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

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Former Joint National EIP leads

IIMHL Manchester 12th June 2014
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External consultant for the Catalyst Individual Placement Support (IPS) Training Programme with Janssen-Cilag Ltd., UK.

External Consultant on an EI 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.*
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)  

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 EI 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.
- Provides evidence-based individual, family, social, medical, psychological and vocational interventions within an optimistic, youth-friendly, intensive 3-year program of care.
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
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?
“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)
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

Early Intervention in Psychosis

IRIS

Initiative to Reduce the Impact of Schizophrenia

Clinical Guidelines and Service Frameworks

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.
Injustice
IRIS
Guidelines
‘big idea’
Policy

From research based EIS in Australia, Birmingham & Lambeth

First episode research
First EIS
EPPIC

1986 / 92
1995 / 98

Emperors new clothes?
…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... EI Policy Support

- NSF Adult Mental Health (DH 1999)
- NHS National Plan (DH 2000)
- Planning and Priorities Framework (2003-2006)
- EI CAMHS Target and Childrens’ NSF (DH 2003)
- DH EI Recovery Plan 2006/7 (DH 2006)
- NHS Operating Framework 2007-2013
- New Horizons (DH 2009)
- LDPr quarterly activity return (vital signs): EI new cases and total EI 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’

**EI Recovery Plan:**
Provide EI to 7500 new patients in 06/07 and 22,500 patients by April 09 to put EI development back on target

Selbie 2006
...and a National EI Programme

Early Psychosis Declaration at its heart

Infrastructure to support EI 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 EI Policy Implementation Guide

- 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
Investment in EIP Services...

Investment in Priority Areas 2002/03 - 2010/11 in £' millions at 20010/11 pay and price levels

- Assertive Outreach: £76
- Crisis Resolution / Home Treatment: £38
- Early Intervention in Psychosis: £8

$\Delta$ Investment in £'millions
“Something that has sprouted legs and run all over the place”…

Growth in EIP cases and services 1998-2010
(21,944 cases in March 2012)

Teams:  2  24  41  109  127  160  145  153  178
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

Jo & Dave's Hothouse Bus

Non-conforming enclaves
fast grow ideas
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 EI practice...

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

Promoting Recovery in Early Psychosis
A Practice Manual

WILEY-BLACKWELL

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 Care 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 trainers

Can be used for:
- Family work training as part of the Meriden 3-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 will be added to the DVDs 2, 3 and 4 when available)

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

Mrs Sam Farooq, Business Manager, The Meriden Family Programme,

Tall Trees, Offside Centre, Queens Road, Moseley, Birmingham B13 0BY
(Tel: 0121 678 2296 Fax: 0121 678 2297 Email: sam.farooq@meriden.nhs.uk)

Developed by the Meriden Family Programme
Acknowledged worldwide for its expertise in the field of family work since 1986

www.meridenfamilyprogramme.com

of Worcester

www.worcester.ac.uk
### Demonstrating EIP Service Outcomes:
**Worcestershire EI Service data 2006-2011**

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

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

CAMHS EI cost savings: £24K per patient over 3 yrs (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)

EI 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 EI services (Knapp et al 2014)

**EI 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.
- Annual savings of £1,024.40 per person for EI compared to standard care from a longer-term reduced risk of suicide
  (Knapp et al 2014)

**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 cost-savings of £3,299 per person per annum
  (McCrone et al 2011)
“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)

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

Professor Louis Appleby
TRACK Event Birmingham Jun 1st 2009
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.
“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…

Too good to be true? Not now…
But the potential dismantling of EI 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
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

Meaningful Lives

Supporting Young People with Psychosis in Education, Training and Employment

Imagine a world where...

• Young people with psychosis are not stigmatised or discriminated against in education or employment because of their mental health difficulties

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• 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

Potential Benefits

• Enhanced educational attainment and employability
• Improved mental health and well-being
• Better opportunities for meaningful education, training and employment
• Increased social inclusion and participation
• Reduced stigma and discrimination

Key Principles

• Multi-disciplinary team working
• Multi-agency working
• Provider and service user voice

The Challenge

• Young people with psychosis often experience difficulty in obtaining meaningful education, training or employment
• Many return to the education system after years away
• A lack of mental health support in the education system
• A lack of mental health support in the workplace

Our Goals:

• Support young people with psychosis to achieve their education, training and employment goals
• Support the development of psychology knowledgeable staff
• Support the development of psychology informed organisations
• Support the development of psychology informed policies

How Can I support this?

• Support a local or national initiative aimed at supporting young people with psychosis
• Support the development of psychology informed educational, training and employment initiatives
• Support the development of psychology informed policies

Processes to enable this:

• Develop a local or national initiative aimed at supporting young people with psychosis
• Develop psychology informed educational, training and employment initiatives
• Develop psychology informed policies

Further information

The International First Episode Vocational Recovery Group (iFEVR) is an international network of professionals who are working towards the recovery of young people with psychosis. The group is piloting the iFEVR model in several countries around the world. www.iris-initiative.org.uk

International First Episode Vocational Recovery Group (iFEVR 2008)

www.iris-initiative.org.uk

www.worcester.ac.uk
Some unfinished business
Antipsychotic-Induced Weight Gain in Chronic and First-Episode Psychotic Disorders: a Systematic Critical Reappraisal

First episode of psychosis: 12 kg

Established RCT: 4 kg

Alvarez-Jimenez et al; CNS Drugs, 2008
...on a path to obesity, type 2 diabetes, cardiovascular disease and premature death

Acknowledgement to sculptor Keld Moseholm

*Rolling pin* (Sculpture By The Sea 2011 Bondi)

54-62% high risk CVD
Age 40 Established Mental Illness

9% high risk CVD within 12m

6% high risk CVD in FEP (treatment naïve)
“The provision of good medical care tends to vary inversely with the need for it in the population served.”

Julian Tudor Hart Glyncorrwg 1971
Keeping the Body in Mind
...the same life expectancy and expectations of life as my peers who have not experienced psychosis
Healing is a matter of time but sometimes also a matter of opportunity  
Hippocrates (460 BC - 377 BC)

Healing is a matter of time but sometimes also a matter of opportunity  
Hippocrates (460 BC - 377 BC)
HeAL: 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 opportunità di vivere le stesse possibilità delle persone non psicostiche.
- I giovani con psicosi, la loro famiglia e gli altri interessati confessano sinceramente la salute fisica e mentale e rispettano le possibilità informative e coinvolgenti al subjecto.
- Le preoccupazioni grezze dei giovani, della loro famiglia e degli altri interessati, che sono trasformate in iniziative e decisioni.
- Le professionisti della salute mentale degli istituti e organizzazioni coinvolgono attivamente e con saggezza per proteggere e mantenere la salute fisica e mentale dei giovani.
- Uno stile di vita attivo viene promosso come parte di un'alternativa di trattamento, con una sintonia per l'approccio ai fini e l'attuazione del recupero fisico, mentale e sociale.

HeAL: 健康で活発な活動 国際的合意

Healthy Active Lives (HeAL)

健康で活発な生活

こんな世界を想像してください...

- 精神病を抱えている若者が、精神病を経験していない若者たちと同等の体育活動や人の関係に参加できる。
- 精神病を持たない若者が、精神病を持つ若者を支えるための活動や支援を行う。
- 精神病を持つ若者が、自分自身を理解し、自己表現し、自己成長をすることを可能にする。
- 精神病を持つ若者が、地元の社会に融合し、自立し、自己責任を果たすことができる。

- 保健医療専門家やその他の専門家は、精神病を経験している若者と精神健康を守るために一緒に活動していきたい。
- 治療の開始時点から、効果的な治療のための教育や支援を行う。
- 精神病を持つ若者に、自分自身を理解し、自己成長をすることを可能にする。
- 精神病を持つ若者が、自分自身を理解し、自己成長をすることを可能にする。
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
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 Curtis¹,², Andrew Watkins¹, Katherine Samaras³, Megan Kalucy¹,², Simon Rosenbaum¹, Scott Teasdale¹, Janelle Abbott¹, Julio De La Torre¹, Philip Ward²,⁴

13% of KBIM vs. 75% of standard care participants experienced clinically significant weight gain
JAMES MACKENZIE LECTURE
22 November 2012

Don’t just screen, intervene
top GP calls for better care for mental health patients

-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  http://www.youtube.com/watch?v=tqyACm5OQOM
PSYCHOSIS:
THE MESSAGE OF HOPE
<table>
<thead>
<tr>
<th>Normal view of change</th>
<th>‘Movements’ view of change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planned programme with goals and milestones (centrally led)</td>
<td>Change by releasing energy; largely self-directing (top-led, bottom up)</td>
</tr>
<tr>
<td>‘Motivating’ people</td>
<td>‘Moving’ people</td>
</tr>
<tr>
<td>Change is driven by an appeal to the ‘what’s in it for me’</td>
<td>Acknowledges there may be personal costs involved</td>
</tr>
<tr>
<td>Talks about ‘overcoming resistance’</td>
<td>Insists change needs opposition - it is the friend not enemy of change</td>
</tr>
<tr>
<td>Change is done ‘to’ people or ‘with’ them - leaders &amp; followers</td>
<td>People change themselves and each other - peer to peer</td>
</tr>
<tr>
<td>Driven by formal systems change: structures (roles, institutions) lead change process</td>
<td>Driven by informal systems: structures consolidate, stabilise and institutionalise emergent direction</td>
</tr>
</tbody>
</table>
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),