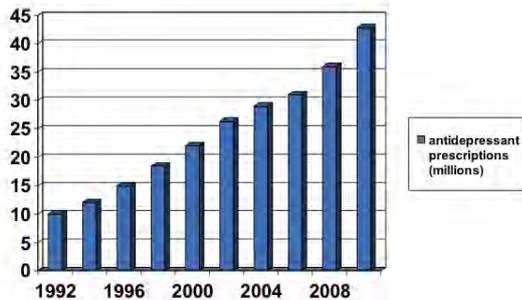
Community antipsychotic prescriptions 1998-2010 (PCA)
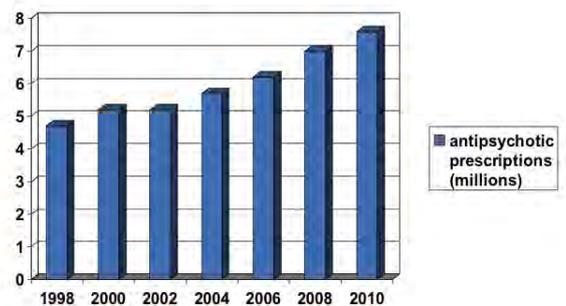
## Trends in prescriptions for stimulants in England
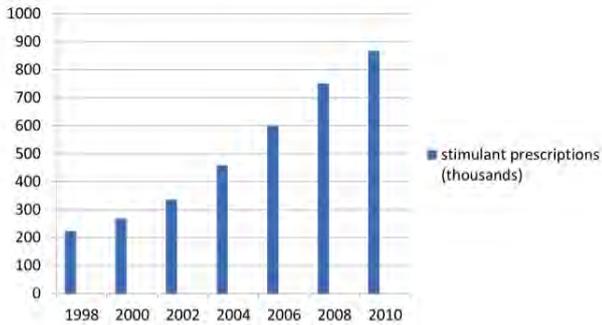
National trends in office-based visits by children and adolescents that included antipsychotic treatment, 1993-2002 (Pincus et al, 2006)
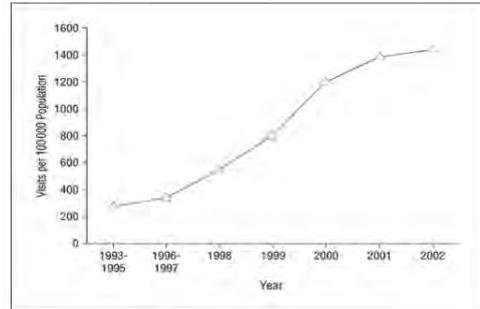
Admissions under Mental Health Act, England
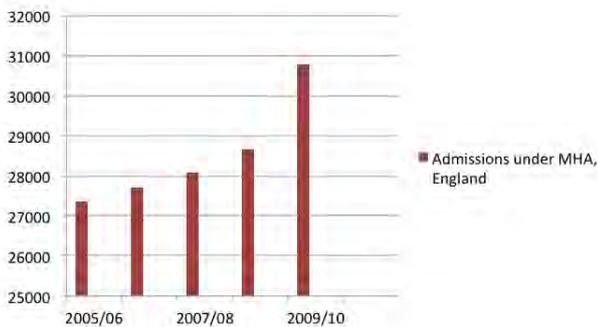
Patients subject to CTOs by 31st March 2012
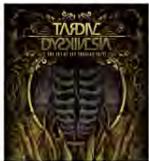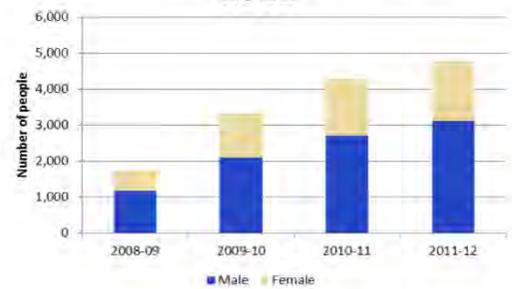
Tardive dyskinesia

- Still affects **4-5% people** on long-term antipsychotics **per year** (Woods et al, 2010; Correll & Schenk, 2008)

- TD involves cognitive deterioration, which emerges over the same period as the abnormal movements (Waddington et al, 1990)

Antipsychotics and brains

- **Lieberman et al, 2005**: haloperidol vs olanzapine trial and MRI study: haloperidol caused reduced brain volume at 12 weeks, haloperidol and olanzapine at 1 year

- **Dorph-Petersen et al, 2007**: macaque monkeys: olanzapine and haloperidol caused 10% decrease in brain weight at 18months

- **Ho et al, 2011**: long-term first episode MRI study: level of antipsychotic exposure strongly predicted brain volume reduction

The Zyprexa papers

Current situation

- Many people on cocktails of drugs, not feeling better but unable to come off
- Coming off may indeed be problematic, but not necessarily because of the original problem (dependence, withdrawal symptoms and withdrawal-related relapse)
- Absolutely no evidence that this situation has reduced hospital admissions, reduced violence or suicide, improved social functioning or quality of life, reduced welfare bill, increased rates of being in work

- Good evidence that drugs cause harm

"Antidepressant nation: is stress making pill poppers of us all?"

"'Staggering' rise in prescribing of anti-depressants"

Peter Gotzche, 2012

- 'Our citizens would be far better off if we removed all the psychotropic drugs from the market, as doctors are unable to handle them. It is inescapable that their availability creates more harm than good'

- "I was desperate with fear- seeing and living with the effects of the risperidone and other drugs my husband was given, and his unwavering belief in them"

- "None of the medications have helped my son with his paranoia. Some have been so sedating he was in bed for 20 hours a day"

- "There is something wrong with your brain, you need this drug to put it right"

- On schizophrenia: 'imbalances of certain chemicals in the brain are thought to lead to the symptoms of the illness. Medicine plays a *key role* in balancing these chemicals' Pfizer, 2006

- "People with depression may have an imbalance of the brain's neurotransmitters" Eli Lilly, 2003

- "Paxil CR helps balance your brain's chemistry" PaxilCR.com, 2009

Disease centred model	Drug centred model
Drugs correct an abnormal brain state	Drugs create an abnormal brain state
Therapeutic effects derived from action of drugs on the presumed disease process	Therapeutic effects are a consequence of being in an altered, drug-induced state.
Drugs as medical treatments	Drugs as psychoactive substances
Paradigm: insulin for diabetes Also aspirin and paracetamol	Paradigm: alcohol for social anxiety

Psychoactive drugs

- Produce altered *mental* and *physical* states
- Tolerance and withdrawal effects
- "spell binding" (Breggin, 2007)

Jean Delay and Pierre Deniker: a special sort of sedative

Mirra-Calm...

Melleril the tranquilliser pure and simple

in acute schizophrenia

Melleril

strikes promptly at the target symptoms: disorders of thought, affect, behaviour and perception

there is no anti-psychotic more effective than Melleril
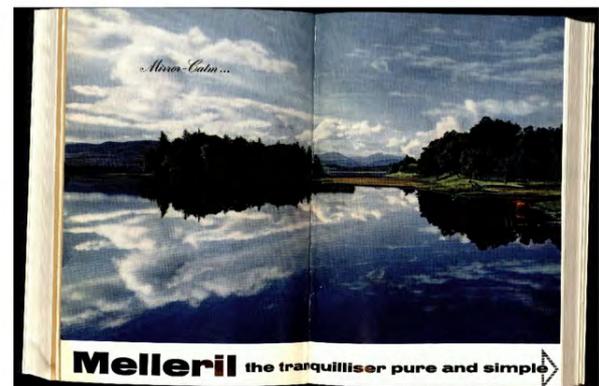
Changes in Therapeutic Concepts

Pre 1950s:

- Sedatives

- Stimulants

Post 1950s:
- Antipsychotics
- Antidepressants
- Anxiolytics
- Mood stabilisers
- Hypnotics

Evidence for disease-centred model of drug action

- Placebo controlled trials do not demonstrate disease-centred effects

But disease-centred model might be supported if:
- We knew the disease mechanism
- Impact of psychoactive effects can be discounted
- 'Specific' drugs were consistently better than non specific ones

Using drugs in a drug-centred manner

Need to know full range of:
- Mental effects
- Physical effects
- Short-term effects
- Long-term effects
- Withdrawal effects
and
- Are the effects a drug produces useful in an individuals particular situation?
- Do they out-weigh the adverse effects?
- Are there alternatives?

The drug-centred model- how do psychiatric drugs 'work'?

- Interaction of psychoactive effects and symptoms

- Placebo and 'amplified placebo' effects

Antipsychotic drug-induced effects

- Healthy volunteer and animal studies show reduced:

Movement, attention, reaction times, co-ordination, intellectual abilities, memory exploratory behaviour, initiative and motivation

Plus emotional flattening or indifference and sedation

'Experimental neurological syndromes and the new drug therapies in psychiatry'

Pierre Deniker, *Comprehensive Psychiatry*, volume 1, 1960.

'patients simply lose interest in their delusions'

Pierre Deniker
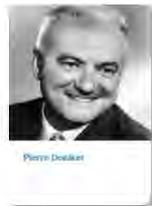
Drug-induced effects of 'antipsychotics'

Comments from 'askapatient.com'

- *Mental and physical stagnance*

- *Emotionally empty, dead inside*

- *A weird spacey empty feeling*

From askapatient.com

- "Although I felt very well, I felt as if I had absolutely nothing to talk about. I kept wondering about whatever [it] was that had been so interesting during most of my life that I had suddenly lost... But I was very much in contact with reality and for that I was thankful" (haloperidol)

Changes in dimensions of psychosis after antipsychotic treatment
Mizrahi et al, 2006

Dimension of psychotic experience	Reduction in dimension after 6 weeks of antipsychotic treatment
Behavioural impact	64%
Cognitive preoccupation	51%
Emotional involvement	56%
Conviction	25%
External perspective	0

A drug centred approach to treatment of psychosis and schizophrenia

- Effects of antipsychotics may be useful to suppress acute symptoms

- But some people recover without the use of these drugs

- Other drugs may be useful and safer (benzodiazepines; ? opiates)

- Long-term treatment has a poor evidence base and adverse effects may outweigh possible advantages for some, maybe for many
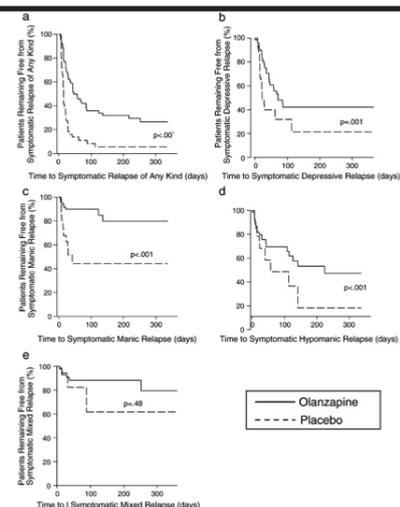
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Slide 1

Wunderink et al, 2013
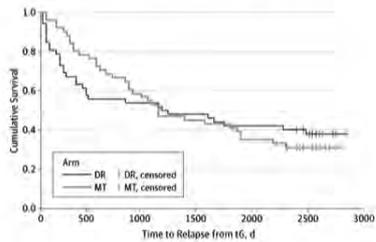
Slide 2

Table 2. Recovery, Symptomatic Remission, and Functional Remission After 7 Years of Follow-up

| | No. (%) | | |
Characteristic	DR (n = 52)	MT (n = 51)	Total Sample (n = 103)
Recovery	21 (40.4)	9 (17.6)	30 (29.1)
Remission			
Symptomatic	36 (69.2)	34 (66.7)	70 (68.0)
Functional	24 (46.2)	10 (19.6)	34 (33.0)

Abbreviations: DR, dose reduction/discontinuation; MT, maintenance treatment

Figure Legend:
Recovery. Symptomatic Remission, and Functional Remission After 7 Years of Follow-up

Slide 3

Adverse effects- antipsychotics

- Tardive dyskinesia
- Brain shrinkage
- Tardive dementia, psychosis?
- Cognitive decline?
- Metabolic disturbance
- Cardio-toxicity
- ?death
- Sexual impairment
- dysphoria

Slide 4

Pychoactive effects of SSRIs and venlafaxine (Efexor): (Goldsmith & Moncrieff, 2011)

- "listlessness and lethargy"
- "sleepy all the time"
- "difficulty focusing"
- "fogginess"
- "total loss of libido"
- "inability to care about anything"
- "general numbness/mental blankness"

- "Increased anxiety.., borderline panic, mild insomnia"
- "mood swings"
- "irritability"
- "sometimes suicidal"

Slide 5

Adverse effects of antidepressants

- Sexual impairment in humans is common (?60%). Includes erectile dysfunction, genital anaesthesia, ejaculatory anhedonia and loss of libido

- **Can persist after discontinuation** (Bolton et al, 2006; Kaufmann, 2008; Farnsworth & Dinsmore, 2009; Csoka et al, 2008).

- Withdrawal effects: sometimes severe and prolonged – years (Fava et al, 1997)

- Psychological effects: psychological dependence may increase risk of recurrence or of non-remission

Slide 6

(How) Do psychiatric drugs work?

- There is something wrong with your brain, this drug will help put it right

- Life is difficult- this drug will numb the problem (make it more manageable)

Slide 7

Stelazine advertisement, 1965

Reproduced with kind permission of GlaxoSmithKline

the first consideration in treating the violently agitated and hostile schizophrenic is to calm, restore insight, and establish rapport

STELAZINE

Slide 8

Real change

- The idea that mental health problems are 'diseases, just like any other' doesn't work

- Drugs can be useful in some situations but:
They do not work by targeting underlying diseases
They have many worrying adverse effects, especially with long-term use

- Compulsory medication should be regarded as a method of control, not a treatment, with proper legal controls and scrutiny

- We need alternatives

The Myth of the Chemical Cure
A Critique of Psychiatric Drug Treatment
Joanna Moncrieff

A STRAIGHT TALKING INTRODUCTION TO PSYCHIATRIC DRUGS
JOANNA MONCRIEFF
STRAIGHT TALKING INTRODUCTIONS TO MENTAL HEALTH PROBLEMS
edited by Richard Bentall and Pete Sanders

Joanna Moncrieff
THE BITTEREST PILLS
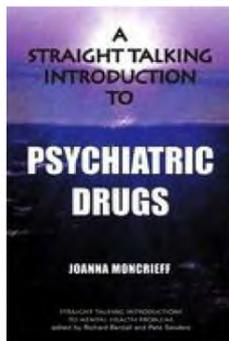
Rachel Waddingham

"The Human Rights Act: What does it mean for us?"

The Human Rights Act
- What does it mean for us?

Rachel Waddingham, Hearing Voices Network
www.hearing-voices.org

Human Rights in Law

HUMAN RIGHTS ARE NOT OPTIONAL

- The UK signed the European Convention on Human Rights in 1951.

- Since then, it is breaking international law if it does not respect the rights within this.

- The UK Human Rights Act (2000) was intended to bring these rights into UK law by placing a duty on public authorities to protect human rights.

Who is responsible?

- Public authorities include:
  - All central and local government agencies
  - The NHS
  - Social Services
  - Any person or agency who's 'functions are of a public nature' (which includes companies and charities when they are carrying out a 'public' function ... e.g. a private hospital hospital that is detaining someone under the Mental Health Act)
- If your human rights are infringed, you have the right to bring a case against the public authority concerned in the UK court system.
- If you are unhappy with the outcome, you have the right to take it to the European Court of Human Rights.
- This applies to anyone within the UK, irrespective of nationality

ECHR Articles

- 2: Right to life
- 3: Prohibition of torture
- 4: Prohibition of slavery and forced labour
- 5: Right to liberty and security
- 6: Right to a fair trial
- 7: No punishment without law
- 8: Right to respect for private and family life
- 9: Freedom of thought, conscience and religion
- 10: Freedom of expression
- 11: Freedom of assembly and association
- 12: Right to marry
- 13: Right to an effective remedy
- 14: Prohibition of discrimination

But ... violations are commonplace in 'mental health', for example ...

- Compulsory admission (article 5 ....)
- Beliefs regarded as 'delusions' that lead to compulsary admission and/or treatment (article 9, 5 & 3)
- Behaviour regarded as 'symptomatic of illness' (article 10)
- Effects of psychiatric drugs (article 3 & potentially 2)
- Community Treatment Orders (most of them!)

How can this happen?

- All Human Rights legislation comes with caveats where many rights can be limited or restricted in certain circumstances.
- These rights are seen as 'limited' or 'qualified' rights.
- If restrictions are deemed 'medically necessary' and are protected by 'proper proceedures' they are seen as OK by these conventions / acts.

What are the exceptions ...

- **Right to life** – intentionality, necessary force
- **Right to liberty** – 'the lawful detention of persons of unsound mind'
- Right to **respect for private and family life, freedom of expression, freedom of assembly and association** – 'in accordance with the law and necessary
  - in the interests of public **safety**
  - for the protection of **health** and **morals**
  - For the **protection** of the rights and freedoms of others

The fundamental issue

- The medicalisation of emotional distress and 'mental health issues' is problematic.
- Someone with a dx mental health problem can be viewed as being 'not of sound mind'
- This allows society to restrict human rights in our 'best interests'.

Society's changing role

- When someone is seen as 'OK', the onus is on society to include and support people's active participation

Society's changing role

- During a crisis, when the person is seen as 'acutely unwell', society's role shifts to one of protection

Notable by their absence

- Whilst it's easy to concentrate on obvious and explicit HR violations in services, its hard to get HR campaigners involved in the more common ones.
- As long as human distress is seen as an illness, it will be hard to address some of these fundamental violations.
- We need to change this.

Lets find a way forward

Molly Carroll

"Man's Handmade Scalpels"

Man's Handmade Scalpels

Molly Carroll

- 3 instruments used to oppress & traumatise across different fields of experience
- A space to reflect on, and share tools of resistance
- Some more ideas of tools of resistance from me
- Questions

1. Removal of Agency & Self Determination

"We are going to help you." May I ask just why I need this help

2. Disbelief, Denial & removing things from their context

"He was certainly not a Soham man"

3. Blaming the victim

And if a man should rape a child
It's not because his spirit's wild
Our system gives the prize to all
Who trample on the weak and small
When fathers rape, they surely know
Their kids have nowhere else to go
Try to forget, don't ask us to
Forgive them -- they know what they do (CHORUS)

When exploitation is the norm
Rape is found in many forms
Lower wages, meaner tasks
Poorer schooling, second class
We serve our own, and, like the men
We serve employers -- it follows then
That bodies raped is nothing new
But just a servant's final due

We've raised our voices in the past
And this time will not be the last
Our bodies' gift is ours to give
Not payment for the right to live
Since we've outgrown the status quo
We claim the right to answer "No!"
If without consent he stake a claim
Call it rape, for rape's the name

Reclaim the Night, Peggy Seeger

How do you resist?

What else…

- Reframing experience: language, 'deconstructing psychopathology' (Georgaca), providing spaces for people to define their own experience

- An intersectional movement & self-critique

- Audre Lorde: "What woman here is so enamoured of her own oppression, her own oppressed status,that she cannot see her heel print upon another woman's face?.....What woman's terms of oppression have become precious and necessary as a ticket into the fold of the righteous, away from the cold winds of self-scrutiny."

- Self- Care
- Audre Lorde: "Caring for myself is not self-indulgence. It is self preservation, and that is an act of political warfare."

- "the power of touching and meeting another woman's difference"

Dave Harper

"Campaigning for change: Ideas from the work of Gene Sharp"

Campaigning for change: Ideas from the work of Gene Sharp

Dave Harper

Are things getting better?

- Better:
  - more optimism (recovery approach)
  - peer support
  - more talking therapies
  - more focus on supporting people into work
  - End of Victorian asylums

- **No change or worsening:**
  - Over-emphasis on risk
  - increasing medicalisation (society, settings)
  - few survivor-run crisis houses
  - Soteria model not taken up
  - psychiatric diagnosis (eg DSM)
  - over-emphasis on medication
  - No real choice of treatment/therapy
  - sectioning (twice the level of 1980s)
  - discrimination (eg employment)
  - Social inequality increasing
  - NHS is reactive and little focus on prevention
  - Little research money goes to social projects compared with biomedical projects

Source: Department of Health Prescription Cost Analysis System.
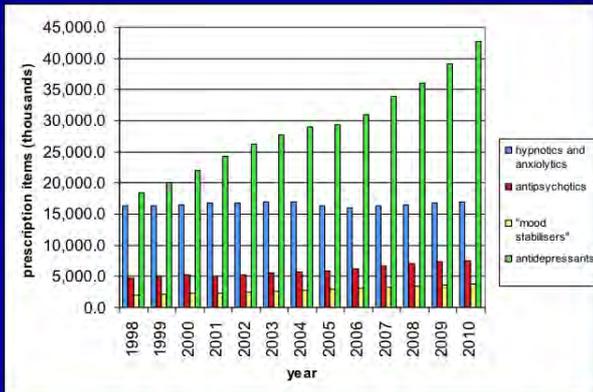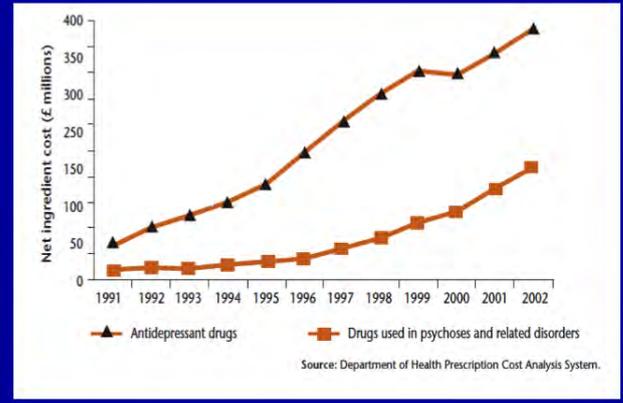
What is our model of change?

- More understanding leads to change which leads to policy and legal change
  - Or?
- Oppressed groups campaign for changes in policy and law, which leads to broader social change

What can we learn from campaigners?

- Gene Sharp -- Political theorist of non-violent resistance to totalitarian dictatorships

- Possible to adapt for other contexts

- Common problem for resistance movements is dependence on one or two campaigning methods
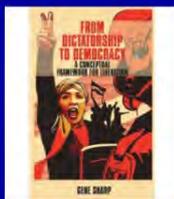
- A key issue is to '*identify the dictatorship's pillars of support and develop a strategy for undermining each*' (Arrow, 2011)

- Need for different tactics with each 'pillar':
  - Professional disciplines
  - Other institutions (including the academy, funding bodies and journals)
  - The pharmaceutical industry
  - Some of those in distress and their relatives
  - The public
  - The media
  - Policymakers
  - Public and commercial health bureaucracies

- Important to remember that these sources of support are not monolithic

- Within each 'pillar' there is some resistance

  - there is debate within the academy and amongst practitioners
  - many of those in distress find diagnoses unhelpful
  - there are also policymakers and journalists who are critical of diagnosis

- An important issue is how these critics may be supported and linked together

- Moreover, important to learn from successful campaigns in the past

- Sharp (2012) suggests that it is important for campaigners to focus on issues which are '*widely recognized and thus hard to neglect*' (p.92)

  - E.g. Campaign against pathologisation of homosexuality broadly successful (followed demonstrations by gay and lesbian activists in early 1970s)

  - E.g. in 1980s, *That's Life*, the light-hearted BBC consumer rights programme and charity Mind, began a large-scale public campaign against the over-prescription of minor tranquillisers, which led to major policy changes (Lacey & Woodward, 1985).

- Important to gain traction with the public through the media

- Example of debates about the DSM:

  – Connect criticism of diagnosis with common media topics with 'news value' (e.g. investigatory stories, human interest stories etc)
  – For example, change in diagnostic criteria has led to iatrogenic 'epidemics'
  – This has led to increased demand on health services
  – Increased public expenditure on medication
  – Increased pharmaceutical company profits


- Danger of being reactive, constantly responding to the actions of the other.
- Danger of naively thinking that simply by stating one's goal or living according to their ideals that change will come.

- Start with low risk methods, focusing on issues which are widely recognized and thus hard to neglect:
  – Employment discrimination
  – megadosing (36% prescribed over BNF limits; 43% on more than one antipsychotic)
  – lack of choice and full information about side effects
  – lack of access to talking treatments (10% with diagnosis of schizophrenia)
  – unethical behavior by drug companies

- Always think of the next steps – requires strategic analysis not simply tactical process.

- Not every action needs total support. Can have a number of 'selective resistance' campaigns, possibly overlapping

- Important to have small victories – maintains morale but also leads to momentum. Should aim at one or more weakness

- Have campaigns taken on by different groups on issues of concern to them (eg journalists, religious leaders etc).

- Allow time for breaks and a rest to avoid burnout!

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198 Methods of Nonviolent Action

- **Formal Statements**
  1. Public Speeches
  2. Letters of opposition or support
  3. Declarations by organizations and institutions
  4. Signed public statements
  5. Declarations of indictment and intention
  6. Group or mass petitions

- **Communications with a Wider Audience**
  7. Slogans, caricatures, and symbols
  8. Banners, posters, and displayed communications
  9. Leaflets, pamphlets, and books
  10. Newspapers and journals
  11. Records, radio, and television
  12. Skywriting and earthwriting

- **Group Representations**
  13. Deputations
  14. Mock awards
  15. Group lobbying
  16. Picketing
  17. Mock elections

- **Symbolic Public Acts**
  18. Displays of flags and symbolic colours
  19. Wearing of symbols
  20. Prayer and worship
  21. Delivering symbolic objects
  22. Protest disrobings
  23. Destruction of own property
  24. Symbolic lights
  25. Displays of portraits
  26. Paint as protest
  27. New signs and names
  28. Symbolic sounds
  29. Symbolic reclamations
  30. Rude gestures

- **Pressures on Individuals**
  31. "Haunting" officials
  32. Taunting officials
  33. Fraternization
  34. Vigils

- **Drama and Music**
  35. Humorous skits and pranks
  36. Performances of plays and music
  37. Singing

- Albert Einstein Institution:http://www.aeinstein.org/

- Free online copy of *From Dictatorship to Democracy*:
  http://www.aeinstein.org/wp-content/uploads/2013/09/FDTD.pdf

- How to Start a Revolution film:
  http://howtostartarevolutionfilm.com

Dictators are never as strong as they tell you they are.
People are never as weak as they think they are

Gene Sharp

Changing The World: What can we learn from effective Human Rights Campaigns?

Together We Can Change The World
What can we learn from Human Rights activism & campaigns

What is an effective campaign? Is it ..

↗ How slick, glossy or well constructed our campaign materials are?

↗ The catchiness of our key message?

↗ How many 'likes' we get on Facebook?

↗ How many people take part in the protest?

↗ **No**. If we want to change a real change, we can only only judge the effectiveness of our campaign by how close it brings us to our goal.

↗ **Actions speak louder than words**
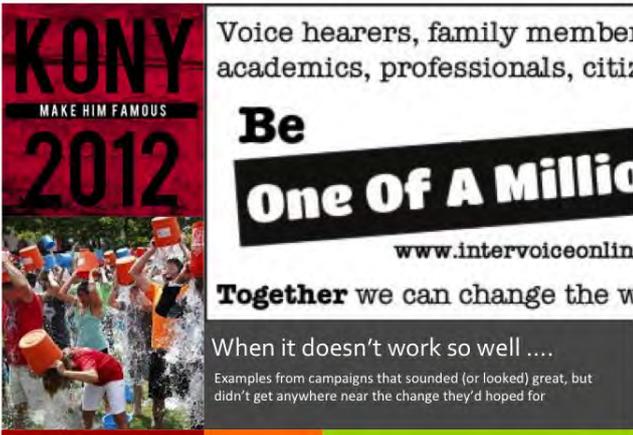
KONY
MAKE HIM FAMOUS
2012

Voice hearers, family member
academics, professionals, citiz

Be
One Of A Milli

www.intervoiceonlin

Together we can change the w

When it doesn't work so well ....
Examples from campaigns that sounded (or looked) great, but didn't get anywhere near the change they'd hoped for

Ineffective Campaigns Might ...

↗ Favour style over substance

↗ Have a confused, or confusing, message.

↗ Sound great, but leave the public unsure about what they need to do about it.

↗ Exclude the public (e.g. feel like 'niche' issues that people don't relate to, or attached to a particular political or religious group)

↗ Leave the public feeling guilty or bad, with no way to alleviate these feelings through positive action.

↗ Be a 'flash in the pan' – real change takes time.

↗ Be badly organised or implemented

Learning From What Worked
The fight against 'Don't Ask, Don't Tell' in the US

A Bit of Background

↗ 'Don't Ask, Don't Tell, Don't Pursue', introduced in 1994, in the context of Clinton's promise to allow all citizens to serve in the military regardless of their sexual orientation.

↗ BUT, in light of the accepted high level of homophobia and prejudice, a compromise was reached:

   ↗ Don't Ask (about someone's sexual orientation)

   ↗ Don't Tell (otherwise you'll be discharged)

   ↗ Don't Pursue (or investigate without 'credible information'

↗ The rationale for this was that the presence of openly gay people 'would create an unacceptable risk to the high standards of morale, good order and discipline, and unit cohesion that are the essence of military capability'.

Don't Persue ... Unless ...
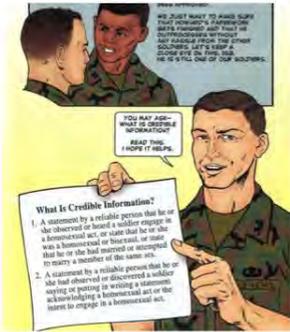
- This excerpt from a training manual explains the army's understanding of 'credible' information under 'Don't Ask, Don't Tell'
- It amounts to a 'reliable' person making an official statement that they heard or saw someone speaking about, writing about their intention to 'engage in a homosexual act'

Legal Challenges

- Successful legal challenges initially challenged process and procedures of individual dismissals, not the law itself:
  - McVeigh successfully challenged a 'search and destroy' mission where the US Navy illegally violated his personal AOL email account as part of their investigation
  - Others focused on challenging whether the legal conditions that must be met to intrude upon people's private lives have been met.
- This laid the groundwork the Log Cabin Republicans to file a lawsuit that showed DADT to be unconstitutional – violating rights to free speech, due process and open association.

Challenging the evidence driving DADT

American Psychological Assocaition (2004)

- Issued a statement that DADT 'discriminates on the basis of sexual orientation' and says that there is no evidence that having openly gay, lesbian or bisexual people in the military will adversely affect morale or safety.

Zogby International Poll (2007)

- This poll showed that only 37% of military personnel opposed openly gay people serving in the forces, and only 27% felt it would have a negative impact on morale.
- These findings led a key respected military figure (former Chairman of Join Chiefs of Staff) to publicly oppose the DADT policy.

Eye-catching imagery
Using powerful images that evoke emotion and are linked to american ideals or sense of pride

Only 5 people? Make one amazing image...

Direct action on camera ... handcuffed

Scathing social commentary

Testimonies: Voices of Honor Tour
Gay and Straight people standing side by side, sharing stories in the media & in public talks – winning hearts

Stimulate Social Action
Asking the general public to organise house meetings, public talks, rallies and screenings of the 'Ask Not' film.

Soulforce: Right To Serve

↗ In 2006 Soulforce, a national LGBT rights organisation, organised a 'Right To Serve' campaign where openly gay people attempted to enlist.

Outside a recruitment centre

We're Stronger Together

↗ As efforts gained momentum, organisations and campaigns began to collaborate for change.

  ↗ Voices of Honor – Human Rights Campaign & Servicemembers United.

  ↗ Voices of Honor tour used testimonies and the Right To Service film 'Ask Not' as a focus for grassroots activism (house meetings & film screenings).

  ↗ Don't Ask Don't Tell Flash Protest at the Whitehouse – No H8 Campaign, Students for the National Equality March & Service Members Legal Defense Network.

A partner – No H8

↗ Originally No H8 was a silent photographic protest created by celebrity photographer Adam Bouska.

↗ 5 years later it now has almost 33,000 faces and has grown to symbolise standing against discrimination and bullying in all forms.

You Tube can be a friend
No H8 release a range of video shorts to engage people

No H8, National Equality March & co at The Don't Ask Don't Tell Flash Protest

↗ A flash protest that used a text service and social media to gather 1,200 people outside the Whitehouse

↗ Many were students in Washington for the National Equality March

Desperation = pushing back

- As the campaigns gathered momentum, they also gathered strong and vicious opposition.
- Counter arguments centred on
  - Homosexuality as immoral
  - If it aint broke, don't fix it
  - Fear mongering, linking the DADT movement with prominent controversies around 'restroom arrests'
- An illegitimate 1000 strong letter supporting DADT was published.


An example of fear mongering ..

- "the liberalisation of DADT would compromise restroom integrity and security … the national shudder and discomfort and queasiness associated with any introduction of homosexual eroticism into the public men's rooms should make us more determined than ever to resist the injection of those lurid attitudes to even more explosive situation of the U.S.military"

A political NOT a military issue

- Whilst initially most politicians were silent, deferring to the military expertise, public pressure helped to place this back in the hands of the politicians and, therefore, the people.
- Obama set a timetable to repeal the law, but campaigning organisations pushed politicians to move it forward. Progress was painfully slow.

17 years and multiple angles ..

Legal Challenges	Media Savvy	Public Engagement	Collaboration	Politics
Focus on procedural issues	Use of media friendly images, slogans, issues, protests	Widen relevance	Different campaigns join forces	Using social pressure to demand change
'Expert' bodies critique the law		Stimulate debate	Finding a strong allied context	Making it a political issue
		Win hearts		
		Grassroots Activism		

But finally - success

"You're the reason… why selfless soldiers won't be **kicked out** of the military because of **who they are** or **who they love…** **You did that.**"

BARACK OBAMA
PRESIDENT OF THE UNITED STATES
2012 DEMOCRATIC NATIONAL CONVENTION

In groups, choose an aim to work with

- Change the way the public view people who hear voices - hearing voices is a common human experience
- Stop forced medication
- Stop Community Treatment Orders
- Embed **true** informed choice in mental health support
- Recognition that mental health is a social issue not a medical one
- Show that the 'chemical imbalance' theory is a fallacy
- Get a public health approach to violence & abuse
- Acknowledge psychosis as a sane reaction to insane circumstances
- Show that fighting for the rights of those deemed mentally ill is the last great civil rights movement

A) Find a clear key message

- In groups, come up with a list of some potential key messages, phrase or slogan that you think could clearly communicate with the general public to achieve your aim.
- **As a group – choose one that you would like to work with for the rest of the exercise**

B) Methods

- In the campaign against 'Don't Ask Don't Tell' people used a range of methods to convey their message.
- Without censoring yourselves, try and get a list of as many different methods that you could use to communicate your message.
- **As a group – choose one that you would like to work with for the rest of the exercise. This might be something you haven't done before … something that you'd like to think more about.**

C) Your campaign ...

↗ In groups, explore one of your methods in more detail.

↗ You might want to think about:

　↗ How might it work?

　↗ What would you need to do?

　↗ Who would you need to involve?

　↗ What resources might you need?

　↗ How would you get the word out?

　↗ How would you know It was successful?

↗ We'll keep a record of everyone's ideas for the event report

Thank you!

↗ These are just a few ideas. Let's keep working together to help create real change.

↗ Remember to sign up to our Time for (real) change discussion list.

↗ No single person or organisation can change the world, after all.

Campaign issues suggested during 'Changing The World' workshops

💧 Change the way the public view people who hear voices - hearing voices is a common human experience

💧 Stop forced medication

💧 Stop Community Treatment Orders

💧 Embed true informed choice in mental health support

💧 Recognition that mental health is a social issue not a medical one

💧 Bad things happen to people which drive them crazy

💧 The 'chemical imbalance' theory is a fallacy

💧 Public health approach to violence & abuse

💧 We are all in this together - mental health and safer communities

💧 Psychosis is a sane reaction to insane circumstances

💧 Fighting for the rights of those deemed mentally ill is the last great civil rights movement

Some methods suggested by participants on the issue of forced meds

💧 Theatrical demonstrations, including 'shock performance' of forced medication (maybe with a celebrity) with good media follow up

💧 Work out the number of pills given by force. Find this amount of sugar pills and dump in front of the DoH.

💧 Use shocking truths in social media, mainstream media and petitions (e.g. change.org & avaaz)

💧 Fight with facts. Community Treatment Orders (CTOs) are not effective and there is no evidence providing their efficacy. Chemical imbalance theory = not true. Drugs alter brain states. Get the message out in different ways to different people.

💧 Collaboration with human rights agencies (e.g. WHO Millenium Goals, Amnesty Int)

💧 Ye olde imagery which shows outdated practices in use today

💧 Visual campaigns: Before meds (using a physically healthy image) vs After meds (using a physically unhealthy image). Or perhaps showing a visual representation of someone being forced to take medication

💧 A prisoner of conscience - a figure to speak out for the cause

💧 Pick a case story

Double Agents: Creating change from inside the system.

Double Agents Workshop:

How to bring about change from within
the system

Steven Coles

Clinical Psychologist

London, 20th April 2015

What is a double agent? My thoughts

- Part of, and makes living from, the dominant psychiatric system
- Disagrees with (many or all) of the dominant values, how distress is thought about and how things are done in services
- Whilst part of the system – tries to alter the system – such as current ways of thinking, values and practices
- Often critically minded staff

Double agents and their advisors (handlers)

- In the workshop there will be questions for:
  - Double agents
  - Advisors / Handlers: People who aren't double agents, but who can advise the agent
- Top secret and sensitive information
  - Only share information you are comfortable with
  - Being respectful of the information that is shared with you

Your mission…

Discuss in groups of 2 – 4 people (try to mix double agents and advisors)

Questions for Double agents and Handlers:

- what do you think needs to change about the psychiatric system? What should the focus of a double agent be? What is their mission?

Tactics, Strategies…

Discuss in 2-4 people:

- If you are a double agent – how do you try to bring about change? What power and / or influence do you have? What strategies do you use?
- Advisor to double agent – what is your advice to the double agent to try to bring about change? What strategies could they use?

Secure doors…and dilemmas

- In 2 - 4 people:
- Double agents:
  - what are the barriers to change? How do you try to overcome them?
  - What are the dilemmas that you face?
- Advisors to double agents
  - What is your advice to the double agent about overcoming barriers? How can they address the dilemmas they face?

Flipchart Notes

- "Psychosis can be a sane reaction to insane conditions"

- We need videos, tweets and films to spread the message.

- We need to find a way to make complex ideas accessible

- Therapy has to be more than just tablets!!

- Is there an extent to which psychiatrists are suffering from delusions in their adherence to a medical model that cannot be evidenced? How could psychiatrists be helped to share the experiences of their service users?

- How can we gain access to all research – especially negative and critical versions?

- Can we change the treatment of people in inpatient settings – to share lived experience and normalise it? Some members discussed examples of good person centred care around the country – how can these be shared and spread?

- How do we challenge the basic assumptions that equate medical knowledge with expertise around how to live? What is it about the scientific method that establishes claims to knowledge and expertise in areas where science has so little certainty to offer?

- How do experts by experience position themselves, how can one be trusted and respected by partners, but also challenging? About building relationships.

- Influence ideas as a practise educator – lead by example – allow people to work through their judgements to get to a more compassionate place.

- What can be done to give service users power in their own services – the group all have experiences of where service users have been involved in this work have become benign – there is something about needing a tremendous confidence to challenge rooms full of professionals when they have power over your life.

- How could we have user groups where psychologists and psychiatrists only take notes and users facilitate with the function as; share knowledge, implement change, critical questioning?

- Establish a framework for people to re-establish their agency – diagnosis removes agency. Double agents as rescuers.

Workshops: Errr … But Flipchart Notes

- We recognise within the group a breadth of explanations for voice hearing.

- We discussed the process that had led to the development of psychiatry in its current form and acknowledged that most psychiatrists have entered the profession with good motives. What kind of conversation with psychiatry can be fruitful?

- Discussion of the impact of austerity on services – is there evidence that cut-backs are making services more risk averse, or that more person centred approaches are more vulnerable to cuts?

- How to educate people about side effects / information before seeing a doctor.

- What would happen if there was a private prosecution of corporate manslaughter against psychiatry for shortening lives with toxic medications?

- How do we publicise this fallacy about a 'chemical imbalance in the brain' and prepare patients on how to tackle this when they are at their most vulnerable.

- How do we get these insights out into the mainstream?

- Could organisations be asked to sign a pledge with a shared slogan? How would we come up with the core message and identify the common ground?

- Make sure that personality disorders are not ignored – the group agree that personality disorder is a deeply stigmatising diagnosis that is as problematic as psychosis.

Workshops: How Can We Work Together? Flipchart Notes

- How might we attempt to use the legal system, both national and international, to challenge the human rights implications of current mental health interventions?

- Assimilation of people with lived experience and peer experts into the mainstream – we discuss what it is about inclusion in services that sometimes leads to user involvement initiatives being less challenging than we would expect?

- How would one rebuild the mental health system using lived experience as the building blocks? How different would this look – how much more humane and recovery focused would services be? Do the nature of services (enforced medication, ECT, locked wards) actually increase stigma by sponsoring tabloid notions of fear and difference?

- Sectioning: what does it mean to be a legitimate risk to oneself or others and what would a humane and balanced approach to this be? Members of the group discussed various interventions that they were aware of.

- How do we start the dialogue with the wider community?

- How do we work together when we have a broad area of shared interest, but also our own specific areas of focus that form the basis of our organisational aims?

- How do we embed 'informed choice' in the existing system, or is the current psychiatric paradigm necessarily in opposition to the empowerment of individuals and choice?

- How does a campaign appeal to those without direct experience of the system?

- Write letters to elected members on mental health issues.

- What are the barriers to seeking the right kind of help? Access to information about where services can be found, particularly which mental health Trusts provide what? Families being stigmatised is an issue, financial consideration hold people back from asking for help, GP lack of knowledge and fear, lack of interpreters, fear of services.

- Challenge of maintaining allegiance to one's own belief systems under pressure.

- Loss of belief in the ability or desire of professionals to want to help
- How do we link up nationally when there is no infrastructure to do this – we need a "Royal College of Alternative Approaches".
- How do we move from a Time to Change mentality that very consciously equates mental illness with physical illness, and a more challenging 'real' change of looking to question the medical model.
- The over prescription of drugs, the growing use of drugs with children, the belief that drugs have a helpful and scientifically validated impact on brain chemistry; what do we do about that when the medication narrative is so mainstream and accepted.
- Over pathologising of experience – how do we move from "what is wrong with you" to "what has happened to you".
- How do we combat a 'diagnosis' culture?
- The group agree that this is a really fantastic start to an embryonic process – how do we maintain this?

Feedback From Participants

After the event we invited participants to share any feedback of thoughts they had after the event. The HVN trustees would like to thank everyone who took part, and especially those who took the time to share their feedback with us.

Ruth Forrest: Personal reflection on the day:

I always find these days challenging as it makes me think about my experiences of using & working in mental health services over the years. I love having the space to talk & think & share ideas about this, and try to take positives from the often sad stories that are shared, along with my own memories.

I want people who experience emotional distress to have their voices heard in future & not to be telling the same sad stories we often hear about mental health treatment today.

On today, I feel that compared to some similar events I have been to I the past, there is more positive energy & less helpless anger & despair. Thank-you for helping us to direct our understandable anger & energy towards positive change, for anger is a positive emotion & we need to share it and use it to make a positive difference :-)

A thought: how do we get people who haven't ever had contact with mental services to care about (or even believe) the things that are happening in the system?

Rachel Freeth: A letter

Dear Trustees,

As a psychiatrist attending this event my impression was that I was in a very small minority, which was an interesting and also at times uncomfortable experience. Nevertheless, I am very glad to have attended and would like to thank you for organising this very important opportunity to share a vision for change. It is a pity that there weren't more psychiatrists attending to hear the depth of yearning for a different way of thinking and helping people with distressing mental experiences – things we are not necessarily going to all that often hear from service users in our clinical environments.

As a Critical Psychiatrist with broadly humanistic values, I am in the position of feeling profoundly

dislocated having to work within a culture and system that is often oppressive and lacking in sensitivity and thoughtful responses that respond to people as individuals with unique experiences. Your event enabled me to sit with my discomfort in a way that was helpful. I think it is important that service users and mental health professionals do have a space to articulate their at times hostile feelings towards the psychiatric profession (feelings which are often entirely understandable). Whilst there was a little hostility expressed on the day, I did appreciate the attitudes and general 'way of being' of Jacqui and Rae that helped me to feel broadly welcomed. That said, I did notice a little reticence in myself to stick my hand up and make myself more known. But I think that is my problem!

So finally, many thanks again. Be assured that I will continue to do what I can to work towards more humane and holistic approaches (although I think I do more of this from the outside than the inside).

With best wishes,

Rachel

Dr Rachel Freeth, Specialty Doctor in Mental Health

Nicky Forsythe: Thoughts after Time for Real Change event

Here are my thoughts on the event, speaking from many angles: as member of a family of Psychiatry survivors, Psychotherapist, mental health researcher, founder of a mental health social enterprise that provides to the NHS, and former member of the Time to Change advisory board (yes, in my opinion it didn't do the right things in the right way).

To me, the event demonstrated the commitment and passion of a broad range of people to come together and act for proper change.

I hope HVN continues to take a key role in hearing and co-ordinating this range of people both from outside the status quo and within it.

Having been through the TTC experience, I do not think a movement for change can be led by professionals or people with a vested interest in the current status quo.   Unfortunately they/we are too influenced, evenat an unconscious level, by their/our position, context, training and current mainstream beliefs.

On the other hand, HVN has a great track record of hearing and embracing conflicting voices both inside and between people, and leading change. You also have a track record of dealing with wide range of stakeholders, over vast reach, in a very effective way and on a low budget.

I see that a 'Time for (real) change' campaign co-ordinated by HVN should have two arms

- a civil rights arm - service user led – members of public to be galvanised. We would need to find a cause that has the potential to inspire all – to focus on no more abuse of human rights through use of coercive, ineffective and harmful treatments.

- a professional arm – bringing together critical professionals to sign up to a simple behavioural charter for non-abusive treatment. E.g:

  - We will never be complicit in coercion and abuse of human rights (this would need to be clearly defined)

  - We will always give full information about meds and treatments (including e.g. information that questions the effectiveness, and explains the downsides, of medications)

  - We will be informed about, and inform service users about, effective alternatives for help beyond the bio-medical paradigm

- Where these are not available in-borough we will point to ways of campaigning for them (e.g. Soteria, Open Dialogue, HVN, SCN).

Professionals should have a way they can display to each other and to service users the fact that they are signed up to this charter.

Nicky Forsythe

Janice

This event really challenged my own belief system and brought me away from my fixed ideas about the Mental Health system, which I have become embroiled in as a patient. I am currently working my way out of it and this event has helped me deal with my anger and fury about the way the system has 'treated' me. Gaining perspectives from an array of organisations and individuals really helps to get a different perspective on the difficulties of supporting people in mental distress within the current MH system. It helped me see we are all in this together and we all want improvement. It seems the recognition of the current limitations is the starting point for bringing about change through forming a body of people to work towards finding the best ways to implement change. Count me in to the discussions and planning please.

Thanks, Janice

Ruth Forrest: Some 'garbled unedited notes from the day!'

Notes from Double Agents workshop... Steven Coles

- How to make change from within - is it possible? What are the barriers?

- What is a Double Agent? Working for a dominant profession or organisation but have a conflict with the status quo - trying to alter a system you are a part of - critically minded

- "Questioning Professional"

- Mental health & distress is about what has happened to someone, whereas the system sees it as a problem within the person to be pathologised & medicated

- Layard & Clark (IAPT) minimise impact of social inequality & social factors in emotional distress - access for BME men hasn't improved, and other marginalised groups

- How do you manage the power imbalance? Our livelihood depends on the existence of the psychiatric system, but we're conflicted about how the system treats people

- (Personal note: I often feel good about my job & the work that I do, then I come to events like this & feel as if my job is pure evil !!!)

- Suggestion from the back row - some people pretend to be double agents but they are co-opters in disguise (triple agents ??!!) - giving lip service to alternative models of mental health whilst really holding onto the medical model (doing this unconsciously or manipulatively..?)

- Discussion about co-option... Before you used to campaign against something (psychiatry, CTOs, forced medication, seclusion, ECT etc) then enter the system with plan to change it from the inside but realise in the end that the system has changed you :-/

Question to discuss:

- What needs to change in my system? What should be the focus of the double agent? What is their mission?

- Main change: get rid of diagnostic system, focus on social factors & inequality (is this a bigger

question about social justice rather than mental health? mental health strongly associated with social justice)

- Is diagnosis the problem or is it medication? If it was a medication free NHS would there be a problem with diagnosis?

- Is part of the problem that we lack confidence in our ability to tolerate other people's distress? (So it's easier to medicate than manage the distress) This seems to be a perceived inability within professionals - we sit with distress in our personal lives but not at work... We don't try to medicate our friends & family at times of distress, we talk to them

- What should we do? Ask questions without being afraid of being shot down!

- How do you try & bring about change? Try to help people to develop skills to prepare them to leave services & enable them to communicate this & convince whoever they need to convince that they are ready to leave!

- Providing space for discourse

- What power and/or influence do you have to bring about change?

- Very little! Small changes at individual / team level.

- Teaching, research

- What strategies do you use? Critical mass of like minded people, never give up!

Sharing ideas (things from other people in the room)

- prosecution against psychiatry suing them for corporate manslaughter of everyone who has died prematurely from taking anti-psychotic medication

- kidnap psychiatrists & lock them up, tell them they're not really psychiatrists & they're suffering from delusions of grandeur (ha!)

- better access to evidence that doesn't support the dominant paradigm

- use lived experience to bring about change

- service users to educate services - user led not co-produced

- how come the multi-disciplinary team doesn't always include the person ??!!

- encourage & support people to challenge the dominant paradigm

- social change towards mutual support & away from competitivism/individualism

- allowing a framework for people who have had their agency removed to get their agency back so that we are not the only agents for change (there are agents not just double agents!)

- capacity based rather than diagnosis based approach

- risk of double agency... we need to make sure that we're not trying to "save" people

- system of moles & invisible double agents within the NHS

- need visible movement within staff so we know who it is safe to talk to

- wear a badge, drop the secret handshake! Come out!

- less secrecy & subversion, openly challenge the system & share ideas

- How do we overcome barriers TOGETHER?

- And how do we look after ourselves? It is draining & demoralising to work in a system you feel

conflicted about... It is very exhausting to live in conflict / dissonance

- Are we actually doing what we think we're doing or are we actually propping up the system?

Change the World workshop with Jacqui Dillon

- Legal challenges on individual cases (e.g. deaths caused by meds / treatment)

- Polls of opinion (survey the public - also raises awareness, e.g. should people ever be detained against their will when they have committed no crime?)

- Eye-catching powerful emotive images (restraint, seclusion, forced medication)

- Direct action & protest (Houses of Parliament when bills being passed, e.g. CTOs)

- Testimonies

- Stimulate social action

- Demonstrate in the right place at the right time

- Collaborate with other organisations (like today - also Amnesty since UN report about torture under the Mental Health Act)

- Flash mob protests

- People in public image & media speaking out (but in a different way to Time To Change - people talking about being detained & more voices for people diagnosed with psychosis, schizophrenia & BPD)

- Desperation/pushing back is a GOOD SIGN - there is only a backlash if the campaign has enough momentum

- Change on multiple levels - what can I do at my level?

- What can I Do with my knowledge & resources to create change?

- I feel helpless :-(

Small group campaign - embed true informed choice in mental health support

- Allies from the inside, not just inside mh services but from all big institutions

- How to make this campaign appeal to people who have no contact with mental health services... what are their assumptions about mental health problems & treatment

- Write to or phone your local representatives, they need public to back up change

- Educating the public about medications

- Trip advisor for mh services

Group campaigning about chemical imbalance theory is a fallacy

- How to make this campaign appeal to people who have no contact with mental health services... what are their assumptions about- link with allies, include in curriculum of training for mhps

- Slogan badge from signing pledge to support cause

- If you start challenging you get diagnosed with BPD - still true

Group campaigning for psychosis as a sane reaction...

- People in public image & media 3min video clip, education at schools, preview at cinemas

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