

Chapter 1 Introduction

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There is one thing stronger than all the armies in the world; and that it is an idea whose time has come.

(Victor Hugo, 1862)

It feels timely to be bringing together a training resource about *Promoting Recovery in Early Psychosis* to support the rapid service development created by the current UK policy platform and proliferating research evidence. In this introduction, we want to paint a backdrop of how policy, research and practice have been harnessed to provide the context in which we hope practitioners will find this practice manual relevant and helpful.

Few could have anticipated 10 years ago prior to the outset of the National Service Framework for Mental Health (DH, 1999) the extraordinary shift in how we understand and treat psychosis, none more so than in the arena of Early Intervention (EI) bringing with it new hope for young people with emerging psychosis and their families. Significant advances in understanding the nature of psychosis have created a whole range of new treatment options included in the NICE Schizophrenia Guidance (NICE, CG82 updated 2009):

- emphasis on recovery
- modern pharmacological practice
- psychological interventions
- working with families

With the completion of the NSF, these treatment advances have been accompanied by major investment and redesign of community-based specialist mental health provision, so that now most young people with a first episode of psychosis in England can access a local EI service. With that in mind, this book has been written by

mental health practitioners and service users and carers to make it accessible to a wide range of clinicians with the emphasis on skills development and sharing new and innovative EI team approaches.

However this book sets out to be more than just a collective guidance. The authors hope learning will be underpinned by a shared appreciation of the vision and values of the **Early Psychosis Declaration** (EPD) (see International Consensus Statement; Bertolote & McGorry, 2005) (Table 1.1).

What is important about the declaration is how it moves away from a disease and deficit model to one focused on improving health and building on attributes. This book is organised to reflect the five themes of the EPD, its component chapters contributing in their different ways to achieving its standards through collaborative and imaginative approaches embedded in the declaration's optimistic message of recovery. For instance, take the EPD theme 'Promoting recovery and the achievement of ordinary lives': what and who needs to be involved in helping a young person achieve this declaration standard? Certainly optimal health care and intervention is essential but is this sufficient? Ask yourself 'how might the young person be supported to secure a meaningful job: the importance of building self-esteem and motivation, of collaborative working with benefits agencies, youth agencies, job centres, and education providers?'

In this way, the book explores the declaration's five themes through contributions selected to encourage the co-production of health, acknowledging that health improvement requires integrated and collaborative care from many people and agencies beyond simply those of health services (Figure 1.1).

Table 1.1 What is the early psychosis declaration?

The EPD is a consensus about the standards of care that those developing early psychosis and their families should expect. First formed by some key people from across the UK with a special interest in early psychosis, the consensus (Bertolote & McGorry, 2005) gained the support of a number of organisations including World Health Organisation (WHO), the International Early Psychosis Association (IEPA), Initiative to Reduce the Impact of Schizophrenia (IRIS), Rethink and the National Institute Mental Health in England (NIMHE) with the ambition to:

- Establish a clear vision, some values and some actions required to achieve early intervention and recovery for all young people experiencing psychosis.
- Generate optimism and raise expectations from young people experiencing psychosis and their families that will influence the development of better services.
- Provide a framework for enabling those young people and their families to work alongside practitioners and services to:
 - Acknowledge the key shared concerns;
 - Develop a set of jointly agreed, valued and measurable goals;
 - Jointly commit to a set of strategic actions to achieve these goals.
- Attract and encourage practitioners from a wide range of health, social, educational and employment services to think about how they can better contribute to supporting these young people and their families.

For more information about the declaration – see www.iris-initiative.org.uk.

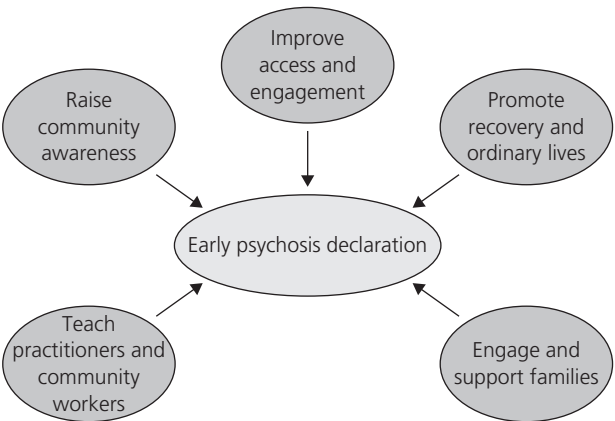


Figure 1.1 The 5 key themes of the Early Psychosis Declaration.

El and reform of mental health practice in England

EI has participated over the last 10 years in a wider mental health reform enabled by a socio-logical and political process informed by evidence. However, the idea that it was desirable to treat conditions like schizophrenia earlier in their course is not new. Radical thinkers such as Harry Sullivan challenged (and may still challenge) traditionalists, convinced by Kraepelin's original description (1896) of 'dementia praecox'

as a single disease entity (schizophrenia) with a universally poor outcome.

I feel certain that any incipient cases might be arrested before the efficient contact with reality is completely suspended, and a long stay in institutions made necessary.

(H.S. Sullivan, 1927)

Some 60 years would elapse before treatment delay became firmly linked to outcome. In 1986,

the Northwick Park study (Johnstone *et al.*, 1986) showed that individuals taking longer than 1 year to access services could expect 3 times more relapse in the subsequent 2 years than those who accessed services in under 1 year. These findings sparked intense research and clinical interest. One of that study's key authors helped to develop the North Birmingham EI service, the first UK EI service(s) (opening in 1989), mirroring service innovations in Australia, Scandinavia and the USA. Thus were laid the modern foundations for EI in the UK. And yet, research and innovative practice of themselves could not have generated the scale of reform that we have seen in England in the last 10 years. This modern era of EI development coincided with UK political sensitivity heightened by high-profile media concerns for public safety (e.g. the tragic killing of Jonathan Zito by Christopher Clunis; Benjamin Silcock entering a lion-cage). The existing UK policy of 'Care in the Community' became severely criticised for neglect of individuals by overburdened community mental health teams that relied excessively on crisis hospital admission and medication. Groups like IRIS (Initiative to Reduce the Impact of Schizophrenia) increased this pressure for change harnessing key researchers, early clinical innovators, users and family members, aligning with voluntary sector organisations such as Rethink and Making Space.

The stage was set for the traditional 'one size fits all' community mental health team approach to be challenged. Heralded in 1999 by the NSF Adult Mental Health, there followed a subsequent string of detailed policy guidance for EI (Table 1.2), including important Policy Implementation Guidance (DH, 2001) which put forward an EI service specification. New teams formed with discrete functions to deliver more intensive and focussed support at key points to break the cycle of crisis response and hospitalisation. These different 'functionalised' teams provided:

- *Early intervention*: intensive case management using age- and phase-specific interventions in the early phase of psychosis.

- *Assertive community treatment* where the patient resides – for example, for patients prone to a pattern of disengagement and relapse in crisis.
- *Home treatment/crisis response* at the point of crisis to avert the need for hospital admission.

These approaches have been continuously researched and developed which in itself distinguished this as a new era of mental health practice in England.

EI: Policy, practice and research

These radical reforms have been underpinned by a synergy between three essential elements, a continuing policy platform, a strengthening research evidence and evolving practice and service development.

Policy: We have already touched on the policy and political drivers – see Table 1.2 for a summary of key EI policy support. The NHS plan (DH, 2000) promised 50 new teams to cover England, configured to a national service blueprint (DH Policy Implementation Guide, 2001) to recruit 7,500 new cases each year and provide 3 years of evidence-based treatment. Full implementation in 2004 would achieve a 'steady state' (new cases balancing discharges) of 22,500 cases. However, this deadline had anticipated neither the complexities of both the service development itself nor some of the wider management and commissioning changes within the NHS and it became obvious that the planned implementation was stalling. The Department of Health restored the trajectory of anticipated caseload and service investment through its EI Recovery Plan (DH, 2006), and then maintained EI service(s) as a top mental health priority in the NHS Operating Framework (2007 to present). The important message here is that EI has enjoyed a sustained policy platform for the last 10 years and continues to hold the attention of policy makers.

Research: EI has enjoyed one of the most rapidly evolving growths in research curiosity of any field of mental health. The challenge is to translate new findings into tangible benefits. Indeed this book continually draws down from these discoveries. Put simply, 'Early intervention

Table 1.2 Policy development to support EI in the UK

National Service Framework Adult Mental Health (DH, 1999) Outlining a 10-year policy commitment. EI service development now becomes a firm policy intention.

NHS Plan (DH, 2000) Mental Health sits as a top priority within the wider plan for modernisation of the entire NHS. For EI the NHS Plan gave specific commitment to:

- Develop 50 EI teams, each serving populations of about 1 million by April 2004 so that, ‘all young people who experience a first episode of psychosis, such as schizophrenia will receive the early and intensive support they need’.
- Reduce the DUP to a service average of 3 months (maximum individual 6 months) and continuous service support for the first 3 years.
- Create a comprehensive CAMHS service.

Priorities and Planning Framework 2003–2006 (DH, 2002) Set out the NHS Plan objectives against timelines, reaffirming EI service(s) as a priority with its own targets.

Policy Implementation Guide (DH, 2001–2002) The ‘PIG’ gave detailed service specifications: The EI model should provide care for 3 years for those aged 14–35 with emerging psychosis. EI service(s) were expected to develop with fidelity to the prescribed ‘PIG’ model, although flexibility was possible provided services could demonstrate anticipated outcomes were being met.

Core Interventions in the Treatment and Management of Schizophrenia (NICE, 2002) Values EI’s role within the care pathway, supported by an evidence base of treatments.

NSF for Children, Young People and Maternity Services (DH, 2004)

Reinforces the commitment to ensure seamless provision of EI for those young people in transitional age, requiring that child and adolescent and adult mental health services effectively integrate through joint commissioning and collaborative working arrangements.

2004 Early Psychosis Declaration (World Health Organisation) Developed by IRIS and the International Early Psychosis Association, an international consensus about service targets to meet the needs of these young people and their families.

2004 NIMHE/RETHINK EI Development Programme A 3-year programme to support and guide the implementation of EI services and action the Early Psychosis Declaration (DS and JS are the national co-leads of this programme).

2006 EI Recovery Plan 2006/2007 required EI provision to 7,500 new patients in 2006/2007 in order to put EI development back on target **(DH, 2006) acknowledged the 2003–2006 trajectories** to provide EI to 22,500 patients by December 2006 was off-course.

2007/2008 NHS Operating Framework EI is a continuing priority ... so that EI services are in place in all areas.

2008 NHS Operating Framework EI is still present in 2008/2009 and expected to be in 2009/2010 framework.

in Psychosis’ provides an evidence-based paradigm of care comprising of three concepts:

- Early detection of psychosis.
- Reduce the long duration of untreated psychosis.
- Importance of the first 3–5 years following onset (critical period) for later biological, psychological and social outcomes.

Worth highlighting has been the improved understanding of the cost impact of EI service(s). This has encouraged an ‘invest to save’ argument for commissioners of services which proves that, despite its higher running costs, EI service(s) can potentially save in the order of £5k in year one, rising to £14k by year three per case compared to treatment as usual (McCrone *et al.*, 2008). These savings reflect mainly reductions in

admission and readmission rates achieved by EI service(s) impacting on more traditional pathways into mental health services by:

- Earlier detection, education and collaboration with primary care and community agencies;
- Stronger engagement and more age/phase appropriate intervention with individuals and families.

The impact of these cost savings has been projected to 2026 in an important strategy document 'Paying the Price' (McCrone *et al.*, 2008) which concludes:

Early intervention services for psychosis have also demonstrated their effectiveness in helping to reduce costs and demands on mental health services in the medium to long-term, and should be extended to provide care for people as soon as their illness emerges.

'Paying the Price' (McCrone *et al.*, 2008)

Practice and service development: England has enjoyed unprecedented growth in EI service(s). From 1998, as the NSF got underway there were two teams providing care for about

80 people. DH Local Delivery Plan Returns at March 2007 revealed 145 EI services serving 15,750 people, in the context of a positive trajectory towards full policy implementation. (Figure 1.2).

The growth of capacity, in terms of number of teams and number of cases 'on the books' is necessary but is not sufficient in itself. One way to look at this was to examine how EI teams complied with the Policy Implementation Guide. Early intervention self assessment data for 2007-2008 (DH and CSIP, November 2008) revealed only 5 % LIT's rated as 'red' (failing to meet the EI policy implementation guide (PIG), minimum fidelity criteria and to provide for at least 50% of caseload trajectory targets), 28% rated as 'amber' (meeting EI PIG and minimum fidelity criteria and providing for between 51 and 90% of their caseload trajectory targets) and 67% as 'green' (meeting EI PIG and minimum fidelity criteria and providing for between 91 and 100% of caseload trajectory targets). The National EI Programme conducted a service mapping exercise (October 2007) to assess service provision against the criteria used in the annual Durham assessment of local delivery plans – Figure 1.3.

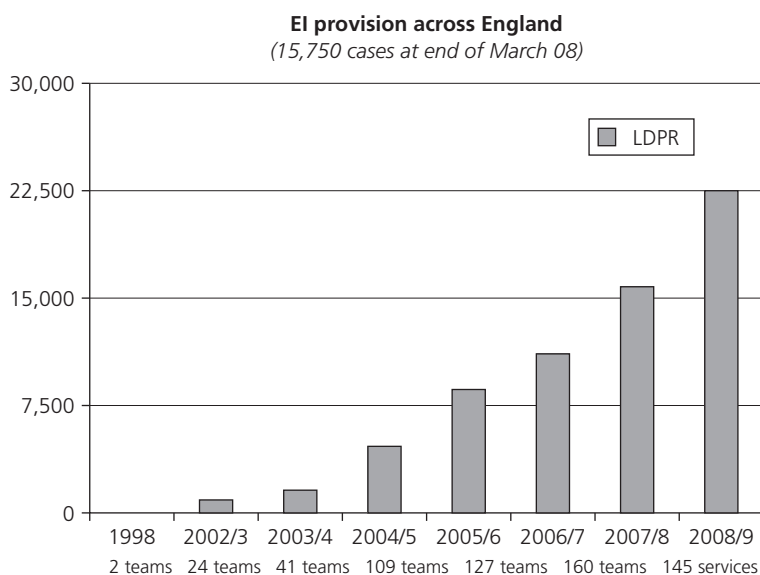


Figure 1.2 EI provision across England.

6 Promoting recovery in early psychosis

| |
|---|
| <p>Majority:</p> <ul style="list-style-type: none"> • provide for full age range (80%)* <p>*some rely on specialist CAMHS/adolescent provision for 14–18 years</p> <ul style="list-style-type: none"> • capacity to provide 3 years intervention (78%)* <p>* some discharge cases earlier</p> <ul style="list-style-type: none"> • caseloads of 15 or less (81%)* <p>*some with higher caseloads have assistant care co-ordinators supporting case managers</p> |
| <p>Many:</p> <ul style="list-style-type: none"> • have early detection strategy (69%) • monitor high risk or suspected FEP cases (58%) with further 23% with limited monitoring capacity |
| <p>Fewer:</p> <ul style="list-style-type: none"> • systems in place for out of hours cover (48%)* <p>* majority rely on Crisis & HT</p> <ul style="list-style-type: none"> • offer flexible hours or evening opening* <p>* one team open for weekend access (South Essex)</p> |

Figure 1.3 National EI Programme mapping in October 2007 of service provision using the Durham annual assessment criteria for fidelity.

Table 1.3 Clinical effectiveness Outcome Data from Worcestershire EI service(s)

| | National | EI service(s) (3 years) 2003–2006 n = 78 |
|--|----------|---|
| Duration of untreated psychosis (months) | 12–18 | 5–6 |
| % admitted in FEP | 80 | 41 |
| % FEP using MHA | 50 | 27 |
| Readmission | 50 | 27.6 |
| % engaged at 12 months | 50 | 100 (79% well engaged) |
| Family involved (%) | 49 | 91 |
| satisfied (%) | 56 | 71 |
| Employed (%) | 8–18 | 55 |
| Suicide attempted (%) | 48 | 21 |
| completed (%) | | 0 |

Source: Smith, 2006.

Finally, the ultimate test of whether this policy imperative is really making a difference to peoples' lives is to assess how the service experience has changed. Can services demonstrate improvement in indicators of quality and outcome? That is precisely why the EPD has been so important in this whole service development with its focus on *co-production of health* rather than *reduction in illness*. EI service(s) have evolved with an ethos of audit and reflective practice centred on some key measures, many linked to the EPD. The routine collection of this type of data by EI service(s) was explored by the

National EI Programme service mapping exercise (October 2007 unpublished) which revealed:

- Majority of EI service(s) measure DUP (79%), readmission (68%), employment (71%) and educational outcomes (68%).
- Fewer measure service engagement (59%), relapse (51%) and parasuicide (47%).

Table 1.3 illustrates the value of such reflective data from Worcestershire Early Intervention Service, a non-research-based EI service(s), replicable by many similar EI service(s) across England.

Table 1.4 Early intervention 2009 and the next 10 years: Some questions?

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- *A youth mental health service model:* Given that 80% of long-term adult mental health disorders commence in those aged 15–25, will the EI model be extended to treat a wider range of young peoples' mental health disorders? If so will EI psychosis become embedded within a youth mental health service?
 - *BME equity:* How will equality of access to EI service(s) and quality of outcome be assured for those from minority ethnic groups?
 - *Early detection:* How will the emerging evidence for the benefits of early detection (*Chapter 11 Early detection and treatment opportunities for people with emerging psychosis. Paul French*) become embedded into practice and new service development?
 - *Length of EI psychosis provision:* Will the current 3-year PIG model be extended to 5 years in the light of evidence for loss of the early benefits of EI (for instance in the elevated suicide rates seen when these young people are discharged to traditional community mental health services)?
 - *EI psychosis as a trojan horse:* Can EI act as a culture-carrier, creating ripples into the still waters further down the care pathway (e.g. *PSI, family work, medicines*), reigniting interest in the therapeutic strengths of home, families and communities?
 - *Offender pathways:* How might those clients presenting with offending behaviours avoid becoming entrapped within a criminal justice system and access EI service(s)?
 - *EI for physical health pathways:* How can EI service(s) work with primary care to provide an EI paradigm for physical disorders in the face of growing concerns about premature deaths due to cardiovascular, respiratory and infective disorders? (Parks et al., 2006)
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EI practice and service development has benefited enormously from reflective practice; this illustration shows how the standards of the EPD can provide quality indicators able to drive local service improvement.

Final reflections

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 reform of the NSF era. Crisis resolution has had the most immediate effect but I think early intervention will have the greatest effect on people's lives.

Professor Louis Appleby, National Director for Mental Health October 10 2008 Policies and Practice for Europe (DH/WHO Europe Conference attended by 35 countries)

Now an established 'normal' part of the architecture of specialist services, EI psychosis has travelled from the margins to mainstream over the lifetime of the NSF, gathering momentum through a synergy of policy, research and practice. However what we have described is a journey and not a destination and we feel the next phase of consolidation is perhaps the most exciting. What might the next 10 years hold for EI service(s) (Table 1.4).

Table 1.4 shows some of the positive opportunities that the paradigm of EI may be able to influence. However there will also emerge risks and cautions, such as the ongoing financial recession or future NHS reorganisations. EI psychosis must avoid being a *victim* of these pressures, but provide a *solution*. Indeed, because of the central importance attached by EI to audit of care pathways, no other part of mental health provision is better equipped to be in touch with clients' journeys. Thus, EI, far from being a *problem* demanding resources, can offer an *answer* by demonstrating how to better use scarce resources.

So what has this EI voyage taught us? Much of the challenge is not about new money but about a different mindset which challenges 'Treatment as Usual' by seeing different ways of doing things. We hope this mindset, defined by the values and principles of the EPD, will be part of what the reader of this book takes away.

Useful information resources

IRIS website on www.iris-initiative.org.uk for

- Leaflet describing the aims of the declaration;
- Launch presentation declaration by Benedetto Saraceno;
- Toolkit for self-assessment of a service against the declaration's standards.

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