

Harnessing Social Movement learning to shift the balance in mental health care systems



Professor Jo Smith

**Professor of Early Intervention and Psychosis,
University of Worcester, Worcester, UK.**

S34 TheMHS Conference, 10th February 2021, 7pm



Social Movement: A Vehicle for Change...

Leadership is the art of mobilising others to want to struggle for shared aspirations”

‘Social movements can be viewed as collective enterprises seeking to establish a new order of life. They derive their motive power on one hand from dissatisfaction with the current form of life, and on the other, from wishes and hopes for a new system of living.’

(Blumer, 1969: 99)



Each of us individually does not count much. But together we are the strength of millions who constitute Solidarity” – Lech Walesa

Normal view of change	'Movements' view of change
A planned programme of change with goals and milestones (centrally led)	Change is about releasing energy and is largely self-directing (top-led, bottom up)
'Motivating' people	'Moving' people
Change is driven by an appeal to the 'what's in it for me'	There may well be personal costs involved
Talks about 'overcoming resistance'	Insists change needs opposition - it is the friend not enemy of change
Change is done 'to' people or 'with' them - leaders & followers	People change themselves and each other - peer to peer
Driven by formal systems change: structures (roles, institutions) lead the change process	Driven by informal systems: structures consolidate, stabilise and institutionalise emergent direction

What are the essential factors to create a movement?

- **Emotional** (feelings and 'sentiment pools')
- **Rational** ('good reason'/compelling case/makes sense)
- **Social, relational and normative** (belongingness and community)
- **Behavioural and Expressive** (active participation)
- **Organisation**
- **Leadership**



"Courage is doing what you're afraid to do. There can be no courage unless you're scared."

(Eddie Rickenbacker)

Early Intervention In Psychosis (EIP) Social Movement

Can you decide to start a social movement or, like me, do you suddenly find yourself involved in one?

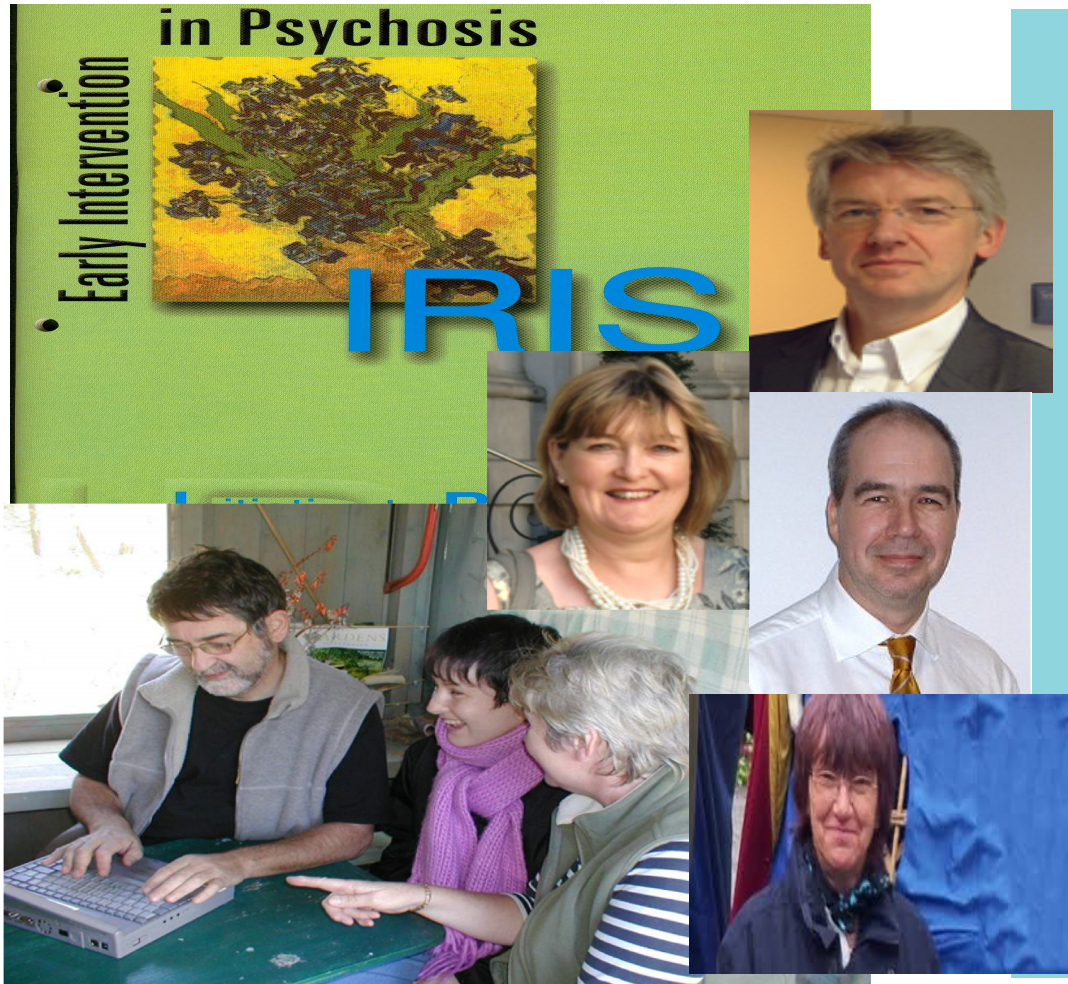


“You can’t connect the dots looking forward; you can only connect them looking backwards. So you have to trust that the dots will somehow connect in your future.”

STEVE JOBS
CEO, Apple Inc.

Stage 1: Emergence

1995: The start of our EIP Journey in England ...



NEVER DOUBT
THAT A SMALL GROUP OF
THOUGHTFUL,
COMMITTED CITIZENS
CAN CHANGE THE WORLD.

INDEED, IT IS THE ONLY THING THAT EVER HAS.

MARGARET MEAD

(RED)



Promoting Recovery
in Early Psychosis
A Practice Manual

Edited by
Paul French, Jo Smith, David Shiers, Mandy Reed, Mark Rayne

WILEY-BLACKWELL

Lived Experience narrative of dissatisfaction
(and anger) with a system experience



Mary aged 16, went from a CAMHS
service that *didn't do* psychosis...

...to an adult service that *didn't do* young
people...

...to a rehabilitation service that *didn't do*
rehabilitation

PSYCHOSIS: THE MESSAGE OF DESPAIR



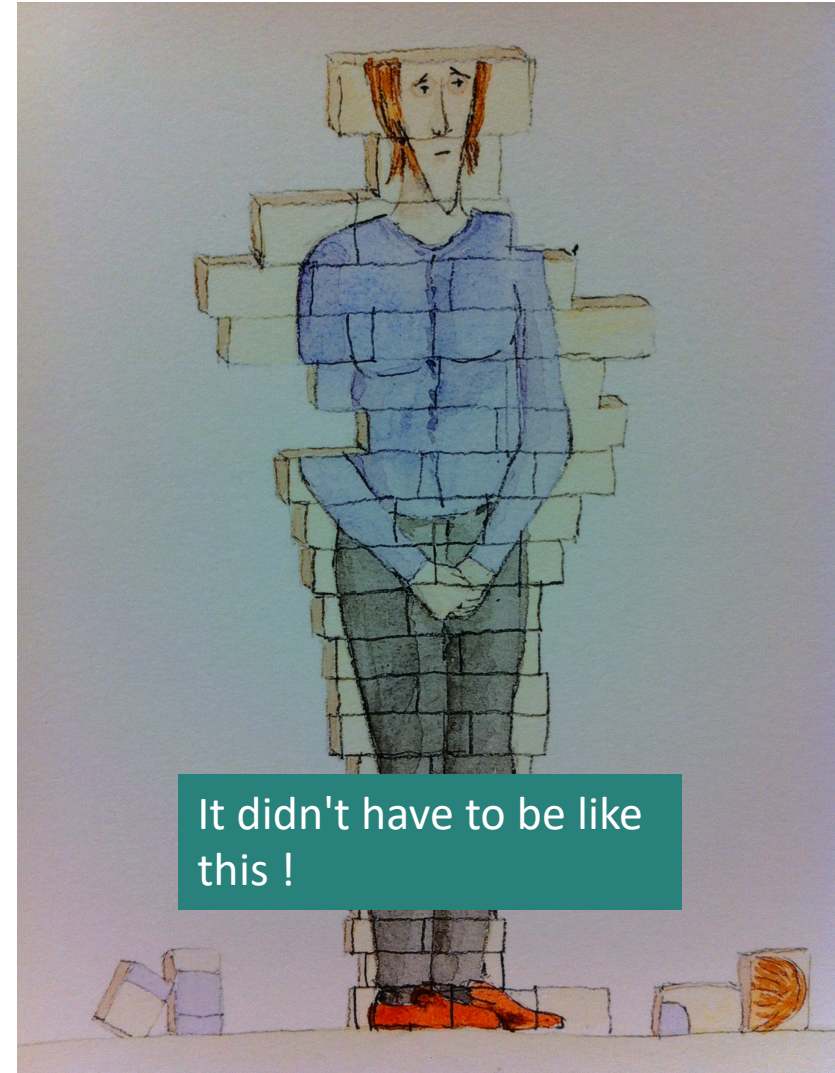
Framing: Social injustice driver...

“ I got help early and when I needed it and so did my family. We were able to see doctors and others who were well trained and knowledgeable about where when and how to make referrals . We saw people who respected us and taught us...I never had to go before a judge or magistrate to get help for me...I got to go to school, live in a decent place, get money, have my pets, have a life without giving up everything else, like my dignity and hopes for a future I want to be in.

No one hassled me about how sick I was or whether I deserved to get help I just got it. And when I talked, people listened...

Too good to be true? It was. That was the only tragedy here”

*‘The Tragedy of Schizophrenia’
Estroff (1999)*



Framing: Dissatisfaction with the status quo...

- Huge personal and familial costs in terms of long term social, emotional and vocational functioning.
- Ranked as third most disabling and costly condition following quadriplegia and dementia (WHO,2001)
- 20x greater risk of serious violence and self harm in early psychosis compared to any time later in illness
- 15-20yrs earlier loss of life: 1/4 from suicide (most in first 5yrs) 3/4 are premature deaths from physical causes
- 0-25% employed or in education at 1 year post psychosis
- Duration of Untreated Psychosis (DUP) averaging 12-18months : sig. impact on life chances
- Recovery at 14 months predicts functional recovery and remission of negative symptoms at 7.5 years



The Vision...Early Intervention in Psychosis (EIP) services- A new model of care



- A specialised service model and philosophy of care providing treatment and support for young people aged 14–35yrs with psychosis and their families
- Identifies and treats assertively and early in low stigma settings, maximising engagement in treatment.
- Provides evidence based individual, family, social , medical, psychological and vocational interventions within an optimistic, youth friendly, intensive 3 year program of care.
- Preferred model of service for young people with psychosis and their families endorsed by NICE Psychosis and Schizophrenia Guidelines (NICE 2009, 2014)

The 'Heart'... an Early Psychosis Declaration

Supporting ordinary lives and recovery from psychosis

“We need committed people, we need good-will people, we need grass-roots people.

...this is a task for us all, each one with their possibilities and capabilities, but all together “



A collaboration between NIMHE, Rethink, IRIS, WHO and the International Early Psychosis Association (2004)

The 'heart'...Tackling continuing Injustices...

Healthy Active Lives (HeAL)

Keeping the Body in Mind
in Youth with Psychosis



Imagine a world where...

- Young people experiencing psychosis have the same life expectancy and expectations of life as their peers who have not experienced psychosis
- Young people experiencing psychosis, their family and supporters know how to, and are consistently supported to, maintain physical health and minimize risks associated with their treatment
- Concerns expressed by young people experiencing psychosis, their family and supporters, about the adverse effects from the medicines used to treat psychosis are respected and inform treatment decisions

- Health organisations united the physical and mental health experience
- Healthy routines focusing on diet, physical activity and reduced tobacco use



Meaningful Lives



Supporting Young People with Psychosis in
Education, Training and Employment

Imagine a world where...

• Young people with

• The challenges

• Our Goals:

We aim to:

- Combat stigma, discrimination and prejudice in education, training and work settings by raising awareness about psychosis and the crucial importance of educational and vocational outcomes for longer term mental health
- Support young people to achieve their education, training and employment aspirations
- Ensure that functional outcomes, such as education, training and employment are seen as equally important in recovery as outcomes in symptom domains
- Advocate with funding agencies to appropriately fund evidence based interventions that address functional outcomes in relation to education, training and employment
- Combat factors that contribute to social isolation and unfulfilled lives
- Encourage professional attitudes that engender hope and optimism that young people with psychosis can achieve meaningful lives
- Seek support from education, training, employment and benefits agencies to assist young people with psychosis to complete their education and procure employment

Processes to enable this:

- Active confrontation of myths that people with mental illness typically do not want to and cannot work
- Equal priority given to educational and work functioning as to symptom levels
- Access to evidence based vocational interventions for young people such as the Individual Placement and Support (IPS) model, for both employment and educational goals
- An active and flexible research programme to ensure the best evidence is available to support vocational interventions for young people with psychosis
- Access to specialist educational and vocational support to enable education and work goals that are sustained
- Incentives for employment agencies to provide early and sustained support for employment goals
- Greater understanding of the processes that contribute to achieving and sustaining employment in EIP
- Greater understanding of ethnic-cultural factors that have an impact on individuals' access to work, including lack of language competency, and dislocation in refugees and asylum seekers
- Employment interventions focusing on retaining and sustaining employment in addition to gaining employment
- More flexibility in employment and benefit systems to be sensitive and responsive to the episodic nature of psychosis for some young people
- Long term protection of housing and healthcare costs when coming off benefits to returns to or start work

- Protection of individual rights to choose not to disclose the nature of a mental health difficulty to prospective employers

How Can I support this?

- Promotion of an evidence based, recovery oriented, clinical culture which supports and gives equal priority to educational and vocational functioning as symptom and social functioning
- Advocacy to government and funding agencies about the economic and social benefits of education, training and employment outcomes for young people with psychosis
- Promotion of positive news stories in local media and with local and larger employers
- Promotion of education for employment agencies, HR departments and other vocational professionals whose mental health literacy may be low

Further information

This statement is a product of an international meeting looking at the benefits of supported employment and education in EIP which took place in London on 30th June 2008 involving clinicians, researchers, economists and policy makers from the UK, USA, Canada and Australia.

Contributors to this International First Episode Vocational Recovery (FEVR) statement include:
Eoin Killackey (Australia), Eric Letimer (Canada), Jo Smith (UK), Miles Rinaldi (UK), Tom Craig (UK), Eric Davis (UK), Martin Hennessy (UK), Anne Lee (UK), David Shiers (UK), Swaran Singh (UK), Geoff Shepherd (UK), Sarah Sullivan (UK), Keith Huebertson (USA), David Fern (USA)

For further information about how you may support and endorse this international consensus statement please contact:

Jo Smith (UK): jodas@neone.net
Eoin Killackey (Australia): eoin@unimelb.edu.au
Keith Huebertson (USA): keith@unimelb.edu.au

A copy of this international consensus statement can be downloaded from <http://www.iris-initiative.org>.

References

- 1. World Health Organization (2002) *Psychosis: A Guide to Recovery*. Geneva: WHO.
- 2. World Health Organization (2002) *Psychosis: A Guide to Recovery*. Geneva: WHO.
- 3. World Health Organization (2002) *Psychosis: A Guide to Recovery*. Geneva: WHO.
- 4. World Health Organization (2002) *Psychosis: A Guide to Recovery*. Geneva: WHO.
- 5. World Health Organization (2002) *Psychosis: A Guide to Recovery*. Geneva: WHO.
- 6. World Health Organization (2002) *Psychosis: A Guide to Recovery*. Geneva: WHO.
- 7. World Health Organization (2002) *Psychosis: A Guide to Recovery*. Geneva: WHO.
- 8. World Health Organization (2002) *Psychosis: A Guide to Recovery*. Geneva: WHO.
- 9. World Health Organization (2002) *Psychosis: A Guide to Recovery*. Geneva: WHO.
- 10. World Health Organization (2002) *Psychosis: A Guide to Recovery*. Geneva: WHO.

...the same life expectancy and expectations of life as peers who have not experienced psychosis

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...the same life expectancy and expectations of life as peers who have not experienced psychosis

Key Principles

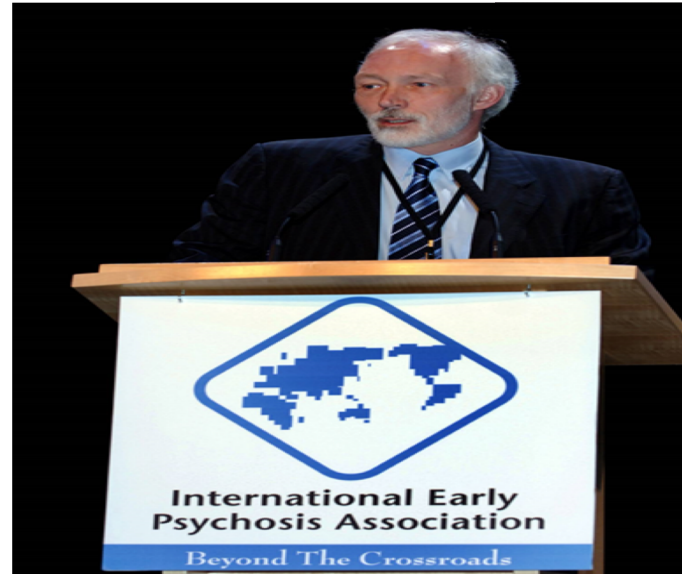
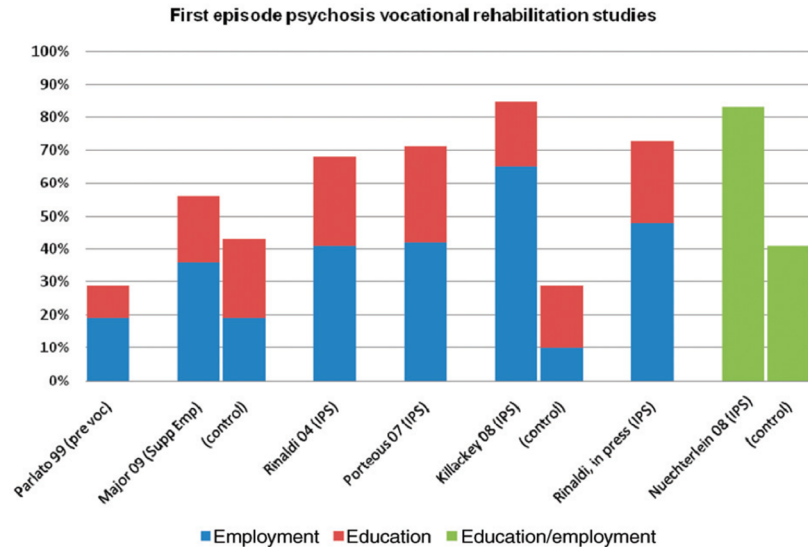
- All young people have a right to education, training and employment
- All young people have a right to citizenship and a basic income which is enough to live on
- All young people have the right to develop a career that gives meaning to their lives and makes use of their talents
- Young people with psychosis should have the same educational and vocational opportunities as their non-psychotic peers
- No individual should be discriminated against or disadvantaged in relation to their educational and vocational aspirations because they have had a serious mental health difficulty
- Educational as well as vocational outcomes should be equally valued and supported in first episode psychosis

People change what they do less because they are given analysis that shifts their thinking than because they are shown a truth that influences their feelings."

John P Kotter (2002), The Heart of

Change

Collective effervescence... part of an International early psychosis movement



iphYs and iFEVR Special Interest Group Meetings

Amsterdam 2010
San Francisco 2012
Japan 2014
San Francisco 2016
Boston 2018

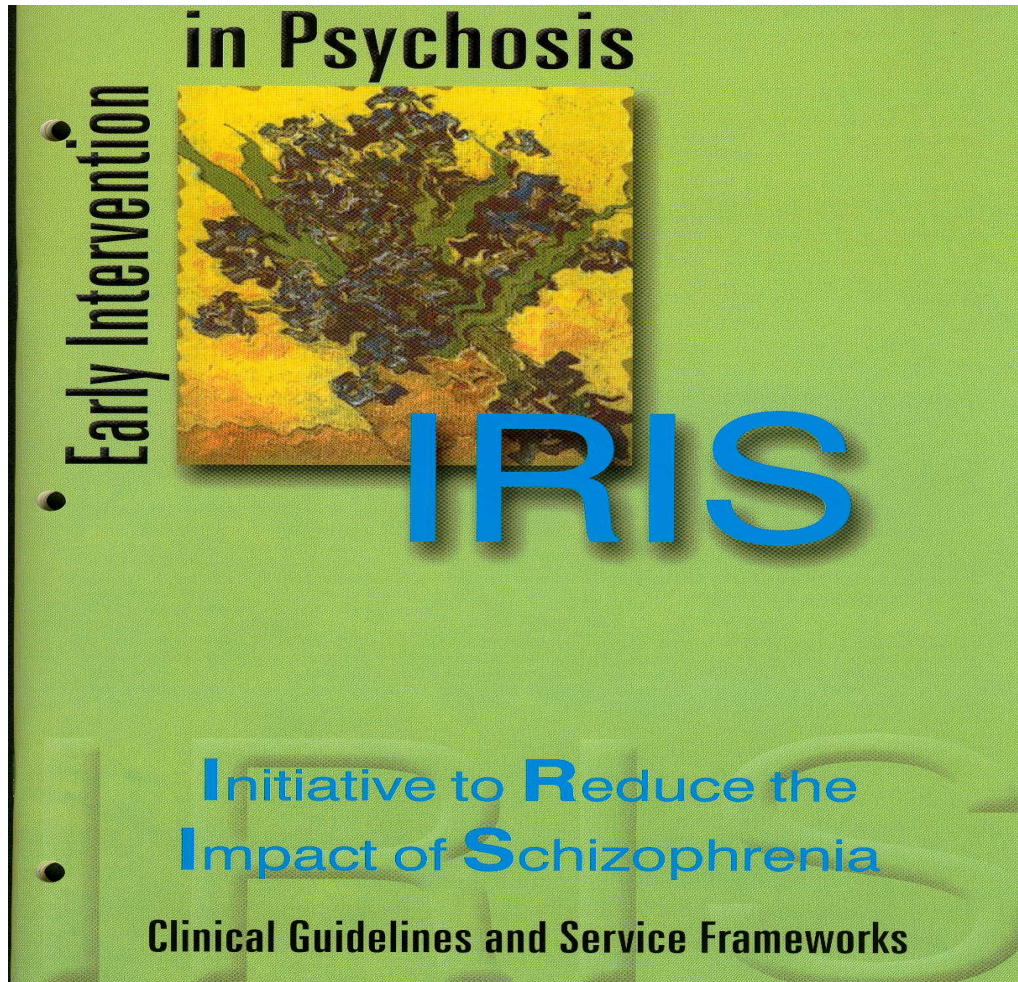


Taking local and collective action...Demonstrating EIP Service Outcomes (head)

Worcestershire EI Service data 2006-2014

	National baseline audit data	2006 (n =78)	2008 (n=106)	2011 (n = 139)	2014 (n = 102)
Duration Untreated Psychosis (median)	12-18 months	182 days (5-6 months)	154 days (5.5 months)	36 days (1 month)	28 days (1 month)
% hospital admission	80%	41%	17.5%	5.75%	10.6%
% involuntary admission (using Mental Health Act)	50%	27%	10%	14%	6.7%
Re-admission rate	50% (in 2 years)	28% (9.5% using MHA)	17% (56% using MHA)	19% (78% using MHA)	15.7%
% engaged at 12 months	50%	100% (79% well engaged)	99% (70% well engaged)	94% (80% well engaged)	91.8%
% Family involvement	49%	91%	84%	81%	80.4%
% In Employment (incl. education)	8-18%	55%	56%	60%	52%
% Suicide attempted (completed)	48% (10%) (in first 5 years)	21% (0%)	7% (0%)	25% (0%)	22.5% (0%)

Coalescence and Framing: 1996-98 IRIS and Rethink Partnership



When your car breaks down
you can get help within **60 minutes**.

When your mind breaks down
you may not get help for **18 months**.

rethink severe mental illness - www.rethink.org

Stage 2: Mobilisation

Inspiring others to take values based action...



“People here aren’t just motivated. This isn’t just their job, It’s a mission, it’s the cause they’re committed to.”

Director HIV/AIDS Programme, NY

*‘If you want to build a ship do not gather men together and assign tasks.
Instead teach them the longing for the wide endless sea’*

(Saint Exupery, Little Prince)

Bureaucratisation: NIMHE National EIP Programme

- Early Psychosis Declaration at its heart
- Infrastructure to support EIP implementation: regional networks and resources
- Provide leadership; Navigate obstacles



“Leadership is the art of mobilising others to want to struggle for shared aspirations”

Produce knowledge: EIP Policy and Implementation Guidance (DH 2001)

- A service for 14-35 year olds
- Multi-disciplinary specialist team
- 15 cases per care-coordinator
- out-of-hours cover
- 3 year follow-up
- Detect psychosis early
- Monitor those 'at risk of psychosis'
- Measure outcome data



Early Intervention in Psychosis
Achieving Ordinary Lives



NEW IRIS Guidelines

Launching 10th October 2012



About IRIS

IRIS seeks to improve the lives of young people affected by psychosis and their families by embracing the aims and principles of the WHO Early Psychosis Declaration. Established in the West Midlands in 1997, it has evolved to become a social enterprise in 2011 and continues to support the sharing of knowledge and good practice through a network of regional leads from across England and Wales.

See www.iris-initiative.org.uk

Frugal Innovations

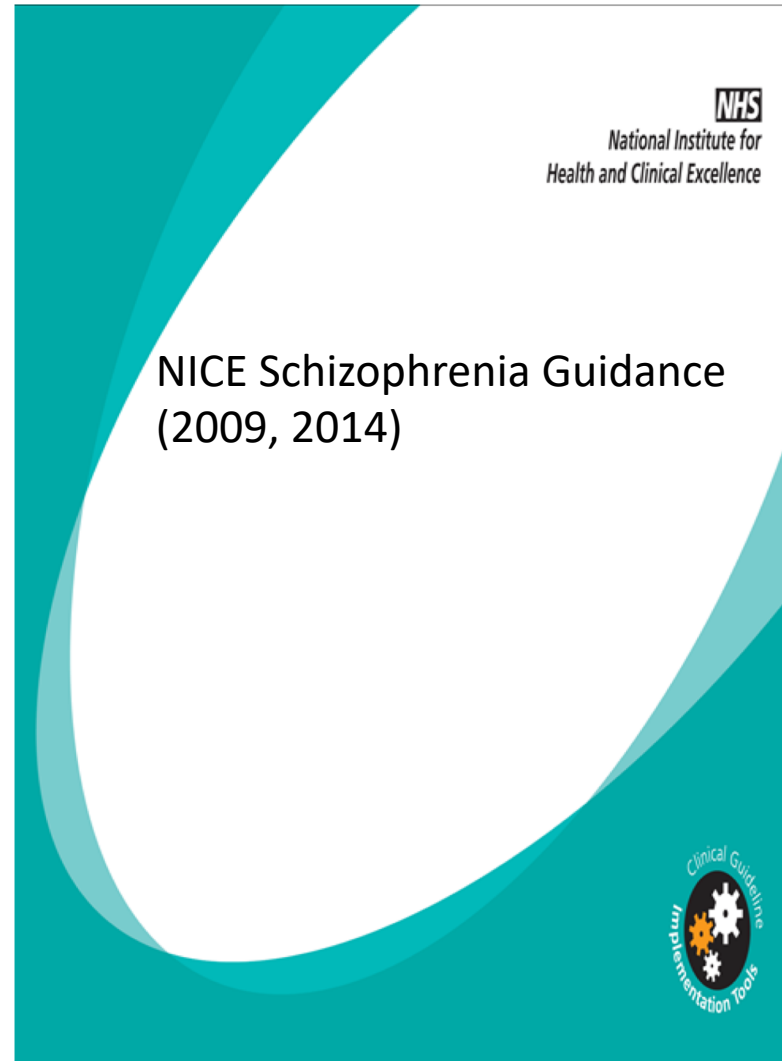
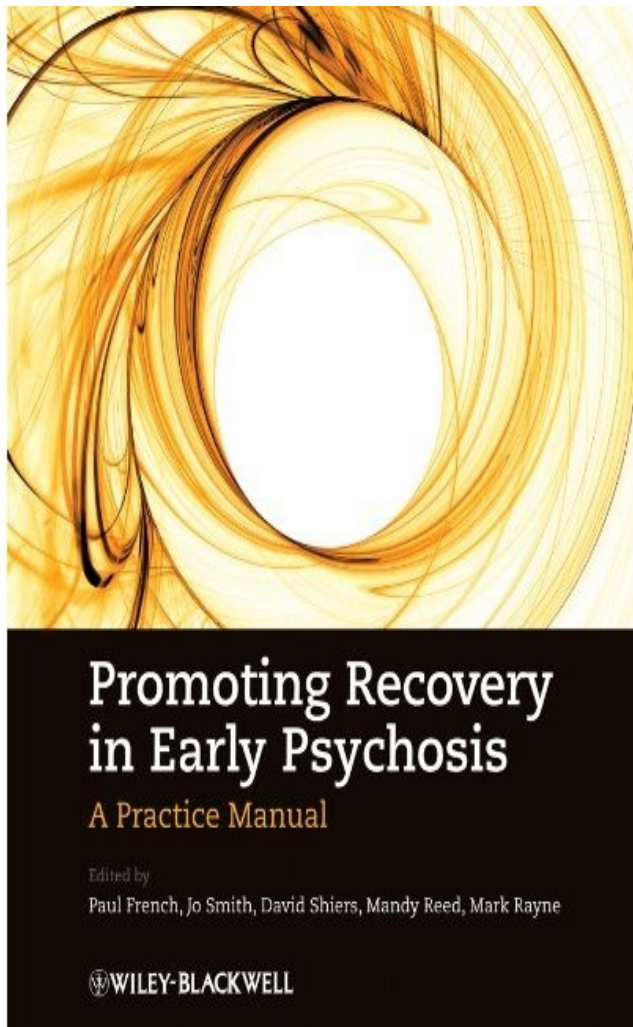
A photograph of a vintage bus, possibly a school bus, that has been extensively hand-painted with vibrant colors including blue, red, yellow, and green. The word 'WOOV' is painted in large, stylized letters on the side of the bus. The bus is parked on a grassy area with trees in the background.


Non-conforming enclaves

fast grow ideas

Regional 'Hothouses' exporting 'outputs' via a national EIP network to other regions and internationally (spread and scale)

Developing EI practice and evidence...





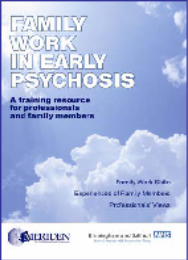
Birmingham and Solihull
Mental Health NHS Foundation Trust

Family Work in Early Psychosis

Training DVDs with over 10 hours of viewing

This set of 5 DVDs covers family work consistent with current Department of Health policy and NICE Guidelines:

- * The impact of psychosis
- * The benefits of evidence-based family work
- * Interviews with service users and family members
- * The impact of psychosis on siblings
- * Demonstration of family work skills with two families
- * Discussion with a multi-disciplinary group of expert healthcare professionals discussing implementation of family work
- * Cultural factors relevant to family work
- * Tried and tested implementation strategies
- * The benefits of Carers' Support Groups in early psychosis
- * The innovative role of the Carer Consultant in Early Intervention services



Who is this for?

- Mental health professionals including Adult and Child & Adolescent services
- Managers
- Commissioners
- Carers, family members and service users
- University lecturers and trainees

Can be used for:

- Family work training as part of the Meriden 5-day training course
- Staff induction
- Awareness raising and education for mental health teams
- University courses for all professional groups
- Supervision sessions
- General learning resource

This series of five DVDs is available to purchase for £200
(An accompanying training manual is currently being developed and together with DVDs 2, 3 and 4 these will be the core training materials used on Meriden Family Work training courses)

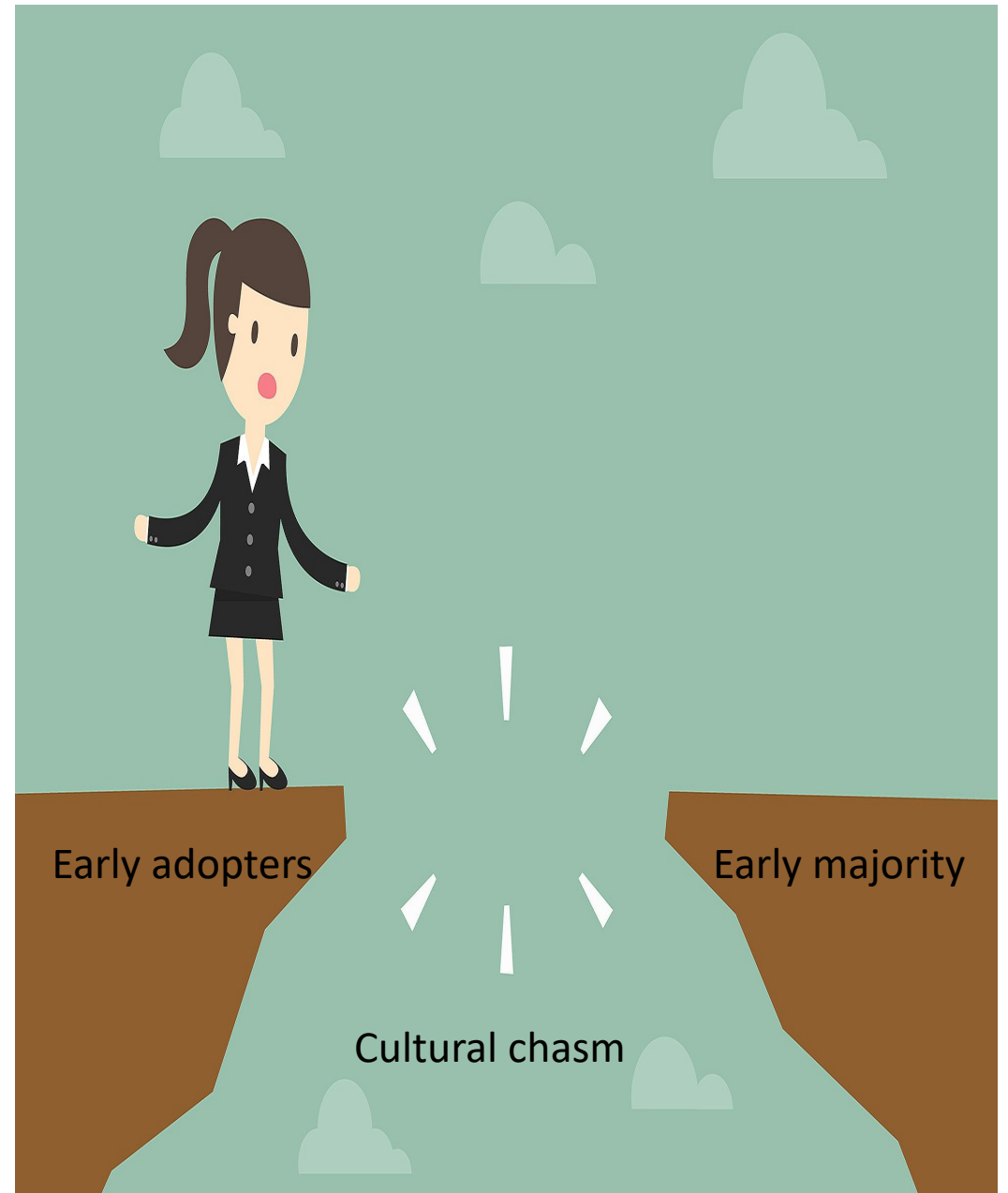
For further information or to purchase copies of this series of DVDs, please contact:

Mrs Sam Farooq, Business Manager, The Meriden Family Programme,
Tall Trees, Uffculme Centre, Queensbridge Road, Moseley, Birmingham B13 8QY
(Tel: 0121 678 2896 Fax: 0121 678 2891 Email: sam.farooq@bsmht.nhs.uk)

Developed by the Meriden Family Programme
Acknowledged worldwide for its expertise in the field of family work since 1998
www.meridenfamilyprogramme.com

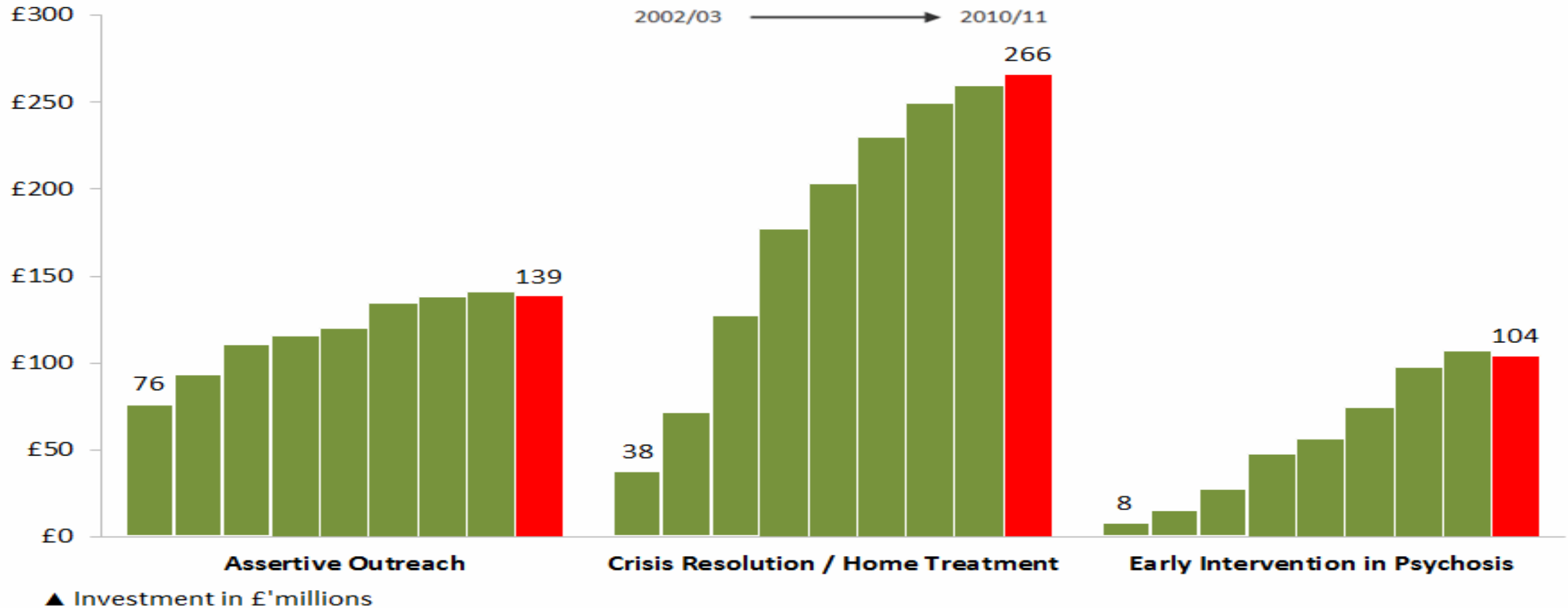
Crossing the 'cultural chasm':

Department of Health restored the trajectory of EIP service investment through its **EIP Recovery Plan (DH, 2006)** when acknowledged trajectory to provide EIP to 22,500 people with a first episode of psychosis was off-course.

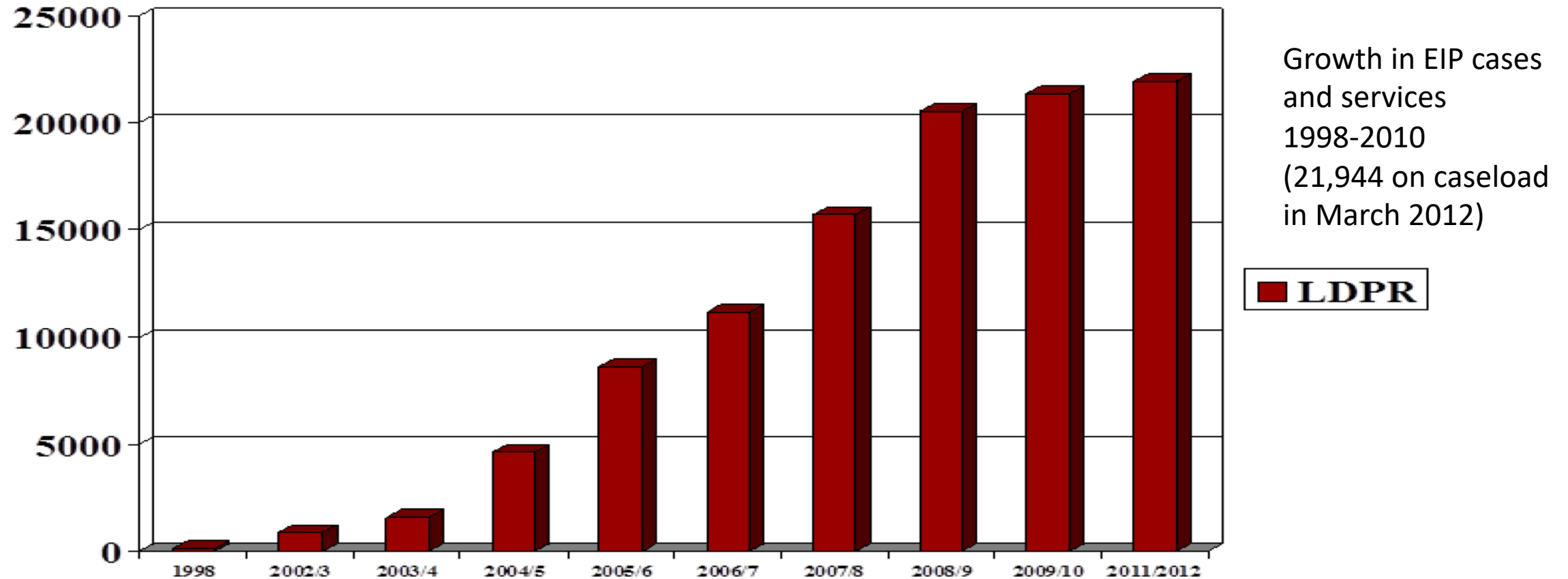


EIP Services Investment 2002-2010

**Investment in Priority Areas 2002/03 - 2010/11 in £' millions
at 2010/11 pay and price levels**



“Something that has sprouted legs and run all over the place” ...



No. of EIP teams: 2 6 24 41 109 127 160 145 153 178

Clinical Benefits and Cost Savings

“EIP more than any other services developed to date, are associated with improvements in a broad range of critical outcomes, including relapse rates, symptoms, quality of life and a better experience for service users”.

NICE Psychosis Guidelines (2014, p.551)

Early Intervention in Psychosis

If everyone who needed Early Intervention in Psychosis received a service, each year the NHS would save



£44 million

Source: National Institute for Health and Care Excellence, 2014. Costing statement: Psychosis and schizophrenia in adults: treatment and management

WE CHANGED VIEWS ABOUT PSYCHOSIS FROM: THE MESSAGE OF DESPAIR

Cost £11.8 billion per year

(Schizophrenia Commission 'The Abandoned Illness' 2012)

- This illness usually relapses or becomes chronic.
- You will need medication for the rest of your life.
- You should lower your expectations of what you will achieve in life.

EIP OFFERS A CLEAR MESSAGE OF HOPE
with a net saving of £15 for each £1 spent on EIP services
(Knapp et al 'Investing in Recovery' 2014)

You are distressed by your experiences now, but we
expect that you will get better.

Medication can be very helpful, but there are a lot of other ways that we can
help you to help yourself.

The aim is that you achieve what you want out of life.

Some movements persist through multiple 'waves' intensifying when collective action becomes opportunistic or adapting to new challenges/successes.

The fight continues but the focus for action changes...



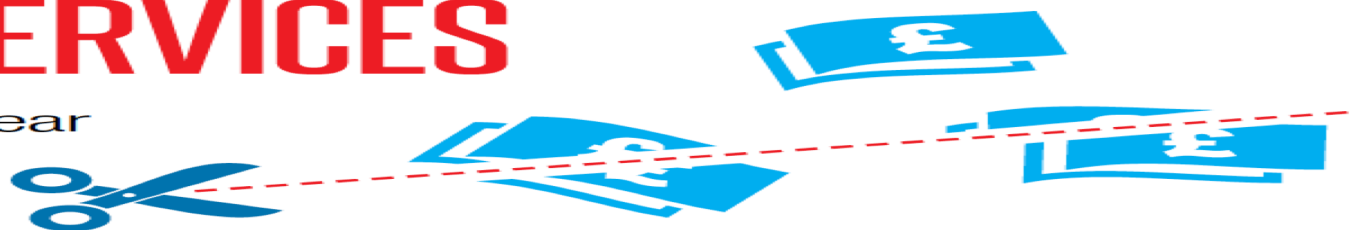
Economic Crisis (2008) Impacts on EIP Services in England (2011-2014)

- Cuts in budgets, staffing , service quality in over 50% of EIP services.
- Decrease in EIP team coverage from 95% to 69%
- Loss of some EIP services

The burning question...
How are we appraising 'value' in mental health?

50% OF EIP SERVICES

have been **cut** in the past year



EIP Access and Wait Time Policy and Quality Audit



Department
of Health



Achieving Better Access
to Mental Health Services
by 2020



EIP National Access and Waiting Time (AWT) policy standard (NHSE 2014):

‘More than 50% of people experiencing a first episode of psychosis will be treated with a NICE approved care package within two weeks of referral’

**NCAP Annual EIP Quality Audit (2016-2022)
(audit of n= >10.500 EIP case notes)**



What has the journey taught us?
A DIFFERENT MINDSET, SEEING DIFFERENT WAYS TO DO THINGS, IMPORTANCE OF
RELATIONSHIPS
AND HOPE

Student suicide - a hidden problem?

Question:

What **actions** are UK universities taking to **prevent** and respond to **student suicide**?

Not all health changes
are social movements,
but can we learn from
and apply social
movement principles to
support system change?

Framing: Lived experience narratives

Bereaved parent:

“But, in truth, we were on our own; there was no proactive contact from police, healthcare or the university; no family liaison. When my study window was broken by a would-be burglar, victim support contacted the family within 48 hours as mandated. After my son killed himself (at University), there was nothing.”

University Vice-Chancellor:

“... students taking their own lives is a tragic event in our institutions and the hardest thing for a Vice-Chancellor is to sit there in front of friends, family, partners, when you are asked “how and why did this happen? “ We want to eliminate suicides and improve mental health and wellbeing across our campuses, because it’s the right thing to do”



CELEBRATING SIX YEARS OF THE UNIVERSITY OF
WORCESTER SUICIDE SAFER PROJECT: 2013 - 2019



Mobilised to take local action

Two PhD studentships:

- Exploring current suicide prevention and response strategies within UK HEI.
- Exploring postvention support needs and roles for HE staff following a student suicide.

"Your work has made a real difference in this space – work that will be added to by your two PhD students in coming months."

Prof David Gunnell, Professor of Epidemiology,
University of Bristol

Use Opposition and Resistance as your friend

Minimisation: *“Its such a low incidence phenomena”*

Denial: *“This isn’t an issue for us” “This is already dealt with and covered by existing student support and counselling services”*

Avoidance: *“Our focus is on education”. “We don’t have the same a ‘duty of care’ as health”*

Judgement: *“Does Worcester have a problem with student suicide?”*

Scrutiny: *“I cant wait for Worcester to have a student suicide”*

Discredit: *“You haven’t worked in Higher Education to understand this context”*

Member engagement and mobilisation

"Our University has benefitted from your valuable work and insight into this most complex and sensitive area. Your contribution to the thinking within the HE sector has been considerable".

Vice-Chancellor, Canterbury University

"You have had a tremendous impact on raising the awareness of and influencing institutions to take steps to prevent suicide "

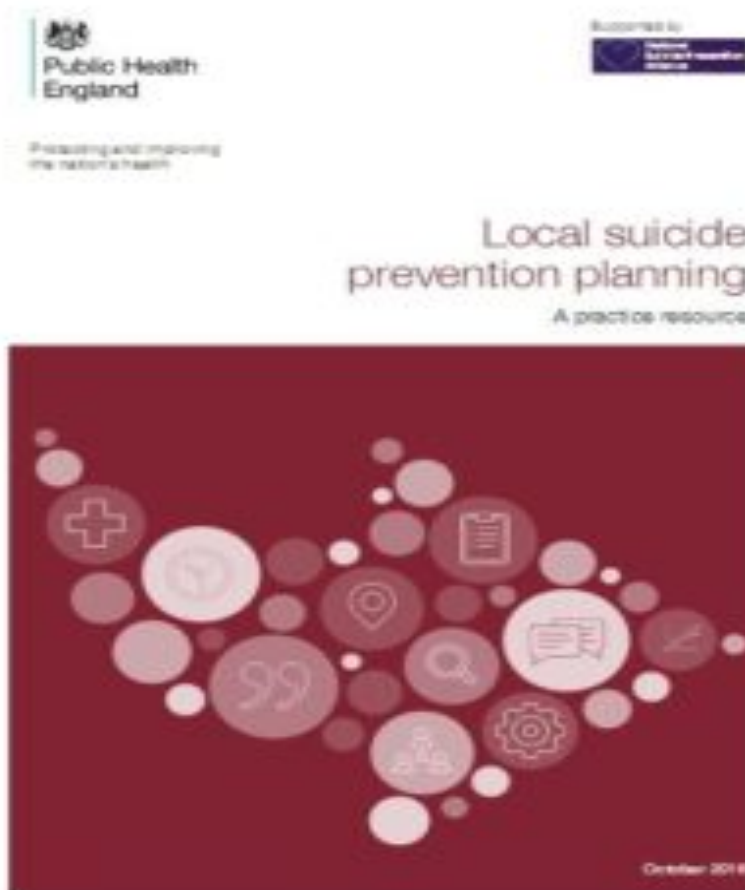
Head of Student Services, York St John University

"This has been an absolute inspiration to me and has motivated me to take the suicide prevention agenda on at WSFC."

Student Well-being Lead, Worcester FE College

Making connections: engaging key influencers in collective action

Public Health England (PHE)



Mental Health and Suicide Prevention:

An in-depth guide for Students' Unions and student activists

National Union of Students (NUS)

Institute for Public Policy Research

IPPR

NOT BY DEGREES

IMPROVING STUDENT MENTAL HEALTH IN THE UK'S UNIVERSITIES

Craig Thorley

September 2017

Institute for Public Policy Research (IPPR)

International Connections: A shared international concern



Ireland's 'National Student Mental Health and Suicide Prevention Framework'
(Higher Education Authority, 2020)

Raising awareness (national BBC News)



National guidance development



Political connections to stimulate top down government pressure...

‘There are some really impressive examples of good practice in universities. For example Worcester University have adopted a ‘whole University approach’ to suicide prevention.’

Taken from the Royal College of Psychiatrists written submission to the All Party Parliamentary Group Suicide Prevention Inquiry (2016)

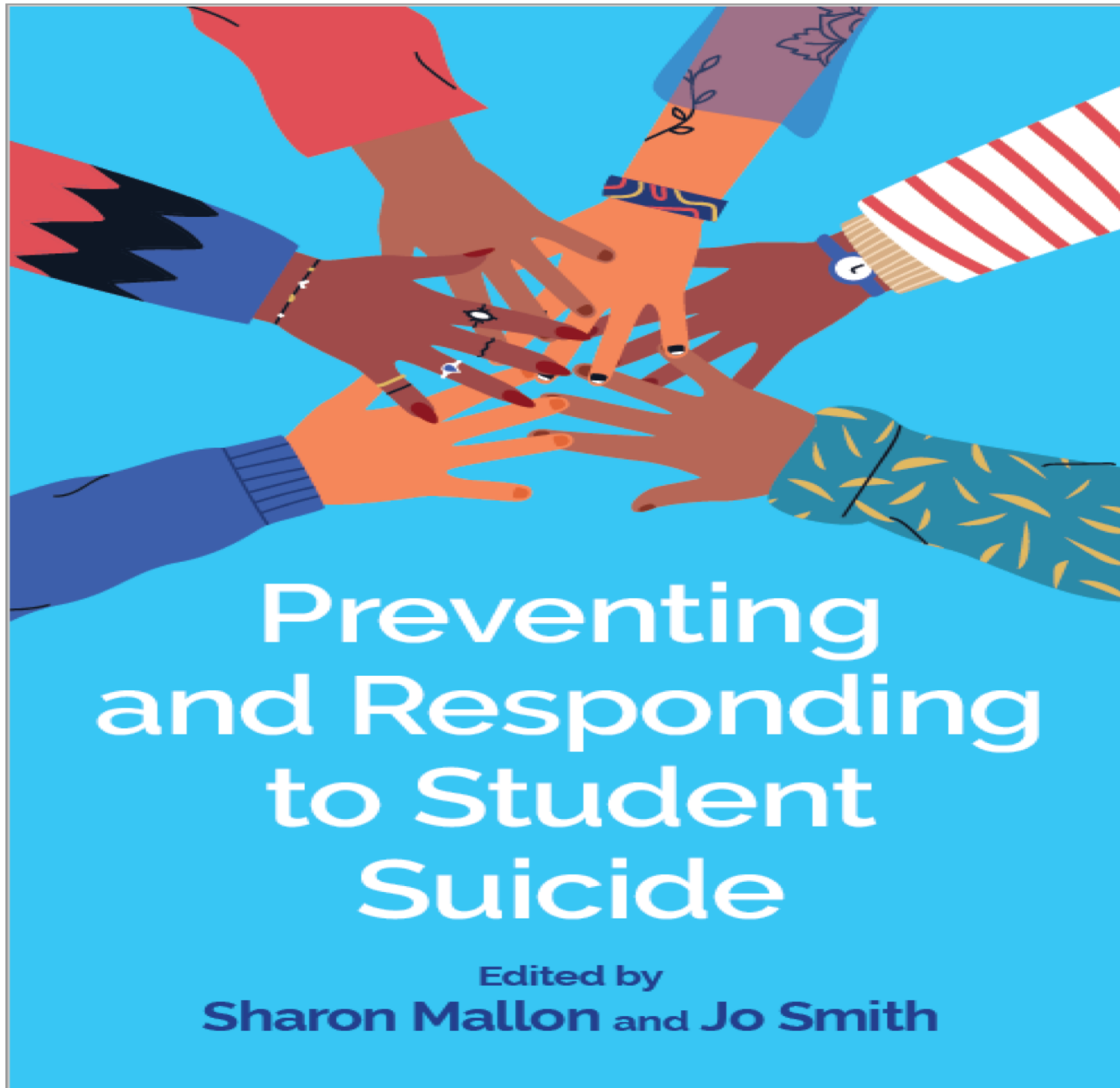
" we know when it comes to suicide you can make big improvements in prevention. This can only be done when you have accurate and reliable data. So Universities UK, Public Health England and the ONS are now working with researchers from the University of Worcester to encourage more accurate reporting of student suicides."

*Jeremy Hunt, Minister for Health,
Times Higher Education, Sept 20th 2017*

Crossing the cultural chasm from early adopters to early majority



Launch of a National Student Suicide Prevention Community of Practice:
50 universities with national organisations including Student Minds,
PAPYRUS and Universities UK.



“We do not need magic to transform our world. We carry all the power we need inside ourselves already.”

J.K. Rowling

TheMHS Conference S34 Keynote:

Harnessing Social Movement Learning To Shift the Balance in Mental Health Care Systems

Professor Jo Smith, Professor of Early Intervention and Psychosis, University of Worcester, Worcester, UK. E-mail: jo.smith2@worc.ac.uk

Abstract

Mental Health services in Australia and the UK face similar challenges of escalating costs and shrinking budgets when responding to the increasing and wide-ranging needs of the population they are designed to serve. Good clinical care is essential but not enough for the complex issues people with mental health problems face. We need to move upstream away from crisis oriented acute treatment interventions to invest in much earlier intervention to prevent mental ill health and community supports to foster and maintain mental wellbeing.

Throughout history, many dramatic social changes have been driven by groups of people who have come together as a 'movement' to fight for rights, solve problems, shift how people think, support each other and demand change in response to need. Social movements have sought out alternative approaches and ways of living which have challenged or rejected the status quo including dehumanised services, marginalisation, inequality, inequity, and the rigidity of entrenched institutions. They have put pressure on systems to accelerate transformation, respond directly to the needs of people and communities and have the potential to impact widely across populations through interpersonal connections and informal networks. Social movements have been gaining increased attention as an effective 'bottom-up' approach to achieve social, cultural and political change in health care systems through activities that include promoting healthy lifestyles, creating dialogue around stigmatised health issues and experimenting with new approaches to knowledge creation, service innovation, and policymaking (Del Castillo et. al. 2016). A health social movement can promote or resist change in the experience of health and health systems. Over time, a social movement can move from early adoption into mainstream routine health care delivery when the change, which may be in the form of a service model, a solution, a belief, a pattern of behaviour or a norm, becomes successfully embedded into an organisation, system or society. That said, the transformative and innovative potential of social movements to achieve their aims does depend, in part, on the ability of an organisation or system to listen and effectively respond to a movement and a shared commitment to engage and dialogue to create better ways of doing things.

In striving to re-balance the mental health system, harnessing social movement learning may offer a potential opportunity to think differently about how to better support mental health and wellbeing by combining the energy and dynamism of a social movement with the desire for radical change in current mental health care practice. This presentation will explore the role and potential value of social movement to drive transformation and achieve mental health system change. The presentation will draw on examples from personal experience harnessing social movement principles to effect changes in mental health care for young people with psychosis through the development of early intervention in psychosis services (Shiers and Smith 2014) and to mobilise suicide prevention interventions in higher education institutions, in the context of growing concerns about increasing rates of student suicide. The examples illustrated in this presentation may give a flavour of the nature and scale of change that social movements are capable of achieving. The presentation is designed to foster debate and stimulate discussion around the potential for harnessing social movement learning to help shift the current balance in mental health care systems.

Introduction

Social movement is described as a *'loosely organized effort by a large group of people to achieve a particular goal, typically a social or political one. This may be to carry out, resist or undo a social*

change. It is a type of group action and may involve individuals, organisations or both' (Wikipedia, 2021). Social Movements are distinctly different from an interest group or political group and are not about a fleeting fad or trend. They are organised, yet informal social entities engaged in extra institutional conflict/challenge oriented towards a goal involving promoting or resisting policy, economic, social or cultural change.

Social Movements are not new, they have existed for centuries and had key roles in achieving cultural, economic and societal change throughout history e.g. Civil rights, Women's movement, LGBTQ, and up to the present day e.g. 'Me too', 'Black lives matter'. Dramatic and transformational social changes have been successfully driven by groups of people coming together in social movements seeking to achieve change. This is reflected in a famous and often repeated quote from Margaret Mead, a social anthropologist, who remarked *"Never believe that a few caring people can't change the world. For indeed that's all who ever have"* (Textor, 2005).

However, social movements are not without their challenges. Nascent social movements often fail to achieve their objectives because they fail to mobilize sufficient numbers of people. They can lead down experimental paths without immediate benefit. We tend to only hear about successful rather than unsuccessful movements. The outcomes of most are modest, operate only on the margins of success and eventually burnout or dissolve into localised interest groups (Bate and Robert, 2010). Social movements by definition cannot be engineered, directed and controlled which makes it tricky to 'plan' a movement. It may, instead, be possible to identify and create a receptive context and trigger conditions that might bring a social movement to life, although as Bate and colleagues observed, 'there is a fine balance between passion and manipulation' (Bate et. al. 2004).

Is it possible to harness social movement processes to achieve or accelerate health care system change and transformation?

In recent years, researchers and healthcare organisations have considered the potential value of social movements to address healthcare challenges and achieve changes in health care and people's lives e.g. the NHS England 'Health as a social movement' programme (Arnold et. al. 2018). Bate and colleagues (2004) considered how a "bottom up, locally led, grassroots movement could offer a complementary approach to healthcare improvement thinking and practice" by putting pressure on health systems to accelerate transformation, respond directly to the needs of people and communities with the potential to diffuse widely across populations through the interpersonal relationships they create. Del Castillo and colleagues from Nesta described a health social movement as 'a persevering people powered effort to promote or resist change in the experience of health or the healthcare systems that shape it' (Del Castillo et. al., 2016, p 6).

In many ways, as Halima Khan from the Nesta observed: 'people powered social movements which emerge outside of formal institutions and from beyond established power structure, to challenge and disrupt accepted institutional values, priorities and procedures are the antithesis of 'command and control' health care systems which are typically highly controlled, with clear hierarchies, rules and protocols. (Del Castillo et. al., 2016, p.5). Equally, programmatic and social movement perspectives on change within a context of health care improvement are based on very different underpinning assumptions about change and change processes (Bate et. al., 2004).

So, can Social Movement offer an opportunity to think differently about how to develop and support mental health care and wellbeing and offer an approach to achieve or accelerate system level transformation? Is it possible to combine the energy and dynamism of social movement with the need for radical institutional change and use that creative tension between people power and institutions to shift the system? How do social movements engage with formal health services without collapsing under bureaucracy, avoid system attempts to control and change them and successfully scale up to cross the 'cultural chasm' between early adoption and mainstream practice? Are entrenched institutions open to listen, be responsive to and meaningfully engage with movements to create better ways of doing things by harnessing 'bottom up' approaches working in combination with more traditional hierarchical 'top down' systems change?

This idea is not without its critics. Some (e.g. Waring and Crompton, 2017) suggest the claim of health leaders enrolling clinicians in change activities and empowering them to develop 'bottom-up' improvements using social movement methods ends up being a more 'hybrid' model. This allows some degree of creative mediation between clinical and managerial interests but more often an alignment with the aspirations of management in achieving pre-determined programmes of 'top-down' change. So is it possible, instead, to use 'bottom-up' social movement approaches to engage senior leaders and government to work collaboratively and provide 'top down' systems support to effect meaningful, sustained system change?

Equally, not all health changes are brought about by social movements, but is it possible to harness social movement theory, principles and processes to support system change? Can you engender a movement mentality or movement sensibilities around system improvement and what might be done to facilitate its development? At a local level, can an activist in their role within a professional group, community and wider network use components of social movement to support organisation change by employing effective social movement methods and strategies as an approach to change, to overcome obstacles and to develop strategic scripts? A combined social movements and programmatic approach need not necessarily be mutually exclusive and may be a useful complementary approach to achieve healthcare system improvement (Bate et. al. 2004).

At this juncture, I should admit I am not a sociologist, social anthropologist or social movement expert and I am not going to talk about how to start a social movement or describe social movements in any depth. Instead, I am going to talk about what I have learnt about social movements from being involved in one (Early Intervention in Psychosis) and then how I have used that learning and experience to influence education system change in relation to student suicide prevention.

Can you decide to start a social movement or do you, like me, find yourself involved in one?

My experience of social movement was a developing, predominantly 'relational process', in which I became involved, that I only was aware of in hindsight but not at the time. In both scenarios that I describe in my presentation, my starting point was an unexpected invitation to meet a dissatisfied parent (set of parents) and listen to a personal 'narrative' of dissatisfaction (and anger) with a system experience:

EIP: ***'a CAMHS service that didn't do psychosis, an adult MH service that didn't do young people and a rehab service that didn't rehabilitate'*** (GP and parent of a 15yr old who developed a first episode of psychosis).

Student suicide: ***"But, in truth, we were on our own; there was no proactive contact from police, healthcare or the university; no family liaison. When my study window was broken by a would-be burglar, victim support contacted the family within 48 hours as mandated. After my son killed himself (at University), there was nothing."*** (University Professor and a parent whose son died by suicide at a UK university).

Both had a conviction that 'it didn't have to be this way'. In both cases, I was asked to assist and, on both occasions, I didn't have a clue how I could help or where this would lead. In both examples, I was engaged by their stories which 'touched me' as a parent myself and as a professional observing a situation through a parent's eyes, their narratives also resonated with my own dissatisfaction with service systems and previous experience of similar narratives. The outcome of both contacts was that I was 'engaged', open to a process and wanting to assist but I didn't have any clarity at that time on where the conversation might lead and the direction it would take.

So what was my role in both system changes?

I am a clinical Psychologist by training and profession who worked for 34 years in the NHS then moved 6 years ago to take up a professorial chair at a local University. My initial role was as an 'Agitator', collecting and sharing stories to raise consciousness around the issue and to mobilise others to want to do something about it too e.g.:

EIP: I carried out a local 3yr retrospective audit of the care and support experience for young people with first episode psychosis and their families. This was combined with audit data from 5 other services in different parts of the country to demonstrate that the narrative described by one parent was not unique and instead was a common experience for many families in a similar position.

Subsequently, I moved into informal and formal 'leadership' and system 'advocacy' roles in both system change processes.

So how does a movement start?

A 'trigger event' often inspires a movement to emerge. This is accompanied by a realisation that there is a problem/issue/social injustice that they want to address either from dissatisfaction they feel (heart) and/or information and knowledge they get about a specific issue (head). The social movement defines the problem it is going to address by articulating the issue, social injustice and values to be addressed. As Brown and Zavestoski (2005) observed, many social movements often start out knowing what they want to do, but not how they are going to do it. Social movements do not just instantly happen when people express upset or dissatisfaction. They have to attract members and require effective leadership to encourage collective action to support movement development and growth over time.

How do you attract movement members?

For a social movement to be successful they have to engage members by making them aware of an issue that they were not aware of before. Participation in a movement doesn't come from knowledge or reason (head) but from felt emotion (heart). For a movement to form, Bate and colleagues (2004) suggest that people must be 'moved'. Snow and colleagues (1986) talked about the need to mobilise 'sentiment pools' i.e. people's inner feelings, internal energies and drivers for change. This is achieved using 'narratives' (stories based on lived experience). How a case is framed

and presented by leaders, in terms of the words and language used that make up the script for improvement, is critical to capturing people's attention and intention.

What kinds of people do you attract to a movement?

Movement members share a common outlook/issue and social goal typically either implementation or prevention of a change in a system's structure, legislation or values or the way people think and where there is a sustained association in pursuit of a shared long-term agenda/aims. A person will join and invest significant emotional energy when their values, aspirations and identity align with the movement's collective identity, commitment and purpose (receptivity to change). Once joined, their interactions and the relationships they build with other members tend to ensure they stay with the movement.

Different groups are important.

- **Agitators/activists (with lived experience) who typically challenge the system from outside**, who raise consciousness around issues and help to develop discontent as well as identifying why the world is as it is, how we can organise to make a difference, how we can create something new. What they identify can be uncomfortable for holders of an office or position because people often express sentiments of anger or pain in doing so.
- **Advocates/Flag bearers who change systems from within** by converting their peers and enlisting a critical mass of support for sustained change and improvement (Bate et al 2004).
- **Key influencers** - to speak out and move issues forward.
- **Political leaders** - it is important to forge relationships with political parties to influence political leaders in order to have access to political power and influence.
- **Adopters** - five different groups of adopters have been identified who all have different motivations to adopt new ideas and ways of working (Rogers, 2010):
 - **Innovators** are opinion leaders who take risks and adopt new technologies.
 - **Early Adopters** want to be ahead of the curve, create opinions and propel trends.
 - **Early Majority** decide to adopt the change based on utility and practical benefits.
 - **Late Majority** are more cautious before committing to a change and need more hand-holding as they adopt the change.
 - **Laggards** tend to be traditionalists and are slow to adapt to new ideas or technology, only adopting when they are forced to or because everyone else has already.

Bridging the gap or '**crossing the cultural chasm**' between early adopters and the early majority is the trickiest task as it requires a fundamental shift from adopting something because it is new to adopting the innovation because it is judged to be valuable, useful, and productive. When this is achieved, it is likely that the innovation will then be more widely adopted.

- **Opponents of and resisters to the change process** are equally Important and valuable ('hold your enemies close'). Listening to their questions, concerns and arguments helps a movement to mobilise counter arguments, build evidence, and responses to questions that need to be addressed. Resistance is necessary for change to happen and energises people to work towards movement ends. Indeed, Palmer (1997) observed that - only in face of opposition has significant social change been achieved.

Social movement leadership

Social movement relies on effective leadership to forge new relationships, frame issues to secure broad commitment, devise strategies, catalyse action, collaborate with others and develop other people's capacity to lead change for themselves by focusing on their skills and confidence to do so.

What do social movements do and how they operate?

Del Castillo et al (2016) described a wide range of activities that social movements engage in:

- **Raise awareness**, visibility and urgency to the issues or needs they fight for and of a product, service or approach.
- **Mobilise 'social capital'** to harness the strengths, capabilities, resources and knowledge of people into collaborative action and empower them to become 'agents of change'.
- **Encourage democratic engagement and participation**: particularly for those who lack conventional routes to power or mainstream political discourse and facilitate interactions between power holders and people lacking formal representation.
- **Lever existing latent potential for change** within a healthcare system to secure wider and deeper participation in a movement and **accelerate change** in an issue not advancing through mainstream practice.
- **Generate knowledge** highly relevant to policy making to challenge current practice and experiment with alternative solutions.
- **Innovate** themselves or provide space for innovation leading to cultural shifts and organisational change.
- **Experiment** with new ideas and approaches using creative ingenuity to develop cost effective strategies and '**frugal innovations**' within resource constraints that potentially can be scaled to reach large numbers of people.
- **Build face to face and online networks for change** which link people with similar initiatives informally across organisations to enable real-time communication and data sharing to accelerate the development and spread of new ideologies, solutions and change tactics and so it becomes a more coherent movement in the eyes of health system leaders.

How does a movement spread?

Bate and Robert (2010) described a three-stage model of social movement spread:

- **Framing**: where leaders 'frame' the aspirations or vision for change in ways that attract and mobilise members into collective action to effect change. 'Frame alignment' is an essential first-step in winning the 'hearts and minds' of clinicians (Bate et al., 2004).
- **Mobilising**: where leaders 'mobilise' clinicians into 'grassroots' collective action aimed at improvement, either at an individual level, where concrete actions are taken by a person in the direction of change, or at an organisational level by rallying/propelling segments of the organisation to undertake joint action and to realise common change goals. As movements formalise, they develop more formal organisational processes and leadership roles to coordinate collective activities. 'Clinical leaders' can act as 'flag bearers' to engage and mobilise clinicians into collective action (Bate et al., 2004).
- **Sustaining and mainstreaming**: changes through collective action, influence within political processes such as changing laws or attitudes, becoming a formal organisation or, in a healthcare context, when the goal of improvement becomes institutionalised and embedded within the cultures of clinical work (Bate et al., 2004).

Social Movement Life Cycle

Del Castillo et al. (2016) described the life stages of a social movement as:

- **Emergence:** when a 'trigger event' inspires a movement to emerge. There is little or no organisation and actions tend to be individual rather than collective. Members serve as agitators raising consciousness about the issues and developing discontent with the status quo.
- **Coalescence/mobilisation** is when people come together and the focus of the movement becomes public. The movement develops a plan of action, recruits members, forms networks, gets resources and becomes organised and strategic in outlook.
- **Bureaucratisation** occurs when the movement has raised awareness to a degree that a coordinated strategy is required involving higher levels of organisation, coalition based strategies and greater political power. The movement might create structures or organisation to run specific functions and support movement activities.
- **Integration or Decline occurs either when** the change becomes integrated and an established part of the mainstream health system or declines because the movement is undermined or destroyed, runs out of resources or loses focus and cohesiveness.

Some movements achieve change swiftly while others persist going through multiple '**waves**' intensifying when collective action becomes opportunistic or adapting to new successes/aims where the fight continues but the focus for action may change.

EIP as a social movement in health care in England and Wales

My presentation starts by describing my involvement in an international early psychosis social movement but predominantly focusing on changes in care for young people with psychosis and their families in England. (See Shiers D and Smith J. 2014)

Student suicide prevention in Higher Education in the UK

The second half of my presentation describes my role in employing an understanding and experience of social movement principles and processes to influence student suicide prevention in Higher Education in the UK. (See University of Worcester and Mallon, S. & Smith, J eds 2021)

Conclusion

This presentation aimed to identify common features of social movements to influence two distinct areas of health and education system change. My belief is that social movements can be a vehicle to achieve change. Understanding their principles and processes can help you to harness social movement methods to support and achieve sustained system change.

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