

## UK Development of Early Intervention In Psychosis (EIP) Services- A Story of Social Movement...



#### **Dr David Shiers**

Retired GP Leek, North Staffordshire

#### **Professor Jo Smith**

Consultant Clinical Psychologist and Early Intervention Lead, Worcestershire Health and Care NHS Trust Professor of Early Intervention and Psychosis, University of Worcester

**Former Joint National EIP leads** 

Worcestershire Health and Care WHS

IIMHL Manchester 12th June 2014



#### Jo Smith: Declaration of Interests

Consultant Clinical Psychologist and El Lead, Worcestershire Health and Care NHS Trust, Worcester, UK.

Visiting Professor in EI and Psychosis, University of Worcester.

External consultant for the Catalyst Individual Placement Support (IPS) Training Programme with Janssen-Cilag Ltd., UK.

External Consultant on an El services development project with Otsuka Pharmaceutical Co. Ltd, UK.

Received speaker honoraria and an educational grant from Janssen-Cilag Ltd, UK.

Received book royalties from Wiley-Blackwell publishers.

Any views expressed are not those of Worcestershire Health and Care NHS Trust, University of Worcester, Janssen-Cilag Ltd.,

Otsuka Pharmaceutical Co. Ltd or Wiley-Blackwell.





#### **David Shiers: Declaration of Interests**

2010 ongoing: Member of IRIS, a social enterprise which supports a network of regional leads who collaborate to promote early intervention in psychosis.

2011 ongoing: National Audit of Schizophrenia: GP advisor (paid consultancy RC Psych CCQI)

2011 ongoing: book royalties from Wiley-Blackwell publishers.

2013 HTA grant number 12/28 examining non-pharmacological ways to prevent weight gain for people with Schizophrenia; lead PI = Prof Richard Holt

**2013** ongoing: National Collaborating Centre for Mental Health: board member – *my views* 

2014 ongoing: Member of NICE quality standard for people with psychosis & schizophrenia – my views

1994 ongoing:
Over-involved dad

#### **Workshop Objectives**

- Consider key features of well known 'social movements'
- Pose the question: Can you use social movement principles to achieve changes in health services?
- Describe our experience in developing and implementing EIP services in the UK from a social movement perspective
- Identify 'key elements' from social movement we harnessed and 'key challenges' we had to address
- Consider: 'How can you now be part of this story in taking the international EIP social movement forward?'

## **Workshop Outcomes**

#### Participants will:

- develop familiarity with social movement principles
- consider how these principles might be successfully applied to achieve health service change
- know what an EIP service does
- Consider personal involvement in an evolving El social movement internationally



## What are Early Intervention in Psychosis (EIP) services?



- 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.
  - Is the preferred model of service for young people with emerging psychosis and their families endorsed by NICE core Psychosis and Schizophrenia Guidelines (NICE 2009, 2014)

www.worcester.ac.uk

#### Why do we need EIP services?

- 7,500 young people develop psychosis in England each year
- 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: 14 from suicide and injury (mostly in first 5yrs) 3/4 are premature deaths from physical causes
- 0-25% employed or in education at 1 year follow up post psychosis
- Recovery at 14 months predicts functional recovery and remission of negative symptoms at 7.5 years
- Early phase is critical: reducing duration of untreated psychosis (DUP) and offering specialist EIP significantly improves life chances



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#### People:

#### I'm a mum of 2 boys aged 17 and 21 years:

- Both are in the risk period for developing a first episode of psychosis (peak risk ages: 14-35 years)
- With no family history of psychosis, they have a 3% (3 in 100) chance of developing a psychosis

As a parent, what would I want for them if they were to develop a psychosis?

What would you want for your own children/siblings?





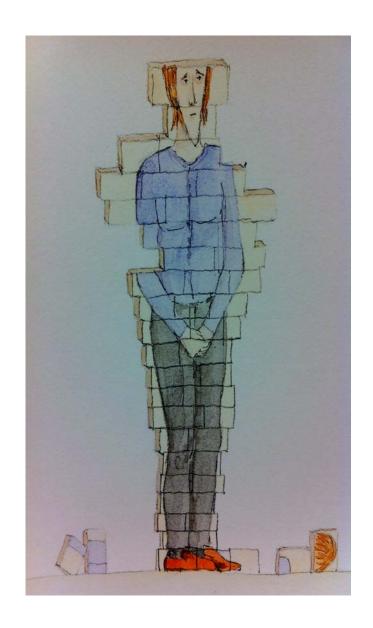
#### Treatment for Early Psychosis 15 years ago...

"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 is.

That's the only tragedy here"

Estroff (1999)



## PSYCHOSIS: THE MESSAGE OF DESPAIR

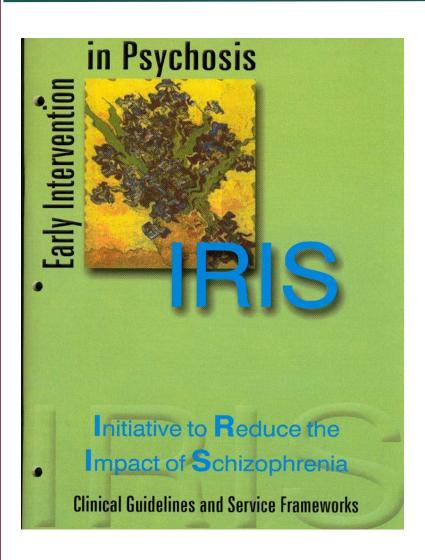
Mary aged 16, went from a CAMHS service that *didn't* do psychosis...

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

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



#### 1996-8 Dissent intensifies



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 <sub>severe</sub> mental illness** - www.rethink.org

#### From research based EIS in Australia, Birmingham & Lambeth



IRIS

**Guidelines** 

**Injustice** 

'big idea'

**Policy** 

First episode research

First EIS

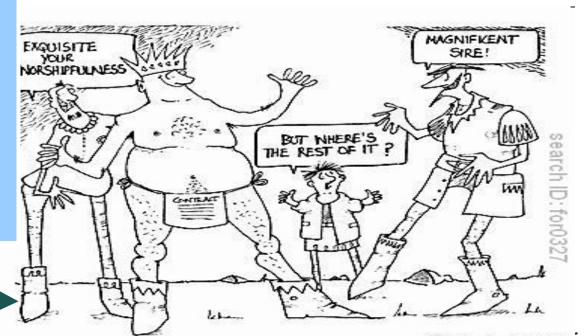
**EPPIC** 

off the ground

1986 / 92 1995 / 98

3

© Original Artist
THE EMPERORS NEW (www.CartoonStock.com



#### ...and an Early Psychosis Declaration

(WHO and IEPA 2004)

"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, the World Health Organisation and the International Early Psychosis Association

"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

#### To mainstream... El Policy Support

- NSF Adult Mental Health (DH 1999)
- NHS National Plan (DH 2000)
- Planning and Priorities Framework (2003-2006)
- El CAMHS Target and Childrens' NSF (DH 2003)
- DH El Recovery Plan 2006/7 (DH 2006)
- NHS Operating Framework 2007-2013
- New Horizons (DH 2009)
- LDPr quarterly activity return (vital signs): El new cases and total El caseload
- Mental health minimum data set (MHMDS) (since April 2011)
- No Health without Mental Health (DH 2011)

#### NHS Plan:

'By 2004, all young people with a first episode psychosis will receive early and intensive support'

#### El Recovery Plan:

Provide El to 7500 new patients in 06/07 and 22,500 patients by April 09 to put El development back on target

Selbie 2006

#### ...and a National El Programme

**Early Psychosis Declaration** at its heart

Infrastructure to support El implementation: regional networks and resources

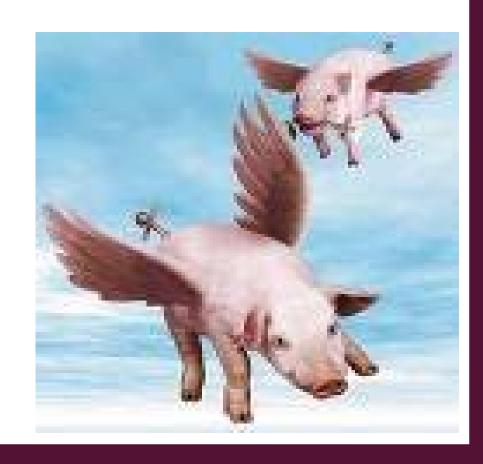
Provide leadership; Navigate obstacles



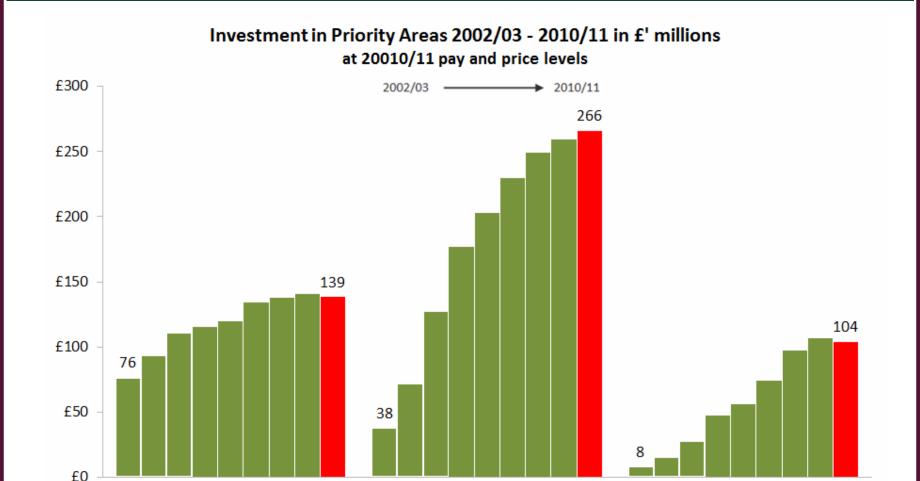
"Leadership is the art of mobilising others to want to struggle for shared aspirations"

#### ...and an El Policy Implementation Guide

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



#### Investment in EIP Services...



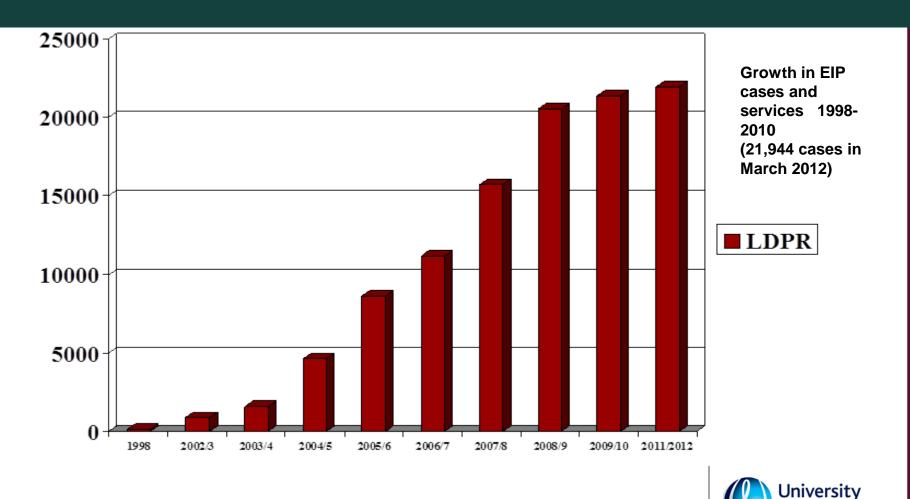
Crisis Resolution / Home Treatment

Early Intervention in Psychosis

▲ Investment in £'millions

**Assertive Outreach** 

## "Something that has sprouted legs and run all over the place"...





#### Practice...



'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)



Regional Hothouses www.



#### Social Movement: A Vehicle for Change...

'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. The career of a social movement depicts the emergence of a new order of life'

(Blumer, 1969: 99)

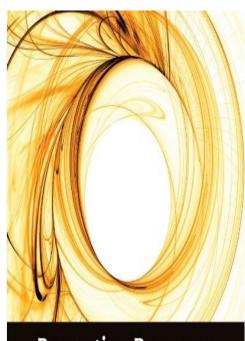


Each of us individually does not count much. But together we are the strength of millions who constitute Solidarity" – Lech Walesa

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



#### **Developing El practice...**



### Promoting Recovery in Early Psychosis

A Practice Manual

dited by

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

WILEY-BLACKWELL







#### **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





#### **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
   Congrel learning recover

#### 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@bsmhft.nhs.uk)

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

WWW.meridenfamilyprogramme.com



#### **Demonstrating EIP Service Outcomes:**

Worcestershire El Service data 2006-2011

	National audit data (IRIS 2000)	<u>2006 (n=78)</u> (22% 14–18yrs)	2008 (n=106) (18% 14–18yrs)	<u>2011 (n=139)</u> (19% 14–18yrs)
DUP (median)	12-18m	5-6m	22 weeks	6 weeks
% admitted with FEP (entry point to EI)	80%	41%	17.5%	5.75% 12.6% (n=25) CRHT
% admitted on MHA	50%	27%	10%	involvement 14%
Re-admission	50% (in 2 years)	28% (9.5% using	17% (56% using	19% (78% using MHA)
	, ,	MHA)	MHA)	,
% engaged @ 12m	50%	100% (79% well engaged)	99% (70% well engaged)	94% (80% well engaged)
Family Involved	49%	91%	84%	81%
Employment (including education and training)	8.18%	55%	56%	60%
Suicide attempted	48%	21%	7%	25%
completed	10% (in first 5y)	0%	0%	0%

#### **EIP: Clinical Effectiveness**

"more effective than the traditional generic CMHT approach. ... results in better course of illness, fewer symptoms at 8 years on and a halving of the suicide rate"

(DH, 2011 No Health without Mental Health pg 66)

"EIP services have demonstrated improved clinical outcomes combined with considerable cost savings through reduced use of hospital beds... reducing the number of young people remaining in mental health services with lifelong disability and has been well received by the clients, families and the referral agencies"

(NHS Confederation briefing 2011 pg 4,7)

"EIS 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 services".

(NICE Schizophrenia Guidelines 2014, pg 551)





#### **EIP Services Proving Their Worth...**

El cost savings over 3 years: £15K per patient over 3 yrs (McCrone et al 2007)

CAMHS El cost savings: £24K per patient over 3yrs (McCrone et al 2012)



"EIP services for psychosis have demonstrated their effectiveness in reducing costs and demands on mental health services in the medium to long-term" (Kings Fund, 2008)

El services ... help to avoid substantial costs to the health and social care system and offer further benefits through greater rates of participation in employment, as well as lower rates of suicide and homicide. Over a 10 year period, £15 in costs can be avoided for every £1 invested in early intervention. (Knapp et al , 2014)

## Net savings per person for Early Detection and El services (Knapp et al 2014)

#### El services:

- Cost-savings of £5,738 in year one
- Additional cost savings of £2,234 per person over three years from improved employment and education outcomes.

#### Early Detection (ED) services:

- Costs avoided by use of ED services is greater than the costs of delivering ED services
- Over two to five years costsavings of £3,299 per person per annum

(McCrone et al 2011)





"EARLY Intervention in Psychosis has been the jewel in the crown of mental health reform"

Professor Louis Appleby TRACK Event Birmingham Jun 1st 2009

"I have seen how much progress early intervention teams have made, how innovative they have been, and the impact they are having. I now believe that early intervention will be the most important and far reaching mental health reform...

I think early intervention will have the greatest effect on people's lives."

Professor Louis Appleby, Oct 10th 2008
Policies and Practice for Europe (DH / WHO Europe conference attended by 35 European Countries)



## 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.



#### EI FOR PSYCHOSIS: 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.

#### Treatment for Early Psychosis in 2014...

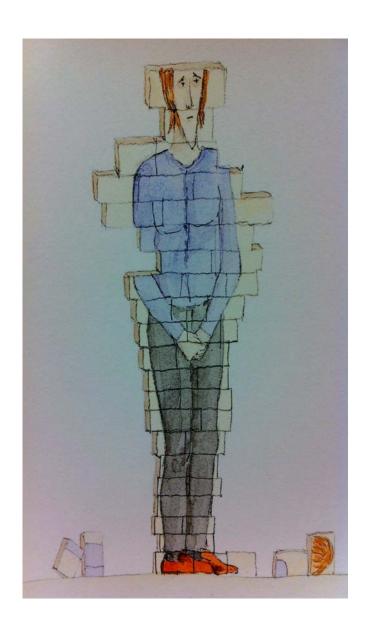
"I get help early and when I need it and so do my family. We are able to see doctors and others who are well trained and knowledgeable about where when and how to make referrals. We see people who respect us and teach us...I do not have to go before a judge or magistrate to get help for myself...

I 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 hassles me about how sick I am or whether I deserve to get help I just get it. And when I talk, people listen...





But the potential dismantling of El services in England may be the current tragedy for psychosis treatment now..."

'Lost Generation' Report (Rethink 2014) evidence from the front line about cuts to resourcing and budgets:

- 50% of EIP services say their budget has decreased in the past year, some by as much as 20%.
- 58% of EIP services have lost staff over the last 12 months.
- 53% say the quality of their service has decreased in the past year



**University** 

# And there are continuing injustices for young people with psychosis ...



#### Impact on Education and Employment

- Onset of schizophrenia associated with a pronounced decline in employment and education (Mueser et al., 2001; Kessler et al, 1995): 0-25% employed at 1 year follow up
- The experience of psychosis can exclude a young person from a sense of autonomy, employment and youth culture (Birchwood *et al*, 1997)
- Independent of course of illness, the best predictor of being in employment for people with schizophrenia is completion of education (Waghorn *et al*, 2003)
  - 5 GCSE's or their equivalent at grades A-C (UK)



#### Trapped in Welfare benefits System...

# Early dependence on welfare benefits is sustained 5 years later (Ho et al 1997):

- 15% on benefits at time of admission
- A further 63% initiated receipt of benefits within 7 months from admission
- Only 5% stopped receiving benefits over 5 years
- 73% continued to receive benefits at 5 years



## Where we want to get to...

#### Imagine a world where...

- Young people with psychosis are not stigmatised or discriminated against in education or employment because of their mental health difficulties
- Educators and employers are informed and supported in providing meaningful education and work opportunities for young people
- Young people with psychosis remain in school to complete their education and sustain paid employment surrounded by those who understand and care
- Hopes and dreams for education, training and employment are fulfilled

www.iris-initiative.org.uk

#### Meaningful Lives \*

Supporting Young People with Psychosis in Education, Training and Employment

# Imagine a world where...



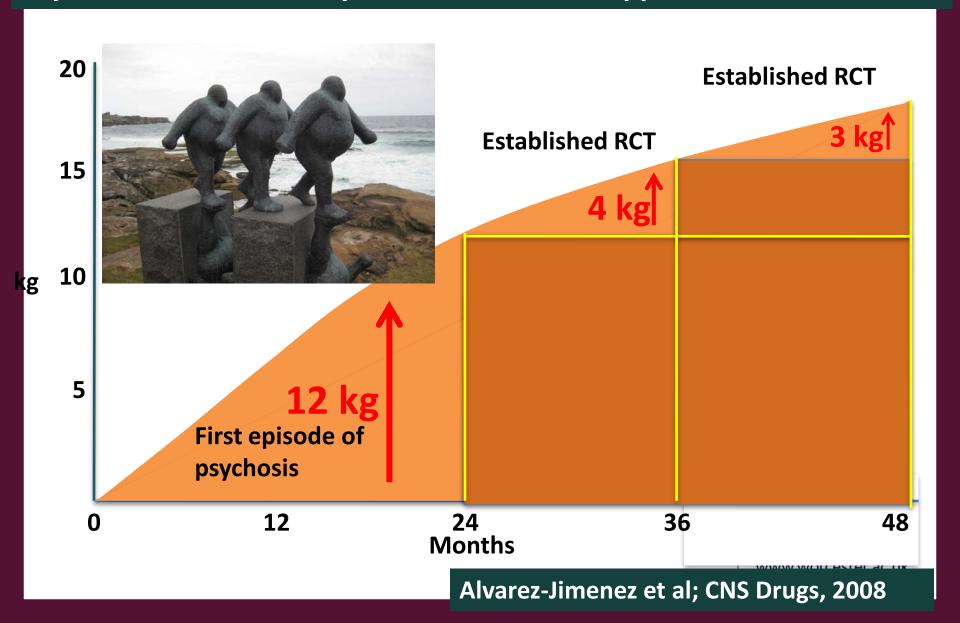


# PSYCHOSIS: THE MESSAGE OF DESPAIR

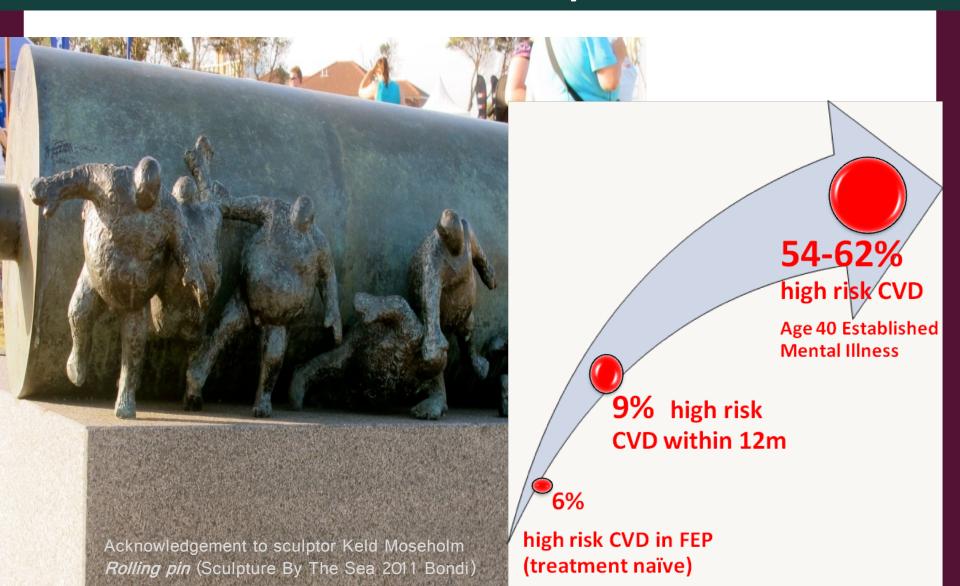
# Some unfinished business

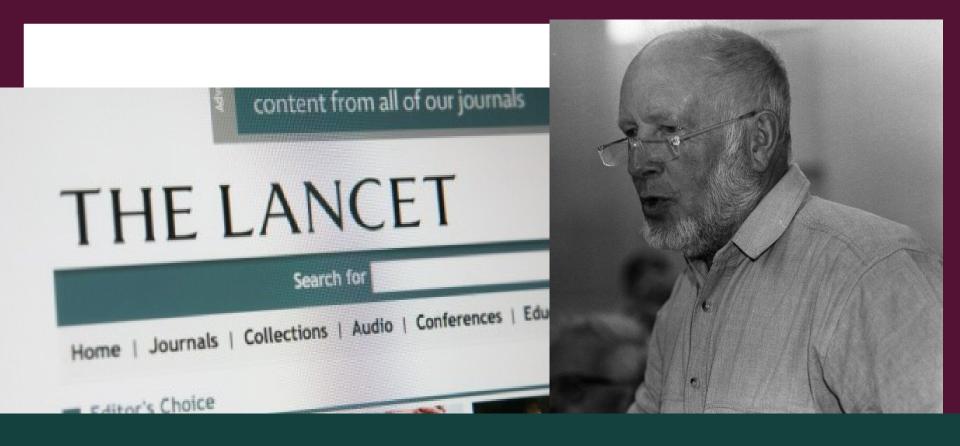


# Antipsychotic-Induced Weight Gain in Chronic and First-Episode Psychotic Disorders: a Systematic Critical Reappraisal



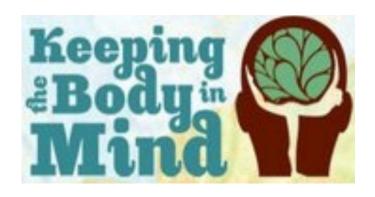
# ...on a path to obesity, type 2 diabetes, cardiovascular disease and premature death





"The provision of good medical care tends to vary inversely with the need for it in the population served."

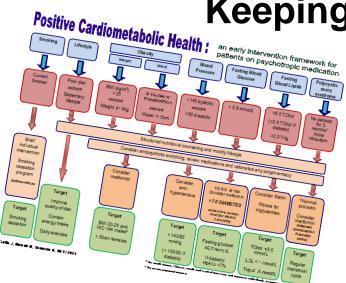
Julian Tudor Hart Glyncorrwg 1971





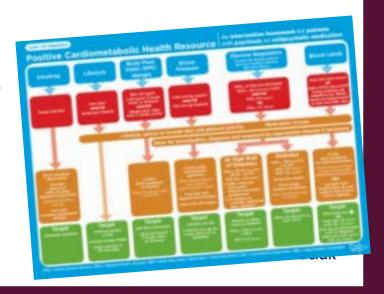
# iph Ys

#### **Keeping the Body in Mind**



**Special Interest Group** 

Amsterdam 2010





#### Healthy Active Lives (HeAL)

Keeping the Body in Mind in Youth with Psychosis



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

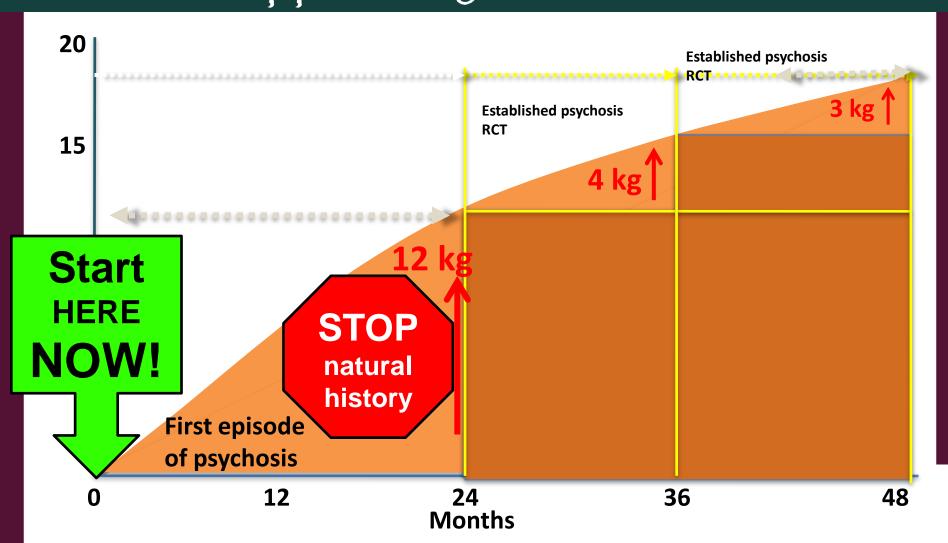








# Tealing is a matter of time but sometimes also a matter of opportunity Hippocrates (460BC-377BC)



# HeAL:Vite Sane e Attive

# Vite Sane e Attive



**Healthy Active Lives (HeAL)** 

Teniamo in mente il corpo nei giovani con psicosi

#### Immagina un mondo dove...

- I giovani con psicosi abbiano la stessa aspettativa di vita e le stesse possibilità dei loro coetanei non psicotici
- I giovani con psicosi, le loro famiglie e gli altri caregiver sappiano come mantenere la salute fisica e minimizzare i rischi associati al trattamento e siano costantemente informati e supportati al riquardo
- Le preoccupazioni espresse dai giovani, dalle loro famiglie e dagli altri caregiver sugli effetti collaterali dei farmaci antipsicotici siano rispettate e considerate nelle decisioni d'intervento
- I professionisti della salute mentale e le loro organizzazioni cooperino attivamente e congiuntamente per proteggere e mantenere la salute ficica dei giovani in cura
- Uno stile di vita attivo venga promosso come prassi sin dall'inizio del trattamento, con un'attenzione per l'alimentazione sana e la dieta, l'attività fisica finalizzata e la riduzione dell'uso di tabacco.



# HeAL:健康で活発 な活動 国際的合意

#### Healthy Active Lives (HeAL)

# Y

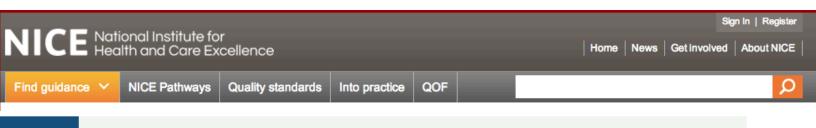
### 健康で活発な生活

精神病を持つ若者の 身体に目を向ける

#### こんな世界を想像してください…

- 精神病を経験している若者が、精神病を経験していない仲間たちと同等の平均寿命と人生への期待を持てる
- 精神病を経験している若者、そのご 家族や支援者らが、身体的健康を保っ ための方法、ならびに治療にともなう リスクを最小限にするための方法に ついて知り、機続的に支援される
- 精神病を経験している若者、そのご 家族や支援者らによって表される 精神病治療薬の副作用に関する心配 が尊重され、治療選択についての情報 が提供される
- 保健医療専門戦やそれらの団体は、 精神病を経験している若者の身体的 健康を守り保持するために一致団結 して取り組む
- 治療の開始時点から、健康的な栄養 摂取や食事、身体を使った目的のある 活動、タバコ使用の低減に焦点が あてられ、健康で活発な生活が常に 促される





CG178

#### Psychosis and schizophrenia in adults (CG178)



#### Psychosis and schizophrenia pathway

Fast, easy summary view of NICE guidance on 'psychosis and schizophrenia'

#### Psychosis and schizophrenia in adults: treatment and management

Clinical guidelines, CG178 - Issued: February 2014

This guideline updates and replaces NICE clinical guideline 82 (published in March 2009). It offers evidence-based advice on the care of adults with psychosis and schizophrenia.

#### March 2014:

A correction has been made to the wording of recommendation 1.1.3.3 to be clear that it is the hydrocarbons in cigarette smoke that cause interactions with other drugs, rather than nicotine.

The corrected recommendation reads:

Offer people with psychosis or schizophrenia who smoke help to stop smoking, even if previous attempts have been unsuccessful. Be aware

Guideline formats ?





Psychosis and schizophrenia in adults

Information for the public

Clinical guidelines CG178 Issued: February 2014

Implementation tools and resources

Baseline assessment tool

Healthy Active Lives (HeAL) consensus statement - International Physical Health in Youth working group

for psychological interventions with people with people with people

disorder
An intervention framework
for patients with
psychosis on
antipsychotic medication

See time guidance in practice

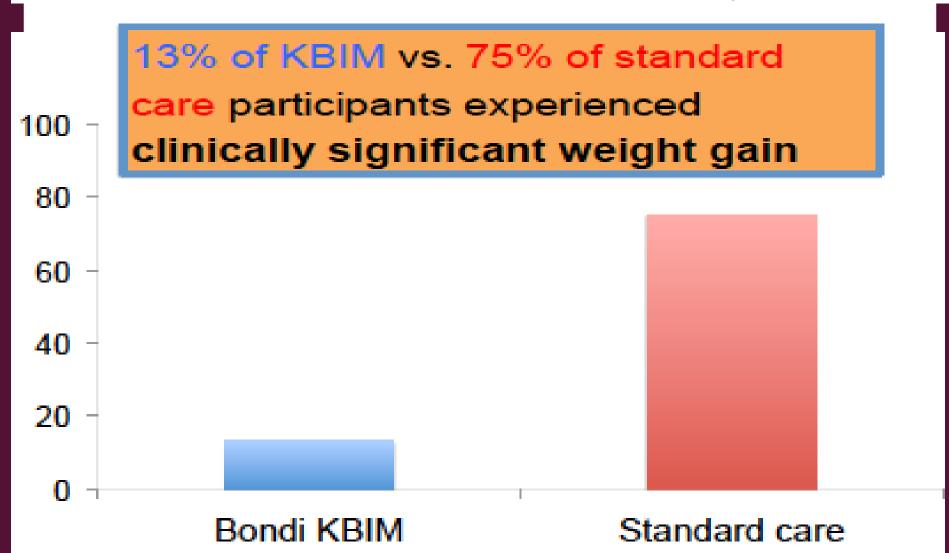
Research recommendations



#### Keeping the Body in Mind for young people with first episode psychosis

A life skills-building intervention focusing on healthy eating and physical activity to attenuate antipsychotic-induced weight gain

Jackie Curtis<sup>1,2</sup>, Andrew Watkins<sup>1</sup>, Katherine Samaras<sup>3</sup>, Megan Kalucy<sup>1,2</sup>, Simon Rosenbaum<sup>1</sup>, Scott Teasdale<sup>1</sup>, Janelle Abbott<sup>1</sup>, Julio De La Torre<sup>1</sup>, Philip Ward<sup>2,4</sup>





#### JAMES MACKENZIE LECTURE

**22 November 2012** 

#### Don't just screen, intervene

top GP calls for better care for mental health patient



-Subtle changes in the attitudes and actions of health professionals could significantly improve the quality, and even the length, of their lives.

The late Professor Helen Lester

James Mackenzie Lecture to the Royal College of General Practitioners' AGM.

Youtube <a href="http://www.youtube.com/watch?v=tqyACm50Q0M">http://www.youtube.com/watch?v=tqyACm50Q0M</a>



Normal view of change	'Movements' view of change
Planned programme with goals and milestones (centrally led)	Change by releasing energy; 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'	Acknowledges there may 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 change process	Driven by informal systems: structures consolidate, stabilise and institutionalise emergent direction

## What Is To Be Done?

**BURNING QUESTIONS of our MOVEMENT** 

Lenin V.L. (1901) What is to be done? In "Where To Begin", published in Iskra, No. 4 (May 1901),